FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

INQUIRY INTO SOCIAL INCLUSION AND VICTORIANS WITH DISABILITY

Committee functions

Extract from the *Parliamentary Committees Act 2003* (Vic)

S.11 The functions of the Family and Community Development Committee are, if so required or permitted under this Act, to inquire into, consider and report to the Parliament on:

(a) any proposal, matter or thing concerned with–

    (i)   the family or the welfare of the family

    (ii) community development or the welfare of the community

(b) the role of Government in community development and welfare, including the welfare of the family.

Committee membership

Committee Members

Ms Dee Ryall, MP (Chair)	Mitcham
Ms Bronwyn Halfpenny, MP (Deputy Chair)	Thomastown
Mrs Andrea Coote, MP	Southern Metropolitan
Mr Justin Madden, MP	Essendon
Mr David O'Brien, MP (until 27 March 2014)	Western Victoria
Mrs Jeanette Powell, MP (from 27 March 2014)	Shepparton

Secretariat

Dr Janine Bush	Executive Officer
Ms Vicky Finn	Research Officer
Ms Natalie Tyler	Administration Officer

Terms of Reference

To the Family and Community Development Committee — for inquiry, consideration and report no later than 6 August 2014* on social inclusion and Victorians with a disability, and the Committee is asked to inquire into:

(a) define 'social inclusion' for Victorians with a disability;

(b) identify the nature and scale of relative inclusion (exclusion) and participation of Victorians with a disability in the economic, social and civil dimensions of society;

(c) understand the impact of Victorian government services and initiatives aimed at improving inclusion and participation;

(d) identify examples of good practice on inclusion and participation driven by local government and the community sector;

(e) assess how the *Disability Act 2006* has impacted on the social inclusion of people with a disability with respect to Victorian government services; and

(f) recommend ways to increase social inclusion, including the roles of and collaboration between local, state and federal governments, the community sector, individuals with a disability and their carers.

*The deadline for reporting was subsequently extended to 17 September 2014

Chair's foreword

Circumstances for people with disability in Victoria have markedly improved with shifts away from past approaches that were characterised by segregation and institutionalisation.

Over the past decade numerous national, international and Victorian legislative and policy interventions have sought to create conditions for increased social inclusion. Despite these efforts, people with disability continue to report experiences of exclusion from social, economic and cultural life in Victoria.

This Inquiry is timely. The introduction of the National Disability Insurance Scheme (NDIS) in 2013 is contributing to a major transformation of the disability support system. It is shining a light on social inclusion and disability, and bringing the issue to the forefront of the minds of Victorians. It is an opportune time to continue Victoria's leadership in disability by moving away from a focus on people with disability as recipients of care and strengthening efforts on their social inclusion in the Victorian community.

Social inclusion extends beyond simply being present or passively participating in activities in the community. For people with disability, like everyone, social inclusion means experiencing respect for difference and for individual aspirations. It means having control over their own lives and having opportunities to contribute and participate in society in meaningful ways. It means feeling valued and experiencing a sense of belonging. It involves having significant and reciprocal relationships. It can also mean having the appropriate support to be socially included.

The Committee determined that the *Disability Act 2006* (Vic) and the *State disability plan 2013–16* provide the Victorian Government with a strong policy and legislative basis to shape its future social inclusion agenda. And the Building Inclusive Communities Program provides local government with a solid foundation to continue grassroots efforts in local communities across the state.

Numerous individuals and organisations took the time to provide written submissions and appeared at public hearings. This valuable evidence assisted the Committee to understand the nuances and complexities of social inclusion (or exclusion) experienced by people with disability. The Committee is grateful for the considered and thoughtful evidence provided to the Inquiry that were fundamental to its deliberations and the recommendations it ultimately makes to the Victorian Government.

In addition to the need to provide clarity of definitions and implement further measurement tools to assess the social inclusion of people with disability, the Committee identified that existing legislated tools could also be further strengthened. This would help determine how the aspirations of people with disability are changing over time, and put greater focus on the importance of creating favourable conditions for sustainable relationships and social connections. The Committee also makes recommendations to provide greater opportunities for people to meaningfully participate and contribute to the social, economic and cultural life of Victoria.

On behalf of the Committee I thank the staff of the Secretariat for their ongoing dedication to the work of the Committee and for their work in producing this report — Janine Bush (Executive Officer), Vicky Finn (Research Officer) and Natalie Tyler (Administration Officer).

And finally, I would personally like to thank Committee Members for their commitment and cooperative approach to this Inquiry — Bronwyn Halfpenny MP (Deputy Chair), Andrea Coote MP, Justin Madden MP, David O'Brien MP, and Jeanette Powell MP.

Dee Ryall, MP

Chair

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Glossary

Aboriginal—The term refers to both Aboriginal and Torres Strait Islander people.

Accessibility—In common language, the ability to reach, understand, or approach something or someone. In laws and standards on accessibility, it refers to what the law requires for compliance.

Aspiration—A hope or ambition of achieving something in the future.

Attitude—An expression of favour or disfavour towards a person, place, thing, or event. Attitudes and corresponding behaviour are related in complex ways.

Block funding—The process by which governments directly fund service providers with lump sum payments. These payments are then used by the providers to deliver support services.

Building Inclusive Communities Program (formerly the Community Building Program)—Established in 2002 to build and strengthen the community's capacity to provide support to people with disability and their families and to facilitate integrated local community planning to engage and involve people with disability and their families, disability service providers and community organisations.

Dignity of risk—The right of people to choose to take some risk in engaging in life experiences.

Disability Act 2006 **(Vic)**—The Act sets out principles for people with disability and for disability service providers. The Act aims to provide a stronger whole of government, whole of community response to the rights and needs of people with disability, and a framework for the provision of high quality services and supports for people with disability.

Disability Action Plan—Under the *Disability Act 2006* (Vic) all public services—government departments, statutory authorities and statutory corporations—must have a Disability Action Plan, which is a plan to reduce barriers for people with disability as community members and make it easier for people with disability to use services available to all Victorians.

Disability Service Provider—A person or body (for example a community service organisation) that provides disability services under the Disability Act and is registered on the register of disability service providers. The Department of Human Services is also a disability service provider.[1]

Disability Services Commissioner—The Disability Services Commissioner was established on 1 July 2007 under the *Disability Act 2006* (Vic) to improve services for people with disability in Victoria through assisting in the resolution of complaints raised by or on behalf of people who receive services. The Commissioner is a statutory body that functions independent of government, the

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[1] Department of Human Services (2014) *Individual support packages for people with a disability. Handbook.* Melbourne, DHS, p.87.

Department of Human Services and Victorian disability services to provide a free, confidential and supportive complaints resolution process.

Discrimination—Can be direct or indirect:

- Direct discrimination is treating or proposing to treat a person with an attribute unfavourably because of that attribute.

- Indirect discrimination can happen when a requirement, condition or practice is imposed or proposed that is not reasonable and has or is likely to have the effect of disadvantaging a person with an attribute.

Empowerment—The process of enhancing the capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes.

Individualised or self-directed funding—Where government funds can be given directly to service users to then purchase services. This would mean service providers receive funding only after being approached (chosen) by the service user.

Individual Support Package (ISP)—ISPs enables a person to provide direction for the identification and implementation of supports that are most appropriate to their individual needs and circumstances. It enables the person to exercise choice in obtaining support that will assist them to achieve their goals and pursue their own lifestyle.[2]

Individual Support Plan—The *Disability Act 2006* (Vic) requires that a person has a support plan in place if they are in receipt of an ongoing disability support such as an Individual Support Package (ISP). The support plan outlines the person's goals and the strategies and resources required to achieve those goals. If the supports require disability funding, these need to be written in a funding proposal.[3]

Job shadowing—An unpaid opportunity to spend part of a day or more observing and interacting with employers in a workplace.

Kindergarten Inclusion Support Package (KISP)—The objective of KISPs is to build the capacity of funded kindergartens to support the access and participation of children with disability and high support needs and/or with complex medical needs.[4]

National Disability Insurance Agency (NDIA)—An independent statutory agency whose role is to implement the National Disability Insurance Scheme (NDIS).[5]

National Disability Insurance Scheme (NDIS)—The new way of providing individualised support for eligible people with permanent and significant disability, their families and carers.[6]

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[2] Department of Human Services (June 2014) *Individual support packages for people with a disability: Guidelines.* Melbourne, DHS. Accessed on 26 August 2014 from http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/policies,-guidelines-and-legislation/individual-support-package-guidelines.

[3] Department of Human Services (2009) *Individual Support Package handbook.* Melbourne, DHS, p.41.

[4] Department of Education and Early Childhood Development *Kingergarten Inclusion Support Packages.* Accessed on 26 August 2014 from http://www.education.vic.gov.au/childhood/parents/needs/pages/kinderinclusion.aspx.

[5] National Disability Insurance Scheme *About us.* Accessed on 26 August 2014 from http://www.ndis.gov.au/about-us.

National Disability Services (NDS) Victoria—The Victorian state office of the national peak body for non-government disability service organisations. Its purpose is to promote quality service provision and life opportunities for Victorians with disability.[7]

Natural networks—Refers to the real world links between groups or individuals, such as networks of friends, family networks or networks of former colleagues.

Productivity Commission Report—In February 2010 the Australian Government requested the Productivity Commission undertake an inquiry into a national disability long-term care and support scheme. The inquiry assessed the costs, cost effectiveness, benefits, and feasibility of the scheme. On 31 July 2011, the Productivity Commission provided the *Disability care and support* report to the Australian Government, which was released on 10 August 2011.

Reverse integration—The process whereby people without disability are integrated into activities that previously were limited exclusively to people with disability.

Self-directed funding—see Individualised funding.

Social capital—Relates to the social norms, networks and trust that facilitate cooperation within or between groups. It can generate benefits to the whole community by reducing transaction costs, promoting cooperative behaviour, diffusing knowledge and innovations, and through enhancements to personal wellbeing and associated spillovers.

Social exclusion—The process of being shut out from the social, economic, political and cultural systems which contribute to the integration of a person into the community.

State Disability Plan—Under the *Disability Act 2006* (Vic), from 2013 the Minister for Community Services is required to prepare a State Disability Plan every four years that must:

- identify the needs of persons with a disability

- establish goals and priorities for the support of persons with a disability

- identify objectives and policy priorities for the development and delivery of services for persons with a disability

- identify strategies for achieving those objectives and priorities.[8]

State Disability Plan 2013–16—Articulates the Victorian Government's view for the future and sets a direction for the next four years. At the centre of the Plan is the framework, which outlines the vision and principles of the Plan, the long-term goals, shorter-term outcomes and four-year strategies that guide the two-yearly implementation plans. Its vision is an inclusive Victorian society that enables people with disability, their families and carers to fulfil their potential as equal citizens.

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[6]   National Disability Insurance Scheme *Welcome.* Accessed on 26 August 2014 from http://www.ndis.gov.au/.
[7]   National Disability Services *About the National Disability Services.* Accessed on 26 August 2014 from
       http://www.nds.org.au/about.
[8]   *Disability Act 2006* (Vic) s.37.

Survey of Disability, Ageing and Carers (SDAC)—Conducted by the Australian Bureau of Statistics (ABS) throughout Australia from 5 August 2012 to 2 March 2013 and is the seventh comprehensive national survey conducted by the ABS to measure disability. The survey collects information from three target populations:

- people with disability

- older people (those aged 65 years and over)

- people who care for people with disability or older people.

Data from this survey is used to measure the prevalence of disability in Australia, measure the need for support of older people and those with disability, and provide a demographic and socio-economic profile of people with disability, older people and carers compared to the general population.[9]

UN Convention—Australia ratified the United Nations (UN) Convention on the Rights of People with Disabilities (UN Convention) on 17 July 2008. By ratifying the UN Convention, Australia joined other countries around the world in a global effort to promote the equal and active participation of all people with disability.

The purpose of the UN Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all people with disability, and to promote respect for their inherent dignity.[10]

Universal Housing Design—Designing Australian homes to meet the challenging needs of home occupants across their lifetime. It recommends the inclusion of key easy living features that aim to make homes easier and safer to use for all occupants including people with disability, ageing Australians, people with temporary injuries, and families with young children.

Victorian Disability Advisory Council (VDAC)—Established under the Disability Act 2006 (Vic), VDAC provides advice to the Minister for Community Services on issues that affect people with disability across all government services. VDAC is a way for people with disability to have a say in decision making on whole-of-government policy issues. Most Council members must be people with disability and they must come from a range of different backgrounds.

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[9] Australian Bureau of Statistics (2013) *Disability, ageing and carers, Australia: Summary of findings, 2012.* cat. no. 4430.0, Canberra, ABS. Accessed on 14 August 2014 from http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0.

[10] Attorney-General's Department *Convention on the rights of persons with disabilities.* Australian Government. Accessed on 3 September 2014 from http://www.ag.gov.au/RightsAndProtections/HumanRights/Pages/UnitedNationsConventionontherightsofpersonswith disabilities.aspx.

Acronyms

AAA	Access for all abilities program
ABCD	Assets-based community development
ABI	Acquired Brain Injury
ABS	Australian Bureau of Statistics
ACD	Association for Children with a Disability
ACSO	Australian Community Support Organisation
ACT	Australian Capital Territory
ADEs	Australian Disability Enterprises
AHURI	Australian Housing and Urban Research Institute
AIFS	Australian Institute of Family Studies
AIHW	Australian Institute of Health and Welfare
ASD	Autism Spectrum Disorder
CALD	Culturally and Linguistically Diverse
CBPARS	Community Building Project Achievement Reporting System
CDDHV	Centre for Developmental Disability Health Victoria
COAG	Council of Australian Governments
CQL	Council on Quality and Leadership
CSO	Community Service Organisations
Cth	Commonwealth
DAPs	Disability Action Plans
DD Act	*Disability Discrimination Act 1992* (Cth)
DEECD	Department of Education and Early Childhood Development
DES	Disability Employment Services
DHS	Department of Human Services
DMD	Disability Mentoring Day
DSC	Disability Services Commissioner
DSP	Disability Support Pension
EO Act	*Equal Opportunity Act 2010* (Vic)
EOI	Expression of interest

EPICC	Engaging Parents in Career Conversations
FIDA	Football Integration Development Association
GDP	Gross domestic product
GPs	General Medical Practitioners
HACC	Home and Community Care
ID	Intellectual Disability
IGAs	Inter Governmental Agreements
ISP	Individual Support Package
KISP	Kindergarten Inclusion Support Package
LACs	Local Area Coordinators
LEAD	Leading, Educating and Advocating for Disability Program
LGAs	Local Government Authorities
LYCP	Live Your Community Program
MAV	Municipal Association of Victoria
MBA	Milward Brown Australia
MORF	Measuring Outcomes and Results Framework
NCCD	Nationally Consistent Collection of Data on School Students with Disability
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDS	National Disability Services
NRAS	National Rental Affordability Scheme
OECD	Organisation for Economic Co-operation and Development
OPA	Office of the Public Advocate
OTA	Occupational Therapy Australia
POM	Personal Outcome Measures
PRC	Parenting Research Centre
PTAC	Public Transport Access Committee
PwC	PricewaterhouseCoopers
RAC	Residential Aged Care
RDAV	Riding for Disabled Association of Victoria Inc
RSAs	Regional Sports Assemblies

SAIF	Supported Accommodation Innovation Fund
SCI	Spinal Cord Injury
SDAC	Survey of Disability Ageing and Carers (ABS)
SSA	State Services Authority
SSAs	State Sports Associations
SWAT	Scooter and Wheelchair Access Team
SWEP	Statewide Aids Equipment Program
SYA	Scope's Young Ambassador Program
TAC	Transport Accident Commission
TTR	Transition-to-retirement
UK	United Kingdom
VAEP	Victorian Aids and Equipment Program
VALID	Victorian Advocacy League for Individuals with Disability Inc
VCASP	Victorian Coalition of ABI Service Providers
VCOSS	Victorian Council of Social Service
VDAC	Victorian Disability Advisory Council
VEOHRC	Victorian Equal Opportunity and Human Rights Commission
VET	Vocational Education and Training
VICSERV	Psychiatric Services Victoria
VPLRC	Victorian Parliamentary Law Reform Committee
WA	Western Australia
WDV	Women with Disabilities Victoria
WHO	World Health Organization
YDAS	Youth Disability Advocacy Service

Executive summary

A GREAT LIFE
I'm part of this world and I have a disability
But I don't want it to rule my life
I want to find out what I'm good at and do it really well
I want to do stuff with my brothers and sisters
and I want to be happy at school
and I want people to feel OK around me
I want to hang out with friends and do cool stuff
I love my parents but I don't want to live with them
forever so … I'll need to get a job
I want to fall in love and maybe have kids
And when it's all over, I want to be able to say that I
didn't just have a life
— I had a great life.
Source: *Transcript of Evidence*, Association for Children with a Disability, Melbourne, 17 March 2014 , p. 2.

Numerous interventions over the past decade at an international, national and state level have sought to create conditions that improve the quality of life of people with disability and their social inclusion. These include the:

- United Nations Convention on the Rights of People with Disabilities (UN Convention)

- *National disability strategy 2010–20*

- National Disability Insurance Scheme (NDIS)

- *Disability Act 2006* (Vic)

- Victorian *State disability plan 2013–16*.

The Committee recognises that for the duration of this Inquiry, individuals with disability, their families and supporters, and organisations have continued to work with local communities across Victoria to increase opportunities for social inclusion. New and innovative programs and strategies are continuously being implemented and contributing to change.

Despite policy and legislative interventions and efforts in local communities, the Committee heard that people with disability continue to report feeling excluded from social, economic and cultural life.

The introduction of the NDIS in July 2013 is contributing to a major transformation of the disability support system. While essentially a new scheme for funding and providing disability support for people with permanent and significant disability, the NDIS was also intended to minimise the impact of disability, to raise awareness of disability, and to increase social inclusion by stimulating social capital.

> **Social inclusion**—*means people with disability:*
>
> *—experience respect for their differences, their aspirations and their right to have control over their own lives*
>
> *—have opportunities to contribute and participate in society in a meaningful way and feel valued*
>
> *—experience significant and reciprocal relationships*
>
> *—have appropriate supports, where necessary.*[11]

The NDIS is currently being trialled across Australia with its full roll out to occur between 2016 and 2019.

It is an opportune time to consider what social inclusion for Victorians with disability means, the extent to which it is experienced, and what actions need to be taken to achieve social inclusion. In the context of the transition to the NDIS, the Committee considers that efforts to increase social inclusion need to be ongoing and that governments need to continue to fulfil their obligations.

Given the numerous policy and legislative interventions to improve the quality of life of people with disability, governments need to know if they are effective.

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[11]   Compiled by the Family and Community Development Committee. Refer to Recommendation 1.1 in Chapter 1.

In undertaking its Inquiry, the Committee considered eight key areas relevant to the social inclusion of Victorians with disability.

Chapter	Discusses
1. Defining disability and social inclusion	What is 'social inclusion'? What does it mean for people with disability? And how should it be measured? How can we know over time if the interventions put in place are effectively increasing people's feelings of inclusiveness?
2. Leading the social inclusion agenda	In a context in which responsibilities for assessing and funding disability support are transitioning across governments, who holds responsibility for leading the social inclusion agenda?
3. Aspirations and social inclusion	What do people with disability themselves aspire to in the context of social inclusion? What are their goals and ambitions? Do they have opportunities to pursue them?
4. Sustainable relationships and networks	Social inclusion is more than merely being present or passively participating. It is about social connectedness, relationships and natural networks. How can people with disability increase their social capital through their connections?
5. Foundations to social inclusion	There are core foundations to achieving social inclusion for all members in the community. How do people with disability secure the core foundations for social inclusion, including good health, quality supports, financial security, access to justice, and safe, affordable and secure housing?
6. Contributing and participating	People with disability make valued contributions to Victoria's economic, social and cultural life. What needs to happen to ensure there are new and ongoing opportunities to meaningfully participate in education, employment and other activities?
7. Accessibility	People with disability continue to experience daily barriers to accessing transport, the built environment and information that can facilitate their opportunities to contribute, engage and feel included. How can these barriers be effectively removed?
8. Changing attitudes and behaviours	Negative attitudes towards disability persist in the community and have consequences for how people treat and interact with people with disability. Low expectations, avoidance, discrimination and hostility result in exclusion and non-meaningful participation. How can attitudes be changed to improve the ways that communities interact with people with disability?

Defining and measuring social inclusion

While considerable progress has been achieved in recent decades in improving the lives of people with disability, Victorians with disability continue to express experiences of:

- inequitable access to education, employment, health and housing opportunities

- feelings of isolation, lack of autonomy, and pervasive discrimination and devaluation

- reduced opportunities to pursue goals and ambitions.

Currently it is not possible to accurately measure the extent to which people are included or excluded in Victoria, or to determine the precise nature of exclusion.

> *To me, inclusion means:*
>
> *—having friends with and without disabilities*
>
> *—being part of the work force and the real world*
>
> *—people liking me because of who I am*
>
> *—being part of a team that values my abilities*
>
> *—being free to make my own mind up and have my own opinions.[12] (Heather)*

To measure and understand the social inclusion of Victorians with disability, the Victorian Government needs to adopt a definition of social inclusion. It also needs to establish a robust measuring tool.

The Committee identified that social inclusion tends to be understood in the context of participation alone, or 'passive' rather than 'active' participation. Participation focuses on the level of engagement in particular activities, while social inclusion has a greater focus on the extent to which people feel valued and respected in their contributions to society and the degree to which communities accept and embrace people with disability.

The Committee recommends that the Victorian Government adopts the following definition of social inclusion (see Recommendation 1.1):

- Social inclusion for people with disability means—

  ◆ experiencing respect for their differences, their aspirations, and their right to have control over their own lives

  ◆ having opportunities to contribute and participate in society in a meaningful way and feel valued

  ◆ experiencing significant and reciprocal relationships

  ◆ having appropriate supports, where necessary.

Like others in the community, people with disability are diverse. Their experiences of social inclusion (and exclusion) vary considerably. In the development of any measuring tool, this diversity needs to be taken into account. People with disability vary in their:

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[12]   *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.8.

- age, gender, culture and geography

- social and economic backgrounds, Aboriginal heritage, and cultural and linguistic diversity

- experiences, needs and aspirations

- type of disability and their level of functioning within their disability.

The Committee recommends that the Victorian Government review the range of mechanisms for measuring the social inclusion of people with disability—including local, national and international tools—and identify an appropriate method for determining levels of social inclusion experienced by Victorians with disability (see Recommendation 1.2).

Leading the social inclusion agenda

Since the 1980s, Victoria and Australia more broadly have introduced policy and legislative reform with the goal of moving away from segregation and improving the lives of people with disability.

The policy and legislative context of social inclusion and disability cannot be considered without taking into account the introduction of the NDIS. The NDIS is designed to fund and provide for reasonable and necessary supports required by people with a permanent and significant disability. In addition, the NDIS is also expected to change the way people with disability are treated in the community.

> *Increased social inclusion will not be accomplished solely through reforms such as the NDIS. Instead it requires acknowledgement and understanding of the issues across all Government services and initiatives; followed by rigorous planning that incorporates participation, inclusion and feedback from people with disabilities.[13]*
>
> *(Darebin Disability Advisory Committee)*

While fundamental, support is only one element that contributes to social inclusion for people with disability. Many other barriers to inclusion will not be directly addressed by the NDIS, such as inaccessible environments and negative attitudes towards disability in workplaces and other settings. The long-term success of the NDIS is reliant on people being more socially included.

In Victoria progress towards a social inclusion agenda has been made with the introduction of the *Disability Act 2006* (Vic), the release of the *State disability plan 2013–16* and the establishment of the Building Inclusive Communities Program (formerly the Community Building Program) in 2002.

In particular, these initiatives provide sound legislative principles and a good policy framework from which to further progress a social inclusion agenda. They have led to the creation of partnerships across local government, state government departments and non-government organisations. While evolving, the Committee considered these partnerships are important beginnings and require ongoing commitment to foster their future development.

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13   *Submission S041*, Darebin Disability Advisory Committee, p.12.

The Committee determined that by 2019 the Victorian Government will need to have commenced review of the Disability Act to ensure it aligns with the NDIS, reflecting the Victorian Government's future involvement in disability (see Recommendation 2.1).

The Committee heard that the Disability Act provides a strong legislative basis for increasing social inclusion. It contains three legislated tools designed to improve the lives of people with disability in Victoria:

• Victorian Disability Advisory Council (VDAC)

• State Disability Plan

• Disability Action Plans

The *State disability plan 2013–16* has four goals that are directly related to social inclusion:

• Goal 1—a strong foundation in life

• Goal 2—upholding rights and promoting participation

• Goal 3—accessing information, transport, buildings and places

• Goal 4—a contemporary approach through disability system reform

The Plan contains multiple strategies and 141 implementation actions. Inquiry participants stated that the Plan demonstrates good policy intent and has the right frameworks in place. Yet the Committee heard concerns that the implementation actions do not have measurable outcomes or targets and it recommends that future implementation plans and State Disability Plans include such targets (see Finding 2.7 and Recommendations 5.1, 5.3, 6.1 and 7.1).

The Committee identified that VDAC has considerable powers under the Disability Act, but that these are not often exercised. In addition, it found that VDAC does not have a strong profile in the general community. The Committee recommends that the Minister for Community Services:

• seek advice from VDAC on future directions for social inclusion and that it is incumbent on VDAC to ensure it gathers relevant information to be considered in the development of Tier 2 of the NDIS (Recommendation 2.4)

• request that VDAC develop a strategy to increase its profile and that it will be incumbent on VDAC to implement this strategy (Recommendation 2.2).

Inquiry participants highlighted the potential value that disability action plans can contribute to increasing social inclusion for people with disability. The Committee heard that there is room for strengthening the disability action plan process to increase their effectiveness. Inquiry participants expressed concern that there are no consequences for public bodies that do not develop a disability action plan.

The Committee also heard that there is inconsistency in disability action plans across local government and there are no outcome measures or monitoring of the plans. It recommends that the Victorian Government request the Victorian Auditor-General undertake an audit of the suitability, effectiveness and

implementation, and the monitoring and improvement of disability action plans in local government (see Recommendation 2.3).

The Building Inclusive Communities Program provides a strong basis for ongoing efforts to increase the capacity of communities to be more inclusive of people with disability. The Committee determined that in the NDIS co-design process the Victorian Government should work with the National Disability Insurance Agency (NDIA) to clarify the roles and responsibilities of Local Area Coordinators (LACs) associated with the NDIS and Access Officers in the Building Inclusive Communities Program to ensure their social inclusion interventions are complementary (see Recommendation 2.5).

Following changes to the structure of the Department of Human Services in 2012 the Committee heard the Building Inclusive Communities Program is not being driven effectively where it is currently situated. To ensure the Program's ongoing role in building inclusive communities, the Committee considered that it should be overseen by the Office for Disability (or equivalent) in partnership with the Municipal Association Victoria (MAV).

Aspirations and social inclusion

To understand what social inclusion means for people with disability, a key starting point is to consider their life aspirations and how these relate to inclusion. Not surprisingly, the goals and dreams of people with disability are no different from other people in the community and are equally as unique for each individual.

In 2000, the Victorian Government commissioned a research study on the aspirations of people with disability—*The aspirations of people with a disability within an inclusive Victorian community*. It found that like most people, they want to choose their own living arrangements, to secure meaningful employment, to engage in recreational activities they enjoy, and have social connections and relationships with others.

> *Inclusion is about having the opportunity to fulfil our goals, our aspirations, our dreams and to live in and contribute to a community where these are acknowledged and supported as our rights as equal human beings.[14] (Whittlesea Disability Network)*

The journey of pursuing a goal or dream contributes to people's growth, their ideas and the shaping of their future aspirations. Yet the challenges in pursuing aspirations are often greater for people with disability than for other members of the community. Attitudes, fears and preconceived views about the capabilities of people with disability to aspire towards employment, social connection and other forms of social inclusion can influence the individual aspirations of people with disability themselves. Often expectations are lower than the capabilities of people with disability and their desire to achieve their ambitions.

As with all people, a number of factors influence the aspirations of people with disability. These include:

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[14]   *Submission S037*, Whittlesea Disability Network, p.1.

- individual factors—such as, health status, personal characteristics, diversity, capacity and capability

- life transitions—such as starting and changing schools, leaving school, getting a job, starting a family, moving into later life, or acquiring a disability

- family and friends—such as expectations and level of supports

- society—such as accessible environments and the extent to which communities welcome people with disability.

Negative experiences can reduce the aspirations of people with disability and decrease their opportunities for social inclusion. In addition, many people with disability report that the activities they engage in are limited and not what they would choose to do if barriers to their participation were removed.

The Committee identified that to improve social inclusion there is a need to ensure that people with disability can have the highest of aspirations and have opportunities to fulfil their aspirations and goals. They need access to communities and, for some, support to pursue their hopes and goals.

People with disability told the Inquiry that, like anyone, they want the freedom to pursue their life journey, and the opportunity to take risks and sometimes make mistakes. To do this, the Committee considered there is a need to reduce barriers in the community. In addition, for those who experience difficulties in identifying or articulating their needs and aspirations, formal and informal carers should be encouraged to use a supported decision making approach.

> *I need the ability to run my own life. If I do make a mistake, I only want myself to blame. Not having complete control of my choices makes me feel not quite human, so to me, social inclusion is about freedom.[15] (Bily)*

The Committee determined that the Victorian Government needs to consider how the aspirations of people with disability have changed as a consequence of legislative and policy developments, including the Disability Act. The Committee recommends a follow-up survey to the 2000 study on aspirations. In doing this, the Victorian Government should identify the aspirations of people with disability across Victoria and how they may have changed over time to inform ongoing social inclusion strategies (see Recommendation 3.1).

The Committee also considered that the Victorian Government should work in partnership with local councils and disability advisory groups to develop an agreed approach to identifying the social inclusion aspirations of people with disability in their local communities. This includes how they work with people with disability to pursue initiatives and changes that will contribute to positive outcomes. Such an approach could be linked to the implementation of disability action plans and the work undertaken by Access Officers (see Recommendation 3.1).

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[15]   *Transcript of Evidence*, Summer Foundation Ltd, Melbourne, 17 March 2014, p.4.

Social connectedness

For most people in the community, relationships and social networks are integral to their sense of belonging, feelings of inclusion and general emotional wellbeing. Social connections can lead to other benefits, such as access to resources, services and increased opportunities to participate. Social networks have the potential to contribute to positive economic, social and health outcomes—also known as social capital.

There are different types of relationships, connections and networks that can contribute to these benefits. They might be:

- close bonds—such as intimate partners, family and friends

- distant connections across the community— such as work colleagues, neighbours, or professional service providers

- ties to people in positions of power and authority—such as a local council member or a police officer

- formed through networks, groups or online forums.

> … in the Five Star Project community everyone rallies around each other. People always encourage each other to get out and join in. We are working out how we can look after each other when parents/care givers cannot support us.[16] (Wellington Community)

Relationships and social connections are reciprocal, dynamic and changing. They often evolve over time as people transition through different stages of their lives and forge new links or experience the weakening of pre-existing ties.

Like all members of the community, people with disability can experience difficulties in either establishing or maintaining relationships and social connections for a multitude of reasons. For people with disability, however, there can be additional challenges in nurturing their connections, which can relate to accessibility of the environment, facilitated communication requirements or the need for support to build social skills.

In view of the multitude of benefits that potentially flow from social connections, there is a strong case for creating and supporting conditions that increase opportunities for people with disability to develop sustainable relationships and networks in their communities.

The Committee identified that innovative approaches are being developed and implemented across the state. Local communities are contributing to increased opportunities for people with disability to engage and participate through formal and informal programs and initiatives. The Committee considered there is scope for the Victorian Government to take advantage of this energy and identify innovative and strategic ways for people with disability to build social capital. Such an approach needs to:

- be driven by people with disability

- emphasise the importance of naturally occurring networks

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[16]   *Submission S083*, Wellington (Local Government Area) Community, p.5.

- take advantage of the value that volunteers can contribute

- create opportunities and establish favourable conditions for social connections to develop and be sustained.

The Committee recommends that when developing its next State Disability Plan in 2016 and in consultation with people with disability the Victorian Government incorporate a strategy for effectively and appropriately strengthening connections and social capital (see Recommendation 4.1). This goal would include three objectives:

> *I've been lucky to have had really supportive colleagues and supervisors.*
>
> *… management have been great in identifying that it'll take me a little longer to work it out and have been supportive, and also providing training in areas that will help me get on top of things.[17] (Aaron)*

- creating opportunities for establishing and maintaining connections and networks—such as new networks and building the capacity of people with disability who need support

- establishing favourable conditions for sustainable relationships and networks—such as social 'brokerage' (mentors, coaches) and good public infrastructure

- supporting existing opportunities and networks—such as existing programs that aim to provide opportunities for social interaction.

Foundations for social inclusion

There are core foundations to achieving social inclusion for all members in the community. These foundations include good health, financial security, access to quality support, and affordable, appropriate and secure housing. They are central to self-determination, choice and control.

Some people with disability need support to achieve autonomy in the community and to engage in activities that contribute to social inclusion. The Committee recognises that disability support for people with profound disability will transition to the NDIS in 2019 and that many of the issues raised about access to disability specific supports will be addressed through the transition to the NDIS.

The Committee heard that for people with disability it is well established that they experience more issues relating to their overall health and wellbeing than the general community, are more economically disadvantaged than other members of the community, and have fewer choices about their living arrangements than other community members.

Health

Health and social inclusion are inextricably intertwined. Poor health and wellbeing can undermine a person's capacity and desire to participate in the social, economic and cultural dimensions of society. In turn, social exclusion has consequences for people's health and wellbeing and can result in a limited capacity to participate. The Committee heard that there are unique barriers

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[17]   *Submission S111*, Melbourne City Mission, p.11.

experienced by people with disability that can have an effect on their health and wellbeing:

- attitudes to disability—particularly those of service providers and health professionals

- choice and control—people with disability do not always have control over their own health

- accessible services—accessing relevant services can be difficult (such as sexual and reproductive health services) and health promotion initiatives often do not target people with disability

- provision of information—health information in accessible formats can be difficult to obtain and some people with disability can have limited knowledge and understanding about health, which in turn might impede their decisions to seek medical help.[18]

In addition, the Committee heard that in comparison with other members of the community, people with severe and profound disability report having moderate and high or very high distress levels, including suicidal thoughts. Inquiry participants highlighted that people who acquire a disability are particularly at risk. While there are some programs that target specific groups, such as those with spinal cord injury, the Committee identified a need to consider the mental health of people in rehabilitation and after their release (see Recommendation 5.1).

> *From hospital I went into rehab in a nursing home. It is difficult to know how to describe that time. I can tell you that I tried to end my life.[19] (Bily)*

The Committee recognises that the *State disability plan 2013–16* has multiple implementation actions that address issues relating to health and wellbeing. The Committee recommends that in its future State Disability Plan to be developed in 2016, the Victorian Government needs to incorporate specific strategies, actions and targets to improve health promotion efforts for targeted groups of people with disability, to ensure accessible health information, and to identify and respond to the causes of mental health issues that people with disability experience (see Recommendations 5.1 and 5.2).

Housing

Access to affordable, appropriate and secure housing is essential for all people to feel safe and comfortable in their own environment and as a foundation for social inclusion. People with disability are no different. However, accessibility, economic disadvantage and support requirements can lead to barriers in securing housing that meets the needs of people with disability. There are profound impacts on a person's physical and mental health when they cannot choose or control their living arrangements. This can also affect their capacity and desire to participate in other domains of life.

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[18]   *Submission S051*, Women with Disabilities Victoria, p.15; *Submission S097*, Whitehorse City Council, p.11.
[19]   *Transcript of Evidence,* Summer Foundation Ltd, p.4.

Like others in the community, people with disability live in diverse types of housing and accommodation, and like all members of the community their living arrangements depend on their unique circumstances. Factors such as location, appropriate support and housing design are key considerations for ensuring housing enables social inclusion. People with disability need to choose the living arrangements that are suitable to their lifestyles and the following range of housing generally exists:

> *For most people, it is easy to make a decision and move house. For me it has not been easy at all. The difference has been money and finding a suitable house, end of story. What others have the freedom to do, I do not.[20] (Bily)*

- living in the community—such as their own home, renting, or living with a partner, family or friends

- living in communities with specialist disability support—such as KeyRing models and supported living arrangements

- living in government funded disability accommodation—such as shared supported accommodation.

The Committee identified that people with disability experience ongoing issues in accessing affordable, appropriate and secure accommodation. As a result they often have limited options and choices in their living arrangements.

Inaccessible housing remains a persistent issue for people with disability. The *State disability plan 2013–16* encourages the building industry, councils and social housing providers to incorporate the *Livable housing design guidelines*. The Committee recommends that the Victorian Government is more specific about how it intends to do this and introduce incentives, for example stamp duty concessions (see Recommendation 5.3).

The Committee recognises that some people with disability will need to access mainstream services to live independently in their homes and that the NDIS will assist its participants to achieve this. This includes:

- supports that build people's capacity to live independently in the community

- home modifications to the participant's own home or private rental property

- support with personal care—such as assistance with showering or dressing

- domestic assistance around the home where the participant is unable to undertake these tasks due to their disability.

In addition to these supports, the Committee identified a need for developing flexible housing models that meet the needs of people with disability. The Committee recommends that the Victorian Government work with the NDIA in the co-design stage of the NDIS to ensure resourcing for flexible housing models (see Recommendation 5.4).

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[20]   *Transcript of Evidence,* Summer Foundation Ltd, p.4.

Creating opportunities for participation

Participation in social, economic and community life can provide avenues for social interaction, opportunities for learning and developing skills, and pathways to financial security. Members of the community, including people with disability, can benefit considerably from their experience of participating in society. In turn, there are also valuable returns for local communities, the economy and society generally.

The ways that people participate in the community vary enormously, and people with disability contribute to society in equally diverse ways providing valuable skills, knowledge and experience. People with disability continue to participate in segregated activities—sometimes by choice, sometimes through necessity—such as supported employment, specialist schools, disability sports and cultural activities.

While many people with disability actively strive to engage in the community, the Committee heard that they often experience daily challenges in their efforts to contribute and participate.

In the context of education, the Committee heard that many children and young people with disability continue to experience barriers in mainstream, and some specialist, education environments. These barriers include challenges transitioning into and across schools, education environments that are not accessible, supports that do not meet the individual needs of students, and the attitudes of education professionals and other students.

Inquiry participants emphasised that most people with disability want to work, and that participation in the workforce is a key component of social inclusion. The Committee heard that being employed contributes to people with disability feeling valued and recognised as equal and contributing members of society. Paid employment also allows people with disability to support themselves and provides the means to participate in other social and cultural spheres of society.

> *I have a very expensive passion (being photography), and being on the disability [support pension] basically means I couldn't afford to pursue it.*
>
> *But having a job/income, and a supportive workplace means I can afford to pursue my photography, and cope with the balance between work/study.[21] (Aaron)*

It is well established that the employment of people with disability in Australia is substantially lower than the employment of others in the community, and that Australia compares poorly with other countries in the OECD.[22] The Committee heard that low participation rates and reduced opportunities to contribute to their best potential often relates to the attitudes of employers, inaccessible work environments, assumptions about the productivity of people with disability, and an inflexibility across workplaces to adapt to people with different functioning levels.

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[21] *Submission S111*, Melbourne City Mission, p.11.

[22] Deloitte Access Economics (2011) *The economic benefits of increasing employment for people with disability*. Sydney, Access Economics Pty Ltd, p.ii.

The Committee received information about the State Disability Transition Program in South Australia. This is a partnership between the school and Vocational Education and Training (VET) sectors and the South Australian and Australian governments to promote Open Employment within school communities. The aim of this early intervention approach is to support a smooth transition from school to real work for students with disability and has had demonstrated success.[23]

In addition to education and employment, like others in the community, people with disability participate in a diverse range of other activities, including:

- a multitude of sporting activities, yet at substantially lower rates than other people in the community despite the valuable health benefits

- arts and cultural activities, but often experience barriers that prevent their full participation due to physical inaccessibility, negative attitudes and lack of information about accessibility

- in advocacy and leadership roles within the disability community, but there remain very few people with disability in political and other elected roles in the broader community, such as boards and committees of management.

The Committee recognises that in its *State disability plan 2013–16* the Victorian Government has a multitude of strategies and implementation actions relating to education, employment, sports and recreation, and increasing the voice and representation of people with disability. It also acknowledges the role that the NDIA will have in providing early childhood education supports under the NDIS.

> *I'm involved in local community groups like Whitehorse Disabilities Advisory Group and the Alfred Community Advisory Group. I volunteer, talking to people in hospital who may be about to or who have just undergone limb amputation, and serve in medical research Committees.[24]*
> *(woman with disability)*

The Committee recommends that future implementation plans and State Disability Plans include measurable outcomes and targets for strategies and actions that relate to increasing participation by people with disability (see Recommendation 6.1).

In addition, the Committee recommends that the Victorian Government:

- undertake a study of children with disability who progress from early childhood education into schools over the next five years to identify the extent to which mainstream schools provide inclusive environments for children with disability (Recommendation 6.2)

- commission a review of reverse integration approaches to assess their value and potential to provide exposure and increased awareness for children of all abilities to the diversity of children with disability (Recommendation 6.3)

- consider the feasibility of introducing a partnership program between the school and VET sectors and the Victorian and Australian governments to promote open employment within school communities with the intention of

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[23]   South Australian Government Department of Education and Children's Services (2009) *South Australia's State Disability Transition Program.* Adelaide, SA Department of Education and Children's Services.

[24]   *Submission S051*, Women with Disabilities Victoria, p.7.

supporting a smooth transition from school to real work for students with disability (Recommendation 6.4)

- develop a job shadowing program to assist young people with disability to gain experience in the workplace and to provide employers with exposure to the contributions that people with disability can provide (Recommendation 6.5)

- develop a strategy on access to elected office for people with disability (Recommendation 6.6).

Accessible and enabling environments

Seamless access to information, the built environment and transport networks contributes to social inclusion by ensuring that people can live, work and move around the community as they want and need to. Without this seamless access most people would be unable to function properly in society. Unfortunately, however, this is a reality for many people with disability.

Over the past two decades the Victorian Government has continued to make efforts to improve accessibility in the community, including:

- the physical infrastructure of the public transport system

- accessibility of public spaces and new buildings

- providing information in accessible formats.

Yet despite these efforts, people with disability continue to report that they have challenges in accessing and moving through many parts of the community. The Committee determined that there is a need for ongoing attention to be given to accessibility and creating enabling environments.

Environmental factors that continue to limit the choices and participation of people with disability include:

- transport and moving through the community, with key issues relating to whole of journey travel, customer service staff attitudes in the public transport system, and the accessibility of information relating to travel

- accessing the built environment, particularly in older buildings such as schools where staged change needs to occur

- accessing information relevant to their daily lives and engagement with the community.

I currently choose my doctor, dentist, accountant, where I shop for my clothes, what cafes I go to, what entertainment I choose and where I buy my lunch all based on not what the quality of the service is or what I like about it but whether or not I can get into the building.[25] (Keran)

The Committee heard that advances in technology have contributed to the increased physical independence, functional capacity and social interactions of people with disability. However, technology can also create unintended barriers for the participation of people with disability.

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[25] *Transcript of Evidence*, Women with Disabilities Victoria, Melbourne, 6 March 2014, p.2.

Limited accessibility has consequences for social inclusion and the Committee determined that further improvements are needed to make transport, buildings and outdoor spaces more accessible. Access to technology and information are equally important to the daily lives of people with disability and while they enable social inclusion, many people with disability continue to report that barriers exist to accessing technology and information.

The Committee recognises that many of the concerns raised about accessibility have been identified in the *State disability plan 2013–16*. It recommends that in future implementation plans and State Disability Plans, the Victorian Government sets measurable outcomes and targets (see Finding 2.7 and Recommendation 7.1). It also recommends that the Victorian Government develops a long-term strategy for improving the accessibility of pre-existing buildings, such as schools, and public spaces in the community (see Recommendation 7.2)

The Committee also determined that the Victorian Government needs to explore the evolving role of technology in the lives of people with disability, how it enables their social inclusion and identify ways to intersect technology with current support and accessibility initiatives (see Recommendation 7.3).

Changing attitudes and behaviour towards people with disability

Despite improvements over time in how society understands disability and interacts with people with disability, people with disability continue to identify that the attitudes of others are one of the most significant barriers to social inclusion.

The Inquiry heard that attitudes towards people with disability can affect social inclusion in all areas of their life, including their social connections, their access to places and their involvement in employment, education and other activities.

Attitudes towards people with disability include fear, ignorance and being regarded as inferior or as objects of pity. These attitudes can result in low expectations, discrimination, bullying, hostility and avoidance. The Committee identified that there is still a long way to go to achieve the change in attitudes needed to ensure that people with disability are included in our society.

The NDIS will have a limited role in improving awareness and attitudes towards people with disability. The Victorian Government will continue to have an important role in improving attitudes towards disability and how people interact and treat people with disability. It already has a number of mechanisms in place, such as disability action plans, VDAC and anti-discrimination legislation. The Committee recommends

> *The broader community still keeps people with disability at a distance unless it is somebody they're related to, or know well. Society considers people with disability to be lesser beings. We need to change Society's perception of PWD [people with disability]. We need to value people as human beings. It is easier said than done. People need to change the way they think feel and react to people with disability.[26] (Robyn)*

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[26]   *Submission S121*, Summer Foundation Ltd, p.6.

that the Victorian Government initiate a review of Commonwealth, states and territories discrimination legislation to streamline and clarify existing avenues to make a complaint of discrimination (see Recommendation 8.1)

Evidence has shown that initiatives that go beyond changing attitudes to target the way people treat and interact with people with disability can be effective in increasing social inclusion for people with disability. Changing society's attitudes towards people with disability can be achieved at a reasonably low cost using a multi-pronged approach that includes:

- a focus on positive personal experiences and interactions with people with disability

- broad-based approaches and approaches that target specific audiences

- encouraging initiatives that aim to change the way people treat and interact with people with disability, such as children and young people in schools.

In addition to specific initiatives, the Committee recognises that under the Disability Act, public bodies are required to address attitudinal barriers that lead to discriminatory practices against people with disability in their disability action plans. The Committee has recommended that the Victorian Government reviews the monitoring of these plans (see Recommendation 2.3).

In view of the ongoing role of the Victorian Government in improving attitudes towards and treatment of people with disability in Victoria, the Committee recommends that the State Disability Plan in 2016 incorporates a strategy to change attitudes towards people with disability, which would aim to:

- encourage interactions and positive personal experiences between people with disability and members in the community

- change broad community attitudes, prevent children and young people from developing negative attitudes, and target specific audiences to change negative attitudes (such as employers and business owners)

- promote initiatives that aim to change the way people treat and interact with people with disability (Recommendation 8.2).

It also recommends that the Victorian Government establish an inclusion innovation hub to develop innovative approaches to changing attitudes towards people with disability and how they are treated in the general community (see Recommendation 8.3).

List of recommendations

Number	Recommendation
Defining and measuring social inclusion	
1.1	That the Victorian Government adopt the following definition of social inclusion throughout government:
	• Social inclusion for people with disability means:
	♦ experiencing respect for their differences, their aspirations, and their right to have control over their own lives
	♦ having opportunities to contribute and participate in society in a meaningful way and feel valued
	♦ experiencing significant and reciprocal relationships
	♦ having appropriate supports, where necessary.
1.2	That the Victorian Government review the range of mechanisms for measuring the social inclusion of people with disability—including local, national and international tools—and identify an appropriate method for determining levels of social inclusion experienced by people with disability in Victoria.
Leading the social inclusion agenda	
2.1	That the Victorian Government commence a review of the *Disability Act 2006* (Vic) by 2019 to ensure it aligns with the *National Disability Insurance Scheme Act 2013* (Cth) and reflects the Victorian Government's future involvement in disability.
2.2	That the Minister for Community Services request that the Victorian Disability Advisory Council (VDAC) develop a strategy to increase its profile and that it will be incumbent on VDAC to implement this strategy.
2.3	That the Victorian Government request the Victorian Auditor-General undertakes an audit of the suitability, effectiveness and implementation, and the monitoring and improvement of disability action plans in local government.
2.4	That the Minister for Community Services seek advice from the Victorian Disability Advisory Council (VDAC) on future directions for social inclusion and that it is incumbent on VDAC to ensure it gathers relevant information to be considered in the development of Tier 2 of the National Disability Insurance Scheme.
2.5	That the Victorian Government work with the National Disability Insurance Agency to clarify the roles and responsibilities of Local Area Coordinators associated with the National Disability Insurance Scheme and Access Officers in the Building Inclusive Communities Program to ensure their social inclusion interventions are complementary.

Number	Recommendation
Aspirations and social inclusion	
3.1	That the Victorian Government:
	• Consider how the aspirations of people with disability have changed as a consequence of legislative and policy changes, specifically the *Disability Act 2006* (Vic), by undertaking a follow-up survey to the 2000 study—*The aspirations of people with a disability within an inclusive Victorian community.*
	• Work in partnership with local councils to develop an agreed approach to identifying the aspirations of people with disability in their local communities to be included in disability action plans and the work undertaken by Access Officers.
Sustainable relationships and natural networks	
4.1	That when developing its next State Disability Plan in 2016 and in consultation with people with disability, the Victorian Government incorporate a strategy for effectively and appropriately strengthening connections and social capital with three objectives:
	• create opportunities for establishing and maintaining connections and networks—such as new networks and building the capacity of people with disability who need support
	• establish favourable conditions for sustainable relationships and networks—such as social 'brokerage' (mentors, coaches) and good public infrastructure
	• support existing opportunities and networks—such as existing programs that aim to provide opportunities for increased social interaction.
Foundations for social inclusion	
5.1	That the Victorian Government incorporate into future State Disability Plans specific strategies, actions and targets that aim to:
	• improve health promotion efforts for people with disability
	• ensure accessible health information
	• identify and respond to the causes of mental health issues that people with disability experience.
5.2	That the Victorian Government negotiate with the National Disability Insurance Agency to establish an online forum for the disability service sector to ensure up-to-date and clear information about the services available to people with disability and their families in Victoria, in order to ensure a smooth transition between Victorian supports and supports to be provided under the National Disability Insurance Scheme.

INQUIRY INTO SOCIAL INCLUSION AND VICTORIANS WITH DISABILITY

Number	Recommendation
Foundations for social inclusion (cont)	
5.3	That the Victorian Government is more specific about its intentions to encourage the building industry, councils and social housing providers to incorporate the national *Livable housing design guidelines* and introduces specific incentives to encourage the development of affordable housing that meets livable housing design guidelines.
5.4	That the Victorian Government negotiate with the National Disability Insurance Agency to ensure resourcing for flexible housing models that have proven success in promoting the social inclusion of people with disability.
Creating opportunities for participation	
6.1	That the Victorian Government establish measurable outcomes and targets in future State Disability Plans and implementation plans that relate to increasing participation by people with disability in education, employment, sports and recreation, cultural activities, and political and other elected roles.
6.2	That the Victorian Government undertake a study of children with disability who progress from early childhood education into schools over the next five years to identify the extent to which mainstream schools provide inclusive environments for children with disability.
6.3	That the Victorian Government commission a review of reverse integration approaches to assess their value and potential to provide exposure and increased awareness for children of all abilities to the diversity of children with disability.
6.4	That the Victorian Government consider the feasibility of introducing a partnership program between the school and Vocational Education and Training sectors and the Victorian and Australian governments to promote open employment within school communities with the intention of supporting a smooth transition from school to real work for students with disability.
6.5	That the Victorian Government develop a job shadowing program to assist young people with disability to gain experience in the workplace and to provide employers with exposure to the contributions that people with disability can provide.
6.6	That the Victorian Government develop a strategy on access to elected office for people with disability.
Accessible and enabling environments	
7.1	That the Victorian Government establish measurable outcomes and targets in future State Disability Plans and implementation plans that relate to improved accessibility for people with disability in the built environment and public spaces, accessible information, and whole of journey travel. Tender requirements should give consideration to the priority of the needs of

Number	Recommendation
	people with disability.

Accessible and enabling environments (cont)

Number	Recommendation
7.2	That the Victorian Government identify a long-term strategy for improving the accessibility of pre-existing buildings, such as schools, and public spaces in the community.
7.3	That the Victorian Government explore the evolving role of technology in the lives of people with disability and how it enables their social inclusion to identify ways to intersect technology with current support and accessibility initiatives.

Changing attitudes and behaviour towards people with disability

Number	Recommendation
8.1	That the Victorian Government initiate a review through the Council of Australian Governments in order to streamline and clarify the interaction of state and Commonwealth avenues for lodging complaints about discriminatory treatment of people with disability.
8.2	That the Victorian Government incorporate a strategy into its future State Disability Plan in 2016 to change attitudes towards people with disability and how they are treated in the general community that aims to: • encourage interactions and positive personal experiences between people with disability and members in the community • change broad community attitudes, prevent children and young people from developing negative attitudes, and target specific audiences to change negative attitudes • promote initiatives that aim to change the way people treat and interact with people with disability.
8.3	That the Victorian Government establish an inclusion innovation hub to promote the development of innovative approaches to changing attitudes towards and interaction with people with disability.

Inquiry process

On 26 November 2013, the Parliament of Victoria's Legislative Council asked the Family and Community Development Committee to inquire into social inclusion and Victorians with a disability. The following box outlines the Terms of Reference for the Inquiry.

Terms of reference

Inquire, consider and report on social inclusion and Victorians with a disability, specifically:

    a.   define 'social inclusion' for Victorians with a disability;

    b.   identify the nature and scale of relative inclusion (exclusion) and participation of Victorians with a disability in the economic, social and civil dimensions of society;

    c.   understand the impact of Victorian government services and initiatives aimed at improving inclusion and participation;

    d.   identify examples of good practice on inclusion and participation driven by local government and the community sector;

    e.   assess how the *Disability Act 2006* has impacted on the social inclusion of people with a disability with respect to Victorian government services; and

    f.   recommend ways to increase social inclusion, including the roles of and collaboration between local, state and federal governments, the community sector, individuals with a disability and their carers.

In undertaking its Inquiry, the Committee considered the scope of the investigations it needed to undertake and how social inclusion and participation of people with disability can be improved in Victorians now and into the future.

To ensure it could review the extensive amount of evidence received, the Committee requested and was granted an extension to its tabling timeline to 17 September 2014.

Inquiry method

The Committee undertook a comprehensive range of methods to gather evidence to inform its findings and recommendations. These included calling for written submissions, holding public hearings, and seeking further information from organisations.

Submissions

To assist those who wanted to make a written submission to the Inquiry, the Committee released a Submission Guide. This was published on the Committee's website and circulated to those who expressed an interest in submitting to the Inquiry.

The Submission Guide outlined the scope of the Inquiry and the process for making a written submission. It provided an outline on the types of issues about which it was seeking evidence. It posed questions for individuals and

organisations to consider when preparing their submissions. A copy of the Submission Guide is provided in Appendix 1.

On 14 December 2013, a call for submissions was advertised in *The Age* and the *Herald Sun*. In addition, between 14 and 18 December 2013 advertisements were included in *The Weekly Times* and five regional newspapers across Victoria.

The Committee extended its invitation for submissions through an extensive database comprising a range of individuals and organisations, such as service providers, peak and advocacy bodies, community groups, research institutes and academics, and local government.

The initial due date for submissions was 28 February 2014. Due to the high level of interest in the Inquiry, the Committee continued receiving submissions until 30 April 2014.

The Committee received 133 written submissions from a range of individuals and organisations. The authors of these submissions included:

- individuals

- service providers

- professional organisations from the disability, health and education sectors

- advocacy and community organisations

- local governments

- peak and statutory bodies

- academics and research organisations.
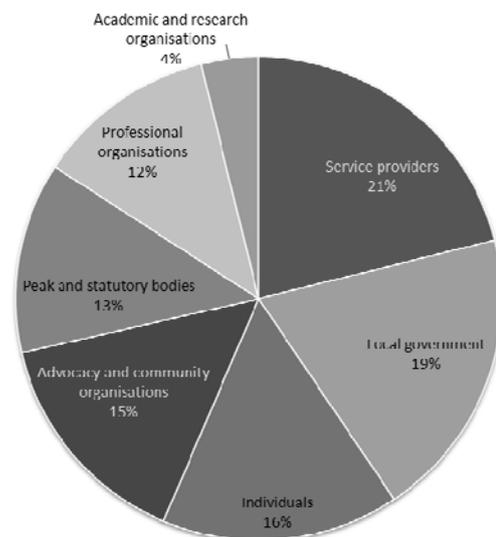
Public hearings

The Committee held hearings between March and May 2014. It heard from a range of organisations, including academics and research groups, peak bodies, service providers and other organisations representing the interests of people with disability. The Committee also heard from the Department of Human Services and the Department of Education and Early Childhood Development.

In total, 75 witnesses (including people with disability) appeared before the Inquiry, representing 39 organisations and government departments.

Additional information

Throughout the Inquiry, the Committee actively sought information via correspondence from organisations, statutory bodies, experts and government departments. This additional information related to queries about evidence or information provided, or concerned newly emerging issues.

Chapter 1
Defining and measuring social inclusion

AT A GLANCE

Background

To understand the social inclusion of people with disability, clear definitions of 'disability' and 'social inclusion' are required. Recent reports, such as the 2009 Shut Out report, reveal that people with disability continue to feel socially excluded in the Australian community. To determine the extent and nature of relative inclusion (exclusion) and participation in Victoria, a robust measuring tool is essential.

Key findings

- Social inclusion for people with disability means:
  - their differences, their aspirations and their right to have control over their own lives are respected
  - they have opportunities to contribute and participate in society in a meaningful way and feel valued
  - they have significant and reciprocal relationships
  - where necessary, they have appropriate support to be socially included. **(Finding 1.1)**

- Participation tends to focus on the level of engagement in particular activities, yet simply being involved in activities does not imply inclusion. Social inclusion, on the other hand, has a greater focus on people's experience of these activities and the extent to which they feel valued and respected for their contributions to society and the degree to which communities accept and embrace people with disability. **(Finding 1.2)**

- Like others in the community, people with disability are diverse. They vary considerably in their:
  - age, gender, culture, and geography
  - Aboriginal, CALD, and social and economic backgrounds
  - experiences, needs and aspirations
  - type of disability and their level of functioning within their disability. **(Finding 1.3)**

- The needs and daily experiences of people with disability vary depending on impairment type, its complexity, community attitudes and perceptions of the impairment. However, it cannot be assumed that all people with a particular type of disability share a common set of needs that is different from the needs of people with another type of disability. **(Finding 1.4)**

- There is currently no effective tool for measuring social inclusion and participation of people with disability that can be used to determine the effectiveness of the Victorian Government's *State disability plan 2013–16*, related initiatives and efforts, or broader disability policies and legislative frameworks, in advancing the social inclusion of Victorians with disability. **(Finding 1.5)**

- Victorians with disability continue to express experiences of social exclusion, lack of belonging and restricted opportunities to participate meaningfully in education, employment and other goals they aspire to. Their reasons include inaccessible environments, community attitudes, financial insecurity, housing issues, and difficulties accessing health and other supports. **(Finding 1.6)**

AT A GLANCE

Recommendations

That the Victorian Government adopt the following definition of social inclusion throughout government:

- Social inclusion for people with disability means:
    - ◆ experiencing respect for their differences, their aspirations, and their right to have control over their own lives
    - ◆ having opportunities to contribute and participate in society in a meaningful way and feel valued
    - ◆ experiencing significant and reciprocal relationships
    - ◆ having appropriate supports, where necessary. **(Recommendation 1.1)**

That the Victorian Government review the range of mechanisms for measuring the social inclusion of people with disability—including local, national and international tools—and identify an appropriate method for determining levels of social inclusion experienced by people with disability in Victoria. **(Recommendation 1.2)**

To address the issue of social inclusion, communities need to understand what social inclusion means for people with disability and the extent to which they experience it. The Committee identified that social inclusion is frequently understood in the context of participation alone, or 'passive' participation rather than 'active' participation.

In 2009, the National People with Disabilities and Carer Council released a report titled *Shut out*. It reported that people with disability continue to experience challenges in simply securing:

> … somewhere to live, somewhere to work. All too often they are unable to access education, health care, recreation and sport—the very things most people in the community take for granted. They are denied access to kindergartens, schools, shopping centres and participation in community groups. They are often isolated and alone. Their lives are a constant struggle for resources and support.[1]

The Committee received overwhelming evidence that the experience for Victorians with disability mirrors the findings of the *Shut out* report, with many feeling socially excluded and unable to participate in society in ways that reflect their aspirations.

While considerable progress has been achieved in recent decades in improving the lives of people with disability, there is prevailing evidence demonstrating:

- inequitable access to education, employment, housing and health opportunities

- feelings of isolation, lack of autonomy, and pervasive discrimination and devaluation

- community attitudes that create barriers to participation.

To determine the nature and scale of current inclusion and exclusion of people with disability, the Victorian Government needs to adopt a definition of social inclusion that reflects agreed community understanding and to develop an appropriate tool to measure experiences of social inclusion.

1.1. The concept of social inclusion

A key purpose of this Inquiry is to define social inclusion for Victorians with disability. As part of this, it is necessary to first consider the concept of social inclusion and how it emerged as a means to understanding disadvantage at a societal level. Despite the extensive use of social inclusion as a guiding principle in social policy frameworks, there is limited agreement about how to define 'social inclusion' or the concept of social exclusion, with the two concepts viewed as sitting at opposite ends of a single dimension.[2]

In its submission to the Inquiry, Scope (Vic) stated that:

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[1]   National People with Disabilities and Carer Council (2009) *Shut out: The experience of people with disabilities and their families in Australia*. Canberra, Commonwealth of Australia, p.vi.

[2]   A. Pate (2009) *Social in/exclusion: Mere words, or a key framework for understanding and addressing disadvantage*, Melbourne, Melbourne City Mission, p.5.

> Various definitions of social exclusion engage with the concepts of poverty, inadequate income, income inequality, impoverishment (as a broader notion), consumption and deprivation.[3]

Social exclusion is a multi-dimensional and complex concept that provides a broader approach to understanding disadvantage and which looks beyond poverty and deprivation. When social exclusion emerged as a conceptual framework in Europe, it represented a shift away from the impact of inadequate resources on the capacity of individuals to access goods, activities and services. Instead it focused on issues of social connectedness, individual rights and different forms of participation in community life. While deprivation was linked to the notion of 'missing out' as a result of inadequate resources, social exclusion was linked to the notion of being 'left out' of activities 'widely regarded as essential for full membership of society'.[4] According to one research study, social exclusion highlights the role of:

> … institutional structures and community attitudes in creating the barriers that lead to exclusion, the role and nature of voluntary as well as enforced exclusion or withdrawal, the importance of relational issues, the denial of social rights, and the importance of the family and community context in shaping exclusion at the individual level. This explains why exclusion research can uncover social divisions based on gender, race, ethnicity and location that are often obscured when studying poverty as a lack of income.[5]

In its submission, Melbourne City Mission stated that public policy often merges the concepts of social exclusion and social inclusion, despite the significant difference between 'creating inclusion' and 'preventing exclusion'.[6] In particular, this difference is reflected in assumptions about where responsibility lies for achieving these two objectives:

- Responsibility for change to enhance social inclusion lies with society to both invest in conditions for inclusion, as well as remove relevant barriers.

- Social exclusion frameworks focus largely on addressing exclusionary practices in economic and social structures, with limited attention to creating inclusive conditions for all citizens.[7]

In the context of disability, Melbourne City Mission argues that placing greater emphasis on social inclusion is consistent with the social model of disability because 'social inclusion for Victorians with disability should be defined as a human rights issue'.[8] The Committee supports this view and that of the Victorian Equal Opportunity and Human Rights Commission (VEOHRC), which stated in its submission that social inclusion and human rights agendas are mutually reinforcing:

> A person cannot enjoy their human rights if they are socially excluded, and inclusion cannot occur in the absence of their human rights being observed.[9]

As discussed in Chapter 2, social inclusion is now a common objective of most national and state policy responses to disability.

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[3] *Submission S129*, Scope (Vic) Ltd, p.8.

[4] *Submission S129*, Scope (Vic) Ltd, pp.7–8.

[5] P. Saunders, Y. Naidoo, & M. Griffiths (2007) *Towards new indicators of disadvantage: Deprivation and social exclusion in Australia*. Sydney, Social Policy Research Centre, pp.12–13.

[6] *Submission S111*, Melbourne City Mission, p.5.

[7] *Submission S111*, Melbourne City Mission, p.5.

[8] *Submission S111*, Melbourne City Mission, p.5.

[9] *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.2.

1.1.1.   Understanding social inclusion for people with disability

Identifying ways to facilitate and enhance social inclusion requires an understanding of what social inclusion means for people with disability. Despite the increasing emphasis on social inclusion in national and state disability policies, there is limited agreement in relevant literature regarding its key dimensions. Researchers have commented that:

> … evidence outlining the dimensions of social integration, inclusion, and participation is still limited in spite of several attempts to define these concepts and provide a conceptual framework or approach.[10]

Inquiry participants provided an overwhelming response to the question in the Committee's Submission Guide about how to define social inclusion for people with disability. The Committee identified common themes in the various definitions proposed, many of which were consistent with the Victorian Department of Health's definition, also referred to in the Submission Guide:

> A socially inclusive society is defined as one where all people feel valued, their differences are respected, and their basic needs are met so they can live in dignity. Social exclusion is the process of being shut out from the social, economic, political and cultural systems which contribute to the integration of a person into the community.[11]

> **Social inclusion**—*means people with disability:*
>
> —*experience respect for their differences, their aspirations and their right to have control over their own lives*
>
> —*have opportunities to contribute and participate in society in a meaningful way and feel valued*
>
> —*experience significant and reciprocal relationships*
>
> —*have appropriate supports, where necessary.*

However, the Committee heard that the Whittlesea Disability Network 'sees a truly inclusive community as far more than the Parliamentary Committee's definition' used in its Submission Guide. It went on to explain that:

> … inclusion is more than having our basic needs met. Inclusion is about having the opportunity to fulfill our goals, our aspirations, our dreams and to live in and contribute to a community where these are acknowledged and supported as our rights as equal human beings.[12]

Participants emphasised the importance of respect, feeling valued and creating opportunities for meaningful participation in society. In particular, the role of participation in employment, education and social activities in promoting inclusion in the community was evident in both the evidence the Committee received and in the broader literature. Participants identified that inclusion can be assisted by the sharing of common interests instead of focusing on disability types or disadvantage.[13]

The Committee also heard that social inclusion is about relationships, social connectedness, and being recognised as a valuable member of the community. For example, Karingal told the Inquiry that:

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[10]   L. Martin & V. Cobigo (2011) 'Definitions matter in understanding social inclusion'. *Journal of Policy and Practice in Intellectual Disabilities*, Vol. 8, No. 4 (276–82), p.276.

[11]   Department of Health *What is social inclusion?* Aged Care in Victoria. Accessed on 14 August 2014 from http://www.health.vic.gov.au/agedcare/maintaining/countusin/inclusion.htm.

[12]   *Submission S037*, Whittlesea Disability Network, p.1.

[13]   *Submission S030*, Belonging Matters, p.1. See also *Submission S056*, Inclusion Melbourne, p.8; *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.4.

> Social inclusion is about connection … It is the opportunity to connect with family, friends and the local community and in doing that feel belonging. It is the difference between participation and what I would call genuine participation.[14]

Chapter 4 discusses the intersections between social inclusion and social connectedness in depth.

In its submission, Belonging Matters emphasised to the Inquiry what does not represent social inclusion—that is, experiences of segregation and isolation. It stated that:

> Social inclusion for Victorians with disability IS NOT being confined to disability-specific groups which exclude people from typical and ordinary opportunities. Similarly, social inclusion is not 'special'—it is not special groups or special programs, such as neighbourhood house groups, day programs, special TAFE programs, 'disability discos,' or congregate social enterprise which exist in isolated enclaves. It is not 'parallel pathways' through life (e.g. special schools, sheltered workshops, supported residential services).[15]

The Research Program Leader and Deputy Chair of the Academic Board at La Trobe University, Professor Christine Bigby, similarly advised the Inquiry:

> You cannot have social inclusion if you are segregated and isolated from the rest of the community.
>
> … the evidence shows too that if you segregate people it not only isolates them from the community, but it gives an impression and it forms public attitudes around where people with disability belong, which is 'over there' and not part of the community.[16]

Inclusion Melbourne suggested that moving beyond segregation extends to the definition of social inclusion and that 'the very essence of inclusion requires there to be one definition of social inclusion for all Victorians, regardless of ability.'[17]

SkillsPlus and BRACE stated in its submission that social inclusion means not having to advocate for every aspect of life, both within and outside disability support services.[18] Similarly, UnitingCare Community Options referred to the notion of access being automatic and provided naturally rather than having to be requested.[19]

The Committee heard that, like everyone, people with disability have the basic human right to determine the course of their own lives.[20] Inquiry participants emphasised that choice, control and self-advocacy are central to achieving social inclusion for people with disability, particularly in the context of client centred service planning and individualised funding.[21] In his evidence the Executive Officer of the Victorian Advocacy League for Individuals with Disability (VALID), Mr Kevin Stone, advised the Inquiry that when talking about inclusion for people with disability, it refers to:

> … a person's right to have choice and control over their own lives as to who they are with, where they go and what they actually do. For people with intellectual disability, that process of empowering them to make those choices is what we call self-advocacy—learning to be a strong self-advocate and speak up for yourself. Our experience is that

14 *Transcript of Evidence*, Karingal, Melbourne, 26 May 2014, p.3.
15 *Submission S030*, Belonging Matters, p.2.
16 *Transcript of Evidence*, Professor Christine Bigby, La Trobe University, Melbourne, 20 March 2014, p.3.
17 *Submission S056*, Inclusion Melbourne, p.2.
18 *Submission S042*, SkillsPlus and BRACE, p.3.
19 *Submission S070*, UnitingCare Community Options, p.4.
20 *Submission S048*, City of Boroondara, p.3.
21 *Submission S088*, Vicdeaf, pp.6–7; *Submission S089*, The Able Movement, p.12.

> when a person starts to take control of their life they start to develop self-confidence and self-esteem, and the no.1 barrier to inclusion in our experience is poor self-esteem and a lack of self-confidence. It is all very well to open up the community — and of course we need to open up the community—but if the barriers are inside a person's own heart and soul, they do not overcome that easily.[22]

At a broad level, the Victorian Council of Social Service (VCOSS) indicated in its submission that while there is limited use in engaging in a debate over definitions, it is important that any definition of social inclusion capture the following components:

> Multi-dimensionality—social inclusion goes beyond a single measure of deprivation to look at the variety of abilities and opportunities that people require in order to live fulfilling lives.
>
> Interactivity—social inclusion emphasises the interaction between people and their physical and social environment, by participating in social and economic activities, connecting with other individuals and groups, and being able to acquire goods and services.
>
> Diversity—social inclusion recognises differences between individuals, including differences in their background and abilities, as well as differences in their desires and aspirations to lead meaningful lives.[23]

In its submission, Scope (Vic) recommended that the Inquiry adopt a model of inclusion which recognises the three distinct components of physical, functional and social inclusion.[24] The framework was developed with Deakin University and uses a definition of social inclusion that encompasses multiple domains, based on research into the experiences of social inclusion of people with disability. Box 1.1 outlines this framework.

Box 1.1: Example of a social inclusion framework

- Social participation—for example participating in:
  - some type of social activity
  - arts and cultural activities
  - sport or recreational activities.
- Social relationships and supports—for example:
  - being treated with respect by others
  - getting help from family and friends when you need it
  - feeling valued by society.
- Services access—for example accessing:
  - disability support services
  - mental health services
  - medical services.
- Economic/Materials—for example:
  - keeping up payments for water, electricity, gas or phone

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[22] *Transcript of Evidence*, VALID (Victorian Advocacy League for Individuals with Disability Inc), Melbourne, 3 March 2014, pp.2–3.

[23] *Submission S126*, Victorian Council of Social Service (VCOSS), p.8.

[24] *Submission S129*, Scope (Vic) Ltd, p.12.

Box 1.1: Example of a social inclusion framework

- ◆ having enough money to fulfil basic needs

- ◆ having decent and dependable home/housing.

- • Political inclusion—for example:

  - ◆ participating in political and civic processes

  - ◆ having a say on issues that are important to you

  - ◆ voting when required

Source: Adapted from *Submission S129*, Scope Vic (Ltd), p.4.

The Committee considered that the Scope provides a useful framework regarding the key dimensions of social inclusion.

In 2009, researcher Sarah Hall conducted a systemic analysis of research into social inclusion and disability. The study identified six key themes from 15 relevant research papers that are important for people with disability to achieve greater social inclusion:

1. being accepted as an individual beyond disability

2. having significant and reciprocal relationships

3. being involved in activities

4. having appropriate living accommodations

5. having employment

6. receiving formal and informal supports.[25]

The study concluded that achieving social inclusion for people with disability should comprise three key elements—involvement in activities, maintaining reciprocal relationships, and having a sense of belonging:

> Involvement in activities included structured recreation, leisure, church, volunteer, and the use of community amenities. Developing and maintaining reciprocal relationships were important with family, friends, co-workers and acquaintances in the community. A person experienced a sense of belonging when she/he was accepted by others, seen as an individual, had positive interactions with others, and was not excluded through marginalisation, teasing, or bullying.[26]

The Committee determined that social inclusion in the context of disability should be understood in the same way it is for all people in the community. It relates to people feeling valued. It means experiencing respect for differences, aspirations and the right to control our own lives. It also relates to having opportunities to participate in society in a meaningful way. Social inclusion should also be understood to occur in multiple contexts and in all aspects of a person's life.

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[25] S. Hall (2009) 'The social inclusion of people with disabilities: A qualitative meta-analysis'. *Journal of Ethnographic & Qualitative Research*, Vol. 3, (162–73), p.167; L. Martin & V. Cobigo (2011) *Definitions matter in understanding social inclusion*, p.277.

[26] S. Hall (2009) *The social inclusion of people with disabilities: A qualitative meta-analysis*, p.171.

Finding 1.1

Social inclusion for people with disability means:

- their differences, their aspirations, and their right to have control over their own lives are respected

- they have opportunities to contribute and participate in society in a meaningful way and feel valued

- they have significant and reciprocal relationships

- where necessary, they have appropriate support to be socially included.

Recommendation 1.1

That the Victorian Government adopt the following definition of social inclusion throughout government:

- Social inclusion for people with disability means:

  ♦ experiencing respect for their differences, their aspirations, and their right to have control over their own lives

  ♦ having opportunities to contribute and participate in society in a meaningful way and feel valued

  ♦ experiencing significant and reciprocal relationships

  ♦ having appropriate supports, where necessary.

1.1.2.   Social inclusion and participation

The Committee identified a tendency for the concepts of social inclusion and participation to be used interchangeably. It determined, however, that while intertwined in a practical sense, the two concepts are different. The Committee heard that merging the concepts of participation and social inclusion can lead to inaccurate measures of social inclusion and ineffective interventions.

In regard to disability and social inclusion, one research study found that:

> … simply being involved in leisure and productive activities (ie. objective measures) yielded much higher rates than did the subjective indicators for those domains. Therefore, if social inclusion is based on participation in activities alone, many more will be deemed included than if it was based on the person's more subjective experience of these activities.[27]

Participation, or lack of, is a key component for understanding the concept of social exclusion. In this context, an individual is considered to be socially excluded if they do not participate or are denied the opportunity to participate in activities that are customary in the society in which they live.[28] These activities typically relate to economic, social, cultural and political spheres of society, and are often used to inform social exclusion research.[29]

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[27] L. Martin & V. Cobigo (2011) *Definitions matter in understanding social inclusion*, p.279.
[28] *Submission S061*, Associate Professor Erin Wilson, School of Health and Social Development, Deakin University pp.5–6; *Submission S129*, Scope (Vic) Ltd, p.7.
[29] *Submission S129*, Scope (Vic) Ltd, p.7.

The Committee acknowledges that participating or being involved in activities is a key indicator of social inclusion. While some Inquiry participants indicated that social inclusion is the overall outcome with participation part of the process, others argued that participation is an important indicator of a program's inclusiveness. Consistent with both of these views is the notion that social inclusion is a two way process that involves both the broader community and individuals. Box 1.2 outlines some of the views of Inquiry participants regarding the terms 'participation' and 'social inclusion'.

Box 1.2: 'Social inclusion' and 'participation'

- The terms 'social inclusion' and 'participation' are not interchangeable. Social inclusion is much more than merely participation. Social inclusion is about people with disability having valued social roles and becoming contributing members of the community. Where participation is tokenistic and largely based on a charity model, social inclusion focuses on empowerment of the person with disability and their family and community development and education. (*Submission S124*, Independent Disability Services, p.2)

- 'Social inclusion' is a collective effort from the community to make provisions for people with disability to participate in social events; hence the onus is on the community (active role) to show that the people with disability (passive role) are welcome to join in. Given an inclusive environment, 'participation' is possible when the person with disability is actively engaged in the social activities that he/she enjoys, sometimes with the assistance from other participants/carers. The person with disability takes a more active role in 'participation' and the community acts in a more passive and supportive role. (*Submission S096*, Knox Disability Advisory Committee, p.2)

- Technically, Deaf and hard of hearing people are able to participate in their local sporting club, but without being able to take part in the social interaction, and without the communication and understanding needed by the sporting club, the participant will not feel socially included unless communication is made easier and more natural. (*Submission S007*, Deaf Victoria Inc, p.4)

- The term 'meaningful inclusion' is important to Down Syndrome Victoria. People with Down syndrome often experience gestures of tokenistic inclusion, resulting in a negative impact on the person and family, and potentially a reluctance to continue with the activity… Meaningful inclusion is not just about having a person with Down syndrome being present in a mainstream school, a workplace, a sporting club or a community group, it's about welcoming that person, reducing the barriers, and allowing the person to participate genuinely in the activities of the group. (*Submission S026*, Down Syndrome Victoria, p.1)

- Participation is when people with disability decide to take part in these economic, political and cultural systems. The distinction is important because it illustrates the two way process of social inclusion in which organisations not only need to ensure that communities are ready to integrate people with disability, but that people with disability feel sufficiently engaged enough to want that integration. (*Submission S017*, City of Stonnington, p.4)

Box 1.2: 'Social inclusion' and 'participation'

- Social inclusion is also an integral right for all Victorians, but participation is distinguished from it due to the complex, nuanced and proactive action it demands from individuals, organisations and the community at large. True, genuine participation is the best expression and result of fully realised equality which social inclusion promises. (*Submission S040*, Early Childhood Intervention Australia (Victorian Chapter), p.3–4)

- … there is a continuum of participation in community groups from very active participation, where there is equal membership and where there are shared activities, to where people with and without disabilities benefit from participation. (*Transcript of evidence*, Professor Christine Bigby, p.4)

In the Committee's view, social inclusion goes beyond mere participation, and ultimately involves the connections that people make when participating in activities in society. Social inclusion is about feeling part of a shared community identity, regardless of the size of that community, and being encouraged to participate and contribute to it in a meaningful way. Social inclusion is more than 'passive participation', which simply refers to someone's presence in the community.

Having a clear understanding of the difference between the concepts of social inclusion and participation is also important when measuring the role and effectiveness of government and community services aimed at enhancing experiences of social inclusion for people with disability. Simply being involved in activities does not result in inclusion. It is also necessary to consider people's experiences of these activities.

Finding 1.2

Participation tends to focus on the level of engagement in particular activities, yet simply being involved in activities does not imply inclusion. Social inclusion, on the other hand, has a greater focus on people's experience of these activities and the extent to which they feel valued and respected for their contributions to society and the degree to which communities accept and embrace people with disability.

1.2.   Measuring social inclusion

In view of the limited agreement on the key dimensions of social inclusion, it is difficult to determine how people's experience of inclusion can be effectively measured. In turn, without a clear definition of social inclusion and adequate tools to measure, it is also difficult to measure the effectiveness of efforts to improve the experiences of inclusion for people with disability.[30] According to Professor Christine Bigby of La Trobe University:

> The lack of clear definitions and methods of measuring social inclusion present a challenge to the field to reach a consensus about its conceptualisation and the domain to act as common umbrellas or indicators.[31]

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[30]   L. Martin & V. Cobigo (2011) *Definitions matter in understanding social inclusion*, p.276.
[31]   C. Bigby (2012) 'Social inclusion and people with intellectual disability and challenging behaviour: A systematic review'. *Journal of Intellectual & Developmental Disability*, Vol. 37, No. 4 (360–74), p.371.

In their 2011 research paper on disability, social inclusion and definitions, Martin and Cobigo explained that 'until there is a clear understanding of what social inclusion is, there can be no "gold standard" for its evaluation'.[32]

There is a clear consensus, however, among researchers, government agencies and service providers regarding the value and necessity of effectively measuring social inclusion. This is imperative with the growing emphasis on social inclusion objectives in disability service provision models, legislative frameworks and policies, including the National Disability Insurance Scheme (NDIS). Measuring social inclusion is essential to assess the effectiveness and quality of services supporting greater inclusion.

In addition, effective measurement of social inclusion outcomes can potentially drive improvements in future services, programs and initiatives.[33] For example, in its submission, Mansfield Shire Council stated that reporting on outcomes allows effective initiatives to be replicated and can inform the development of new or improved initiatives.[34] In addition, Yarra City Council indicated that reporting on the outcomes of its Disability Action Plan reinforces its accountability in reporting on the successes and failures of the Plan, which is appreciated by people with disability, their families and carers.[35] The Council also noted that reporting on outcomes served to strengthen the engagement and participation of people with disability in civic and community building initiatives.[36] Chapter 2 discusses disability action plans and other policy initiatives.

1.2.1.   What is disability?

To measure the levels of social inclusion experienced by people with disability it is necessary to understand what is meant by disability. Disability as a concept can be interpreted in multiple ways. This depends on the context in which it is being used, the purpose in which it is applied and the model that it is based on.

For the purposes of this report, the Committee uses definitions contained in Victorian legislation and the Australian Bureau of Statistics (ABS) *Survey of disability, ageing and carers* (SDAC).

The SDAC defines disability as a limitation, restriction or impairment which restricts a person's everyday core activities and is likely to last for at least six months. A person's overall level of core activity limitation is broken down into four levels as outlined in Box 1.3. These levels are based on whether they experience difficulty, need help, or use aids or equipment to undertake any of the core activities of communication, mobility and self-care.[37]

[32]   L. Martin & V. Cobigo (2011) *Definitions matter in understanding social inclusion*, p.281.
[33]   *Submission S045*, National Disability Services Victoria, p.8; *Submission S079*, North East Primary Care Partnership, p.5.
[34]   *Submission S057*, Mansfield Shire Council, p.4.
[35]   *Submission S118*, Yarra City Council, p.13.
[36]   *Submission S118*, Yarra City Council, p.13.
[37]   Australian Bureau of Statistics *Glossary.* 4430.0—Disability, ageing and carers, Australia: Summary of findings, 2012, Canberra, ABS. Accessed on 22 July 2014 from http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4430.0Glossary602012?opendocument&tabname=Notes&prodno=4430.0&issue=2012&num=&view=.

Box 1.3: Four levels of core activity limitation

- Profound — the person is unable to do, or always needs help with, a core activity task.

- Severe — the person sometimes needs help with a core activity task, and/or has difficulty understanding or being understood by family or friends, or can communicate more easily using sign language or other non-spoken forms of communication.

- Moderate — the person needs no help, but has difficulty with a core activity task.

- Mild — the person needs no help and has no difficulty with any of the core activity tasks, but uses aids or equipment, or has one or more of the following limitations.

  ♦ cannot easily walk 200 metres

  ♦ cannot walk up and down stairs without a handrail

  ♦ cannot easily bend to pick up an object from the floor

  ♦ cannot use public transport

  ♦ can use public transport, but needs help or supervision

  ♦ needs no help or supervision, but has difficulty using public transport.

Source: Australian Bureau of Statistics *Glossary*. Disability, ageing, and carers, Australia, Accessed on 22 July 2014 from http://www.abs.gov.au.

In the context of social inclusion, the Committee also considered the definition contained within Section 4 of the *Equal Opportunity Act 2010* (Vic) which is broad in a similar way to that used by the ABS SDAC. It states that disability means:

    a. total or partial loss of a bodily function, or

    b. the presence in the body of organisms that may cause disease, or

    c. total or partial loss of a part of the body, or

    d. malfunction of a part of the body, including—

        (i) a mental or psychological disease or disorder

        (ii) a condition or disorder that results in a person learning more slowly than people who do not have that condition or disorder, or

    e. malformation or disfigurement of a part of the body — and includes a disability that may exist in the future (including because of a genetic predisposition to that disability) and, to avoid doubt, behaviour that is a symptom or manifestation of a disability.

In addition to defining activity limitations, the ABS SDAC broadly groups disability into the areas of sensory, intellectual, physical, psychological, and head injury, stroke or brain damage.[38]

The *Disability Act 2006* (Vic) provides the framework for the protection of the rights and needs of people with disability, as well as the provision of high quality services and supports they might require. It also contains specific definitions of intellectual disability and developmental delay, for which the purposes of the

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[38] Australian Bureau of Statistics (2013) *Appendix 2 - Disability groups*. 4430.0—Disability, ageing and carers, Australia: Summary of findings, 2012. Accessed on 22 July 2014 from http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0.

Disability Act are defined separately. Its definition of disability is outlined in Box 1.4.

Box 1.4: Defining disability — *Disability Act 2006* (Vic)

Disability:

in relation to a person means

1. a sensory, physical or neurological impairment or acquired brain injury or any combination thereof, which—

    a.   is, or is likely to be, permanent, and

    b.   causes a substantially reduced capacity in at least one of the areas of self-care, self-management, mobility or communication, and

    c.   requires significant ongoing or long term episodic support, and

    d.   is not related to ageing, or

2. an intellectual disability, or

3. a developmental delay.

Intellectual disability:

in relation to a person over the age of 5 years, means the concurrent existence of—

1. significant sub-average general intellectual functioning, and

2. significant deficits in adaptive behaviour—

each of which became manifest before the age of 18 years.

Developmental delay:

means a delay in the development of a child under the age of 6 years which—

1. is attributable to a mental or physical impairment or a combination of mental and physical impairments, and

2. is manifested before the child attains the age of 6 years, and

3. results in substantial functional limitations in one or more of the following areas of major life activity—

    a.   self-care

    b.   receptive and expressive language

    c.   cognitive development

    d.   motor development, and

4. reflects the child's need for a combination and sequence of special interdisciplinary, or generic care, treatment or other services which are of extended duration and are individually planned and coordinated.

Source: Adapted from the *Disability Act 2006* (Vic) s.3.

The definition of disability in the Disability Act does not include 'psychiatric disability'. Psychiatric disability is a contested term and the mental health sector tends to use the phrase 'severe and enduring mental illness'. The National Disability Insurance Agency (NDIA) provides supports for people with a 'psychiatric condition who have significant and permanent functional impairment'.[39] This includes people with a 'psychiatric' impairment that results

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[39]   National Disability Insurance Scheme *Mainstream interface: Mental health services.* NDIS fact sheet, p.1. Accessed on 3 September 2014 from
http://www.ndis.gov.au/sites/default/files/documents/supports_ndis_fund_mental_health2_0.pdf.

in 'substantially reduced … psychosocial functioning in undertaking' a range of activities relating to communication, social interaction, learning, mobility, self-care and self-management.[40]

For the purposes of this Inquiry, the Committee adopts the social model of disability, while also acknowledging the diversity of people with disability.

Prevalence and trends

The Committee referred to the ABS SDAC in its consideration of the prevalence and trends relating to people with disability in Victoria. It is the official national survey that measures disability, older people (aged 65 years and over) and those who care for people with disability or older people. The most recent survey was conducted in 2012, with a final sample of approximately 79 200 people, comprising 68 800 from the household component and 10 400 from the cared accommodation component. The Victorian sample of 16 300 comprised 13 800 from households and 2 500 people from cared accommodation.[41]

As shown in Figure 1.1, the prevalence of disability in Victoria has remained reasonably constant over time, increasing by about 1 per cent from 2009 to 2012. The Victorian 2012 rate of 19.4 per cent is slightly higher than the national rate of 18.5 per cent (4.2 million), which according to the Regional Director of the ABS in Victoria, Ms Judy Henson, is due to the older demographic in Victoria compared with other states and territories. In particular, the Victorian disability rate was significantly higher for the 65 to 69 age group compared with the rest of Australia.[42]

Figure 1.1: Percentage of Victorian population with disability
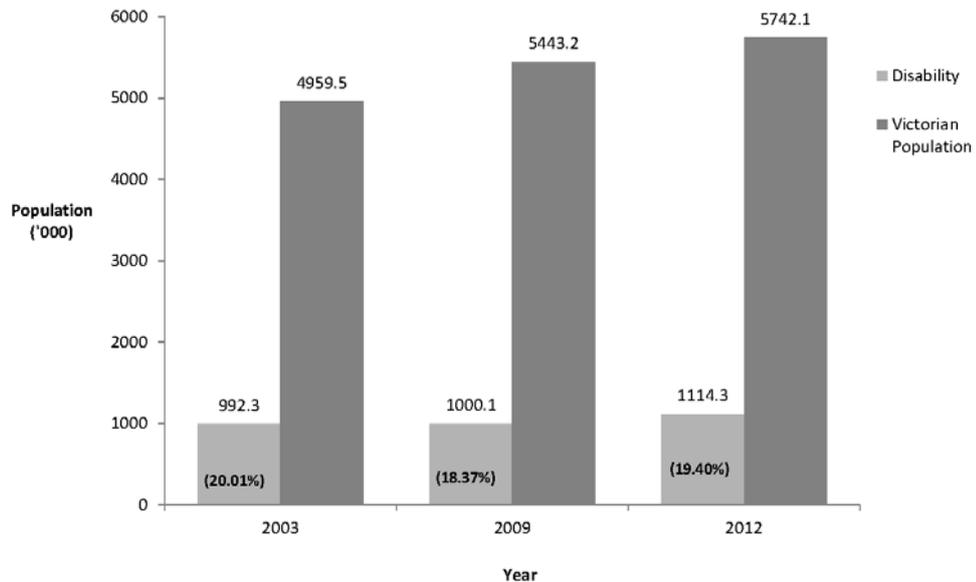
Source: Compiled by the Family and Community Development Committee based on Australian Bureau of Statistics (ABS), Australian demographic statistics from December 2003, 2009, and 2012.

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40   *National Disability Insurance Scheme Act 2013* (Cth) s.24(1)(c).
41   *Transcript of Evidence*, Australian Bureau of Statistics, Melbourne, 17 March 2014, p.2.
42   *Transcript of Evidence,* Australian Bureau of Statistics, p.3.

Figure 1.2 compares the 2009 and 2012 trends in disability prevalence according to age. While there is little difference across most age groups, there are notable increases in disability among the age groups of 15–24, 25–34, 45–54 and 65–69.

Figure 1.2: Percentages of Victorian population with disability (2009 to 2012)
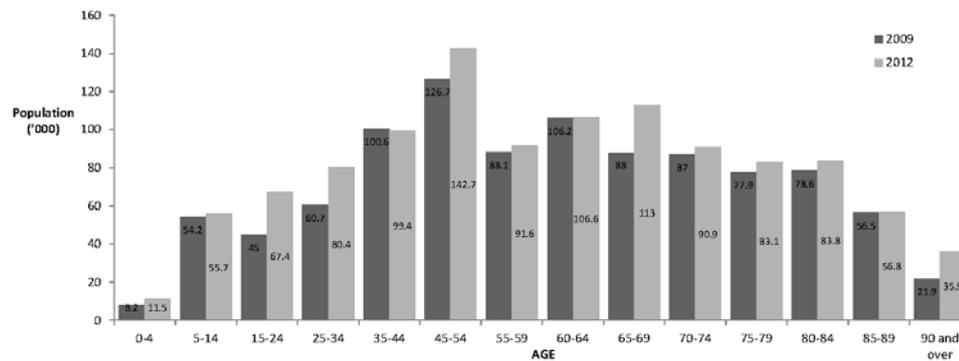
Source: Australian Bureau of Statistics (2014) *Disability, ageing and carers, Australia: Victoria 2012.* cat. no. 44300DO002, Canberra, ABS. Accessed on 14 August 2014 from http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02012?OpenDocument.

1.2.2.   Disability and diversity

Measuring social inclusion is complicated by the vast diversity among people with disability and the multiple influences of disadvantage and discrimination. This was a common theme in the evidence the Committee received. For example, Women with Disabilities Victoria (WDV) stated in its submission that 'social inequity is reinforced by intersecting characteristics, such as gender, disability, ethnicity, education, class, age and geography'.[43]

Some of the influences Inquiry participants identified included gender, cultural diversity, aboriginal background and living in rural and regional locations. Any discussion about disability needs to recognise that people with disability are diverse. Like other people in the community, they have varying backgrounds, demographic characteristics, experiences, needs and expectations. They also live their lives in many contexts and are diverse in their values, attitudes, and roles in society. Ultimately, these differences influence their individual experiences of disability.

Recognition of diversity as it relates to disability is an increasingly common theme in disability policy and legislation. One of the key principles in the Disability Act stipulates that disability services should:

> … be designed and provided in a manner that recognises different models of practice may be required to assist people with different types of disability and at different stages in their lives to realise their physical, social, emotional and intellectual capacities.[44]

In its preamble and general principles, the United Nations (UN) Convention on the Rights of People with Disabilities (UN Convention) also clearly acknowledges disability and diversity, as articulated in Principle (d) of the UN Convention:

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[43]   *Submission S051*, Women with Disabilities Victoria, p.4.
[44]   *Disability Act 2006* (Vic) s.5.

> Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.[45]

Diversity was a common theme in evidence provided to the Inquiry. For example, according to the Darebin Disability Advisory Committee:

> Each person is unique and will have different interests, needs and experiences. This is no different for a person with disability. Social inclusion recognises, acknowledges and celebrates the great diversity in human beings regardless of a person's disability. Diversity within disability includes: people with disability who are ageing, parents with disability, people with a dual diagnosis of disability and a psychiatric disability/mental health condition, women with disability, people with disability who identify as being Gay, Lesbian, Bisexual, Transgendered, Intersex or Queer (GLBTIQ), people with disability from the Aboriginal and Torres Strait Islander community, people with disability from a culturally and linguistically diverse (CALD) background and people with disability who are financially disadvantaged or living in insecure/inappropriate accommodation (e.g. Young People in Nursing Homes). Disability should not be the sole defining feature for a person with disability.[46]

Similarly, the Victorian Council of Social Service (VCOSS) stated in its submission that:

> People with disability are not all the same. Not only do they differ in the types of impairment they experience, they also have different backgrounds, characteristics and life trajectories which affect the requirements they have and the disadvantage they experience. The requirements and views of people with disability may differ, including because of their gender, age, sexuality, cultural and language heritage, Aboriginality, geographic location or family and caring responsibilities.[47]

In this context, Carers Victoria highlighted the need for 'continual vigilance against the "de-differentiation" of people with disability which can assume that all people with disability have similar needs, wants and aspirations'.[48] Carers Victoria indicated that diversity within specific categories of diagnosis of disability should be recognised. It explained that it cannot be assumed that all people with a particular type of disability share a common set of needs that is different from the needs of people with another type of disability.[49]

In the context of impairments, the Committee heard that the daily experiences of people with disability can vary depending on their impairment type, its complexity, and in many cases community attitudes and perceptions towards that impairment. For example, the experiences of a person with an intellectual impairment will differ considerably from a person with a physical impairment. In particular, if the capacity of a person with intellectual disability is severely limited, this is likely to create additional complexities in understanding their needs. However, a person with physical disability, while restricted in a physical sense, may have greater capacity to advocate for their own needs.

The Committee also heard that diversity exists in broader community attitudes and perceptions regarding different types of disability. In her submission, Associate Professor Erin Wilson from Deakin University indicated that various

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45   United Nations Enable (2006) *Guiding principles of the convention.* Convention on the rights of persons with disabilities. Accessed on 21 July 2014 from http://www.un.org/disabilities/default.asp?navid=16&pid=156.
46   *Submission S041*, Darebin Disability Advisory Committee, p.2.
47   *Submission S126*, Victorian Council of Social Service (VCOSS), p.20.
48   *Submission S087*, Carers Victoria, p.2.
49   *Submission S087*, Carers Victoria, p.2.

studies have evidenced more negative attitudes towards people with intellectual disability compared with people with physical disability.[50]

There is also considerable diversity within impairment types, which can impact the types of services and support that each person needs to assist them on a daily basis, and also their priorities and aspirations, and their capacity to participate in the community. For example:

- In the context of acquired brain injury (ABI)—the Victorian Coalition of ABI Service Providers (VCASP) told the Inquiry that every ABI is different. It explained that ABI affects individuals in various ways, depending on the nature and severity of the injury and the appropriateness of the rehabilitation provided, including access to early intervention.[51]

- In the context of loss of vision—people experience varying levels of vision impairment and sometimes blindness. As a consequence, a 'one size' fits all approach is not appropriate for providing accessible information to people with vision loss.[52]

Diversity in the experiences of people with disability is also compounded by individual characteristics or intersecting identities relating to age, gender, and geography, and Aboriginal, cultural, and social and economic background. This can be social or physiological—different circumstances can increase the incidence and complexity of a type of disability or the risk of acquiring a disability. For example, in the context of people with vision loss, Vision Australia stated in its submission that it is:

> … by and large, disability that is age-related, and the ageing of Australia's population is a primary factor in this upward trend. However, secondary contributing factors, such as aboriginality and coming from a culturally and linguistically diverse background, also increases the incidence of blindness and low vision. Certain medical conditions, such as diabetes, are also linked to an increased risk of vision loss.[53]

The impact of the interrelatedness of disabilities with other personal factors on people's experience of social exclusion is discussed throughout this section.

The Committee determined that a focus on the individual rather than the disability is essential to understand experiences of social inclusion for Victorians with disability. This underlies how it has approached this Inquiry and informs its consideration of how to increase opportunities for social inclusion.

Finding 1.3

- Like others in the community, people with disability are diverse. They vary considerably in their:

  ♦ age, gender, culture, and geography

  ♦ Aboriginal, CALD, and social and economic backgrounds

  ♦ experiences, needs and aspirations

  ♦ type of disability and their level of functioning within their disability.

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[50] *Submission S061*, Associate Professor Erin Wilson, School of Health and Social Development, Deakin University p.11.
[51] *Submission S069*, Victorian Coalition of ABI Service Providers Inc (VCASP), p.6.
[52] *Submission S082*, Blind Citizens Australia, p.2.
[53] *Submission S112*, Vision Australia, p.2.

Women with disability

Figure 1.3 outlines the age and sex differences in the number of Victorians with disability. Overall, there is a higher estimated number of females with disability across all of the age groups. Ms Henson also advised the Inquiry that disability rates increase steadily with age, with a rate of 86.8 per cent in people aged 90 and over compared to around 3 per cent of children aged 0 to 4 years.[54]

Figure 1.3: 2012 Victorian population with disability according to age and sex
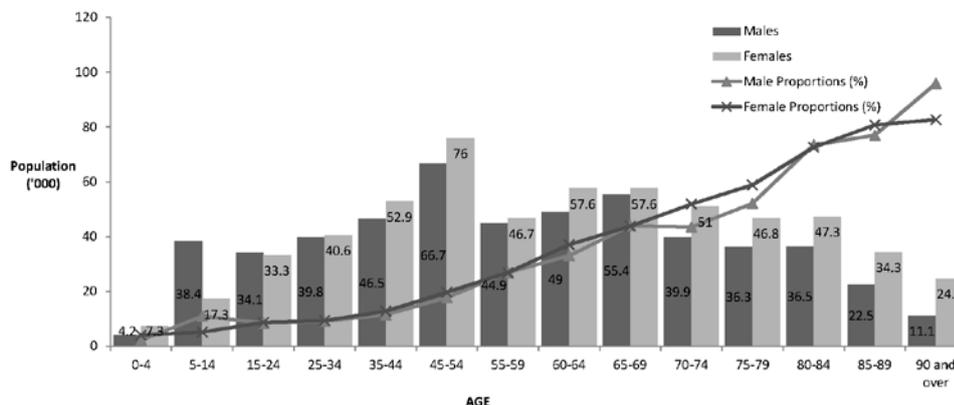
Source: Australian Bureau of Statistics (2014) *Disability, ageing and carers, Australia: Victoria 2012 (Table 3.2).* From http://www.abs.gov.au.

The Committee heard that women with disability can experience particularly high levels of disadvantage and exclusion. For example, Women's Health West directed the Committee to research findings that demonstrates women with disability experience more acute exclusion across more domains, compared with both men with disability and women without disability.[55]

Women's Health West and WDV both raised the issue in their submissions of women with disability being at a much higher risk of violence, with violence against them in the home, institutional and residential care settings continuing to occur at unacceptably high rates.[56] This is discussed further in Chapter 5.

People with disability from CALD backgrounds

In the context of people from culturally and linguistically diverse (CALD) communities, the ABS SDAC asked specific questions about people's country of birth and main language spoken at home. Regarding country of birth, 19.2 per cent of people with disability were born in a non–English speaking country. This rate did not differ significantly from the number of people with disability born in Australia (19.1 per cent). However, when excluding people who recently migrated to Australia, the disability rate increased to 24.6 per cent.[57]

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[54] *Transcript of Evidence,* Australian Bureau of Statistics, p.3.
[55] *Submission S071*, Women's Health West, p.3.
[56] *Submission S071*, Women's Health West, p.8; *Submission S051*, Women with Disabilities Victoria, pp.12–13.
[57] Australian Bureau of Statistics (2013) *Disability, ageing and carers, Australia 2012.* cat. no. 4430.0, Canberra, ABS. Accessed on 14 August 2014 from http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0.

Figure 1.4: Country of birth of people with disability across Victoria (2012)
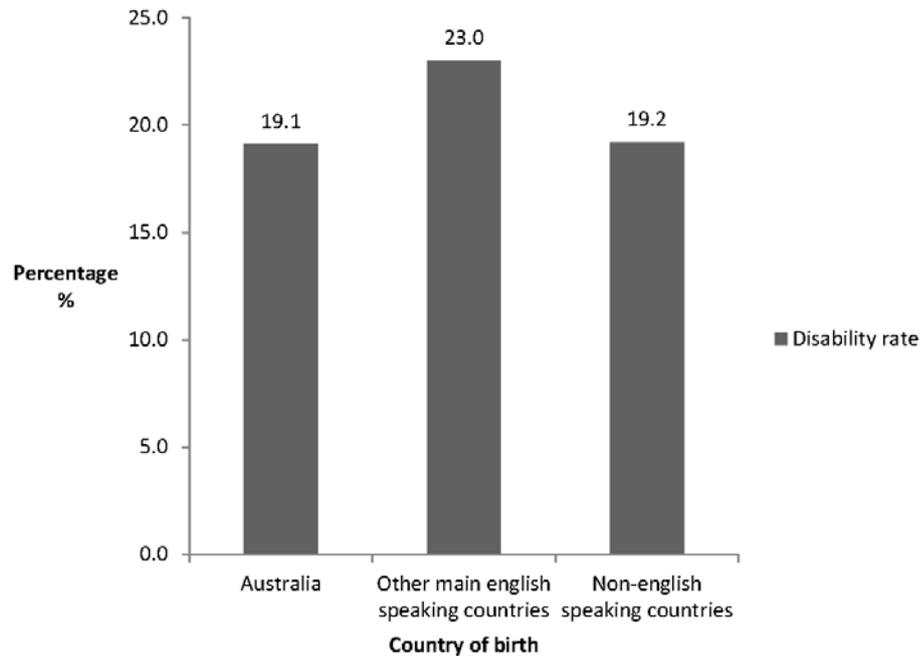
Source: Australian Bureau of Statistics (2014) *Disability, ageing and carers, Australia: Victoria 2012 (Table 4).* From http://www.abs.gov.au.

In regard to main language spoken at home, 19.4 per cent of people with disability spoke mainly English, 17.8 per cent spoke a language other than English, and it was undetermined for 26.3 per cent. When excluding people who recently migrated to Australia, 23.7 per cent of people with disability indicated that they speak a language other than English at home.[58]

The Committee heard that people with disability from CALD backgrounds are more likely to face many problems and be under-represented users of support services. In particular, the Ethnic Communities' Council of Victoria (ECCV) highlighted findings of the Productivity Commission's 2009 annual *Report on government services* which revealed that people born in a non-English speaking country:

> … are four times less likely to gain access to accommodation support services, two and a half times less likely to be the recipient of community support and access services, three times less likely to access respite services, and demonstrate a much lower participation rates in employment services [than people born in English speaking countries].[59]

This is viewed as a consequence of various factors, including limited proficiency in English, lack of familiarity with disability services, and in some cases the cultural inappropriateness of such services.[60]

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[58] Australian Bureau of Statistics (2013) *Disability, ageing and carers, Australia 2012.* From http://www.abs.gov.au.

[59] Steering Committee for the Review of Government Service Provision (2009) *Report on Government Services.* Canberra, Productivity Commission. Referred to in *Submission S019*, Ethnic Communities' Council of Victoria Inc, p.1.

[60] Public Transport Ombudsman Victoria (2013) *Closing the accessibility gap. How the accessibility of public transport can be improved through innovation to customer service standards and information provisions* Melbourne, PTO, p.23.

Figure 1.5: Main language spoken at home of people with disability across Victoria (2012)
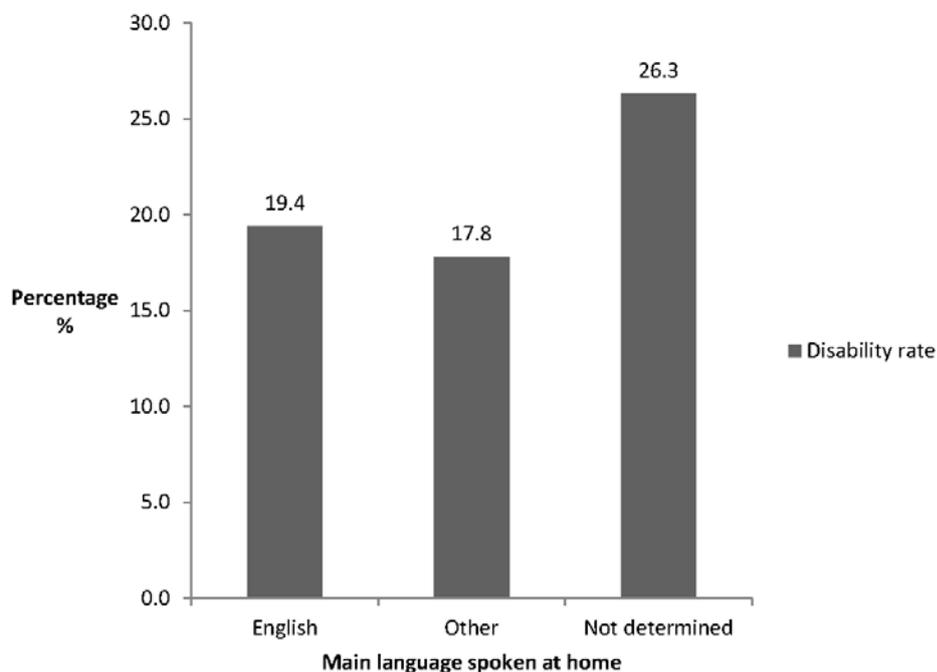
Source: Australian Bureau of Statistics (2014) *Disability, ageing and carers, Australia: Victoria 2012 (Table 4).* From http://www.abs.gov.au.

In addition, Monash City Council stated in its submission that cultural factors can create barriers for families of people with disability in approaching services and participating in support programs:

> It has been noted that some parents, due to cultural factors believe that the disability of a member of the family has been the manifestation of a wrong that they or their ancestors have committed, and that they and their family member with disability will be shunned by their culture and from society in general. As a result of these beliefs families may lock themselves away from mainstream interaction and avoid participating in society to avoid the shame they may feel. It has been pointed out that this is particularly the case where the disability is autism and/or intellectual disability, or cerebral palsy.[61]

In evidence to the Inquiry, the Department of Human Services (DHS) identified that 'there is no specific public information on the social inclusion of people with disability from CALD communities' from the ABS. However, DHS identified other data that helps to demonstrate the level of social inclusion by people with disability from CALD communities:

- In 2010, 73.8 per cent of Australians with a profound core activity restriction from non-English speaking countries had no access to the internet compared to 59.7 per cent from English speaking countries.[62]

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[61]   *Submission S120*, Monash City Council, p.6.
[62]   National Ethnic Disability Alliance (2010) *Analysis of the 2010 General Social Survey*. Civic Square ACT, NEDA. Referred to in *Supplementary evidence*, Response to Questions on Notice, Department of Human Services, 24 March 2014.

- In 2011–12, Victorians with disability born in a non-English speaking country were less likely to access government funded services than Victorians with disability born in an English speaking country. For example:

  ♦ accommodation support services — 0.3 users per 1000 (non-English) compared with 1.7 users per 1000 (English)

  ♦ community support services — 3.1 users per 1000 (non-English) compared with 9.4 users per 1000 (English)

  ♦ community access services — 1.1 users per 1000 (non-English) compared with 2.7 users per 1000 (English)

  ♦ respite services — 1.0 users per 1000 (non-English) compared with 2.9 users per 1000 (English).[63]

Aboriginal and Torres Strait Islander people with disability

According to the ABS 2008 *National Aboriginal and Torres Strait Islander social survey*, 9.6 per cent of Victorian Aboriginal and Torres Strait Islander people had a profound or severe core activity limitation and 46.3 per cent had an unspecified limitation or restriction. This is considerably higher than the 2009 disability rate of 18.4 per cent within the general Victorian population.[64]

Figure 1.6: Disability status of Victorian Aboriginal and Torres Strait Islander people (2008)
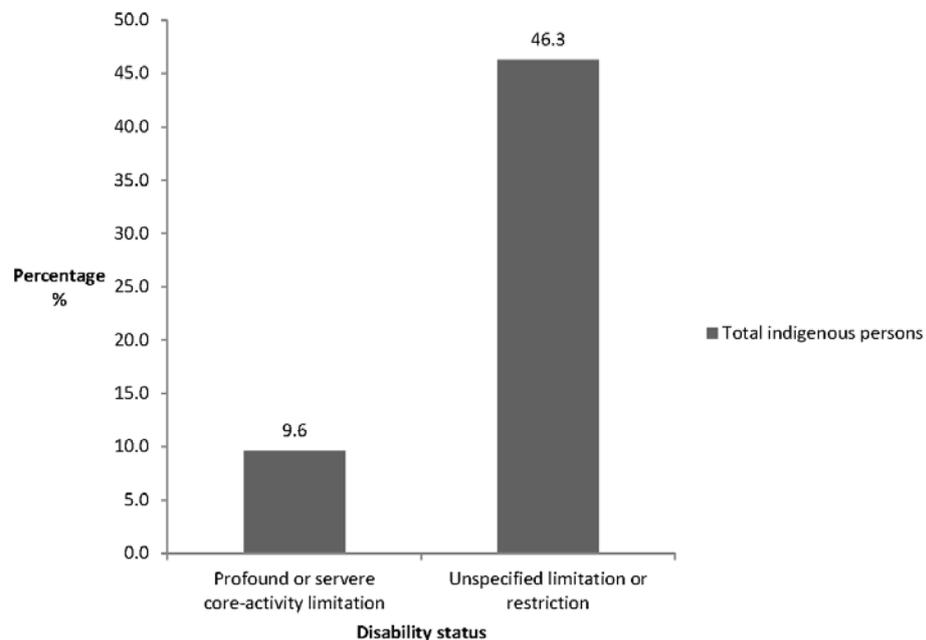
Source: Australian Bureau of Statistics (2010) *National Aboriginal and Torres Strait Islander social survey, 2008 (Table 1).* cat. no. 4714.0, Canberra, ABS. Accessed on 14 August 2014 from http://www.abs.gov.au/ausstats/abs@.nsf/mf/4714.0/.

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[63] Steering Committee for the Review of Government Service Provision (2009) *Report on Government Services.* Referred to in *Supplementary evidence*, Response to Questions on Notice, Department of Human Services, 24 March 2014.

[64] Australian Bureau of Statistics (2010) *National Aboriginal and Torres Strait Islander social survey, 2008.* cat. no. 4714.0, Canberra, ABS. Accessed on 14 August 2014 from http://www.abs.gov.au/ausstats/abs@.nsf/mf/4714.0/.

The Committee recognises that there are different methods for defining disability in the context of the Aboriginal community in Victoria. Some Aboriginal and Torres Strait Islander people, particularly those who live a more traditional way of life, may conceptualise disability differently from mainstream understandings, and therefore may tend to under-report its prevalence.[65]

There is extensive evidence regarding the systemic and double discrimination faced by Aboriginal and Torres Strait Islander people with disability. Similar to other people with disability, Aboriginal and Torres Strait Islander people with disability are frequently not provided with opportunities to participate in key social, economic and cultural activities common to society. These problems are often further compounded by their cultural heritage. In addition, many mainstream disability services and programs are culturally inappropriate. The National People with Disabilities and Carer Council identified that very few service providers grasp the complexities of issues that Aboriginal and Torres Strait Islander people regularly face.[66]

People with disability living in rural and regional locations

Figure 1.4 outlines the geographic distribution of people with disability across Victoria. The disability rate of people living in major cities in 2012 was 17.5 per cent, which was significantly lower than the disability rate of people living in inner regional Victoria (25 per cent), and in other parts of Victoria (28.8 per cent).[67]

The Committee heard that many of the barriers to social inclusion for people with disability living in rural and regional locations are different from those barriers faced by people living in urban settings, yet solutions are typically generated from a metropolitan perspective. According to Mr Ian Parsons, a research fellow with the Centre for Rural Regional Law and Justice at Deakin University:

> … a person with disability living in a regional town is likely to be experiencing two lots of difficulties: one will be around the tendency for their issues not to be seen as an essential part of what it means to be a regional Victorian; and secondly, the solutions that are generated to address their issues are often developed in the cities and are somewhat removed from their local experience and somewhat limited in terms of local relevance. Enhancing inclusion for a person with disability in regional and rural Victoria means addressing both those sides of the problem and changing the mindset in both of those areas — that is, how we think about regional communities and how we think about the issues of exclusion experienced through having disability.[68]

The barriers typically relate to the remote location of communities and limited transport options to access health care and other services, which the Committee heard is either too infrequent, expensive or not available at all.[69] Limited finance was also raised as an issue, with many people spending their disability funding on travel costs for an adult to accompany them to access support services.[70] Participants also highlighted that a lack of available volunteers in rural and

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65   Steering Committee for the Review of Government Service Provision (2011) *Overcoming indigenous disadvantage: Key indicators 2011*. Canberra, Productivity Commission, p.4.85.

66   National People with Disabilities and Carer Council (2009) *Shut out: The experience of people with disabilities and their families in Australia*, pp.58–59.

67   Australian Bureau of Statistics (2013) *Disability, ageing and carers, Australia 2012*. From http://www.abs.gov.au.

68   *Transcript of Evidence*, Centre for Rural Regional Law and Justice, Deakin University, Melbourne, 6 March 2014, p.2.

69   *Submission S013*, Centre for Rural Regional Law and Justice, Deakin University, p.3.

70   *Submission S036*, Mansfield Support Group for Children with Special Needs, p.1.

regional communities has had adverse impacts on the number and quality of activities organised for people with disability.[71]

Figure 1.7: Geographic distribution of people with disability across Victoria (2012)
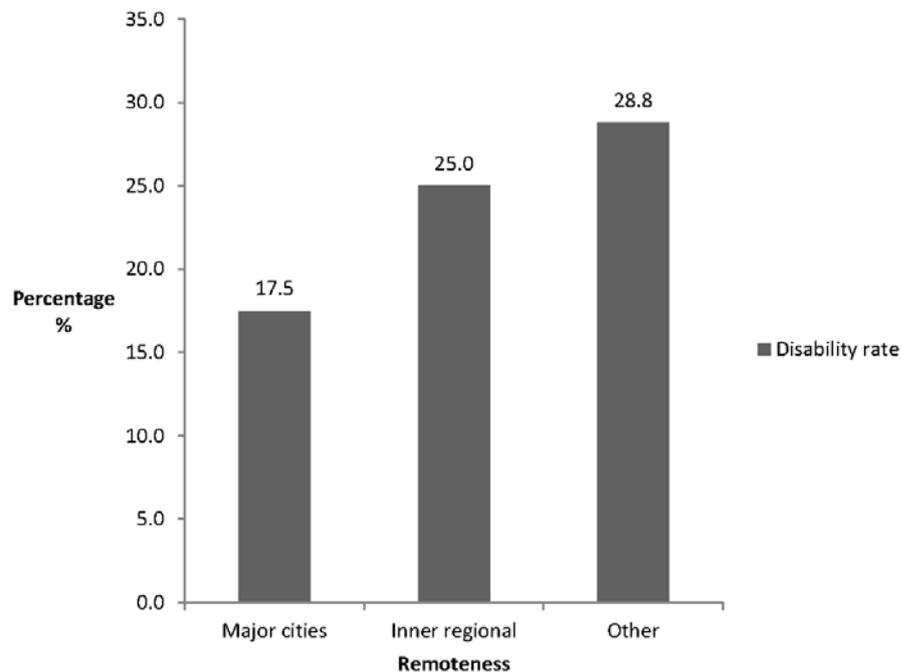
Source: Australian Bureau of Statistics (2014) *Disability, ageing and carers, Australia: Victoria 2012 (Table 4).* From http://www.abs.gov.au.

Finding 1.4

The needs and daily experiences of people with disability vary depending on impairment type, its complexity, community attitudes and perceptions of the impairment. However, it cannot be assumed that all people with a particular type of disability share a common set of needs that is different from the needs of people with another type of disability.

1.2.3.   Existing social inclusion indicators and measurement tools

The Committee identified that existing tools to measure social inclusion have shortcomings, but also have potential. Some measures have been devised to determine participation in relation to specific activities, and others more specifically focus on factors relating to quality of life. In addition, new measures are being devised that have attempted to overcome the shortcomings of existing techniques for assessing social inclusion.

The Committee heard that current measures of social inclusion are 'fraught with challenges'.[72] These challenges stem mostly from inconsistent data collection purposes and the use of different definitions among data collection agencies.

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[71]   *Submission S036*, Mansfield Support Group for Children with Special Needs, p.1.
[72]   *Submission S097*, Whitehorse City Council, p.7.

According to WDV, different definitions of disability in ABS surveys, the Disability Act in Victoria, Centrelink and the national Specialist Homelessness Information Platform also create barriers to research.[73]

Whitehorse City Council claimed that data inconsistencies limit the capacity of comparative analysis.[74] Further, in its submission Melbourne City Mission referred to the need for more valid and reliable measures of social inclusion, highlighting current challenges associated with complexities of data collection, difficulty quantifying outcomes, and a lack of a shared understanding from government about good outcomes.[75]

Disability sector

Disability service providers and other non-government organisations discussed a range of measures that have been considered and sometimes adopted. Inquiry participants suggested they have identified valuable tools for measuring social inclusion. Some service providers currently use these tools for identifying the extent of exclusion experienced by people with disability using their services. For example, Melba Support Services measures outcomes using the US-based Council on Quality and Leadership's (CQL) 21 specified Personal Outcome Measures (POM). These measures are organised around three factors—self, world and dreams. According to Melba Support Services, it measures an individual's quality of life through personal interviews, where the POMs are applied and evaluated in the context of each individual's unique characteristics, needs and desires.[76]

Melbourne City Mission explained to the Inquiry that it uses the Measuring Outcomes and Results Framework (MORF), a results-based method. It uses the framework to measure social inclusion and participation outcomes for its In-Home Behaviour Support Program and Early Years Case Management Program. In particular, MORF is used to measure individual outcomes, track data and drive improvements. Melbourne City Mission advised that it is exploring ways to reduce the subjectivity of the measure as it produces inconsistent results depending on how MORF participants define social inclusion.[77]

Scope (Vic) informed the Inquiry about the 1 in 4 Social Inclusion Measure it developed in partnership with Deakin University. This is a national survey designed specifically to measure social inclusion experienced by people with disability. According to Scope (Vic), development of the measure was informed by existing social inclusion literature. It suggested that the tool is simple to administer and measures social inclusion across multiple domains. These domains include disability type, employment status, gender, location and accommodation.[78]

Scope (Vic) and Deakin University conducted the first survey in 2011—the *1 in 4 poll on social inclusion*. The questions focused on four domains of social inclusion:

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73   *Submission S051*, Women with Disabilities Victoria, p.10.
74   *Submission S097*, Whitehorse City Council, p.8.
75   *Submission S111*, Melbourne City Mission, pp.30–31.
76   *Submission S080*, Melba Support Services Inc, p.2.
77   *Submission S111*, Melbourne City Mission, p.30.
78   *Submission S129*, Scope (Vic) Ltd, p.15.

- social participation

- social relationships

- service access

- economic materials.[79]

A total Social Inclusion Score was established based on the survey results, which in effect provides a benchmark figure to allow future comparisons of social inclusion for people with disability.[80]

In its submission, Scope (Vic) recommended the use of the 1 in 4 Social Inclusion Measure as a possible population-level measure of social inclusion for people with disability.[81]

Government

The *State disability plan 2013–16* is the Victorian Government's key policy response to disability. The vision articulated in the plan is:

> An inclusive Victorian society that enables people with disability, their families and carers to fulfil their potential as equal citizens.[82]

This vision is underpinned by six principles that guide the four key goals of the Plan, each of which comprise individual outcomes that are the improvements required to achieve the goal, and indicators to measure progress towards achieving the outcomes. An example of a key goal and its outcome and indicators is outlined below.

Table 1.1: Goal 2—upholding rights and promoting participation

Outcome	Indicators
Four: Better protection of human rights	• proportion of complaints of discrimination to the Victorian Equal Opportunity and Human Rights Commission that are based on disability/impairment • proportion of people with disability feeling safe in a variety of situations.
Five: Better pathway to employment	• proportion of people with disability of working age who are in the labour force • proportion of students with disability employed after completing a vocational education and training course.
Six: Greater participation in the community	• proportion of people with disability participating in common cultural and recreational activities.

Source: Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014.* Melbourne, DHS.

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[79] *Supplementary evidence*, Response to request for information, Scope (Vic) Ltd, 18 July 2014, p.135.
[80] *Submission S129*, Scope (Vic) Ltd, p.13.
[81] *Submission S129*, Scope (Vic) Ltd, p.25.
[82] Department of Human Services (2012) *Victorian state disability plan 2013–2016*. Melbourne, DHS, p.10.

Most of the indicators in the *State disability plan 2013–16* are measured using ABS data, particularly the SDAC which measures participation in education and employment, source of income, economic wellbeing, housing, and transport and accessibility. In her presentation to the Committee, Ms Judy Henson, Victorian Regional Director of the ABS, advised that the SDAC also measures a person's involvement in various social, community and civic activities both within and away from their home.[83]

The Committee understands that this measure will be used by the Victorian Government to determine the progress of the *State disability plan 2013–16* in achieving outcomes relating to greater participation of people with disability in the community. These social, community and civic activities included in the SDAC are detailed in Box 1.5.

Box 1.5: ABS' SDAC list of social, community and civic activities

- Activities participated in at home:
  - ◆ Visits from family or friends
  - ◆ Telephone calls with family or friends
  - ◆ Art or craftwork (for or with other people)
  - ◆ Church or special community activities
  - ◆ Voluntary work (including advocacy)
- Activities participated in away from home:
  - ◆ Visited relatives or friends
  - ◆ Went to restaurant or club
  - ◆ Church activities
  - ◆ Voluntary activities
  - ◆ Performing arts group activity
  - ◆ Art or craft group activity
  - ◆ Other special interest group activities
  - ◆ Other activity not specified elsewhere
  - ◆ Visited a public library
  - ◆ Visited a museum or art gallery
  - ◆ Attended a movie, concert, theatre or performing arts event
  - ◆ Visited a botanic garden, zoo or aquarium
  - ◆ Participated in physical activities for sport
  - ◆ Participated in physical activities for exercise or recreation
  - ◆ Attended sporting events as a spectator
- Active involvement in community groups
- Active involvement in governance or civic groups

Source: Australian Bureau of Statistics (2014) *Disability, ageing and carers, Australia: Victoria 2012 (Table 4).* From http://www.abs.gov.au.

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[83] *Transcript of Evidence,* Australian Bureau of Statistics, p.4.

While the Committee commends the Victorian Government for establishing indicators in its *State disability plan 2013–16*, it was concerned that some of these indictors used to measure participation by people with disability may not provide an accurate reflection of the levels of social inclusion experienced by people with disability.

The Committee heard that DHS is in discussions with the ABS regarding the most appropriate ways to measure social inclusion. The Secretary of DHS, Ms Gill Callister, explained to the Inquiry:

> Turning to social participation, it is difficult to measure; however, there has been consultation by the ABS with disability groups and people with disability about how to measure this.[84]

Current limitations in tools used to measure inclusion

Researchers have also emphasised the current limitations in tools for measuring social inclusion. For example, Professor Christine Bigby emphasised that research needs to:

> … move beyond an approach that tends to equate social inclusion with simple counts of how many times a person goes out their front door to visit the community.[85]

In this context, Professor Bigby identified issues with high-level measures of social inclusion, explaining that they do not consider individual preferences, which are important to individual planning processes and overall personal inclusion goals.[86]

Similarly, researchers Martin and Cobigo refer to the need to measure both objective and subjective aspects of social inclusion, stressing that using only objective measures cannot provide a clear understanding of the personal experiences of inclusion:

> Reporting rates of employment and frequencies of social activities within the community is not only insufficient to conclude whether or not a person is included, it is also inadequate for determining whether the experience of social inclusion is beneficial and satisfactory for the person being included.[87]

The Chief Executive Officer of Carers Victoria, Ms Caroline Mulcahy, told the Inquiry that as an agency they are currently grappling with how they can more effectively measure the outcomes of their services.[88] The Acting Policy Manager, Mr Ben Ilsely, explained that assessing the effectiveness of service delivery or particular programs in the context of social inclusion needs to be based on personal outcomes rather than service outcomes.[89]

1.2.4. Future measures of social inclusion

The Committee is firmly of the view that the Victorian Government needs to identify a tool for effectively measuring the experiences of social inclusion and

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[84] *Transcript of Evidence*, Department of Human Services, Melbourne, 3 March 2014, p.3.
[85] C. Bigby (2012) *Social inclusion and people with intellectual disability and challenging behaviour: A systematic review*, p.369.
[86] C. Bigby (2012) *Social inclusion and people with intellectual disability and challenging behaviour: A systematic review*, p.368.
[87] L. Martin & V. Cobigo (2011) *Definitions matter in understanding social inclusion*, pp.279, 81.
[88] *Transcript of Evidence*, Carers Victoria, Melbourne, 3 March 2014, p.6.
[89] *Transcript of Evidence,* Carers Victoria, p.6.

participation for people with disability. Without a clear framework for measuring social inclusion, it will not be able to determine the effectiveness of its own Plan, the interventions and efforts, or broader disability policies and legislative frameworks, in advancing the social inclusion of Victorians with disability.

In its submission, Scope (Vic) recommended that social inclusion be measured at population, service/intervention and individual levels.[90] The Committee considers this recommendation has merit. There is a need to increase understanding of both service quality and personal outcomes, including consideration of individual experiences of social inclusion, and their desires and control regarding levels of involvement in activities. The Committee also recognises the value in continuing to assess social inclusion on the basis of objective measures, including employment and education levels, accommodation, transport and accessibility, socio-economic status, health and wellbeing, and participation in social, political and cultural activities.

Another consideration for the Victorian Government when determining how to measure social inclusion in a meaningful way is the use of consistent definitions of disability, social inclusion and participation. It is also important that the definitions of social inclusion and participation be conceptually robust and measurable.

Lastly, on the basis that social inclusion is multi-dimensional, an effective measure needs to understand and capture how the various dimensions interact and their contribution to an individual's quality of life and wellbeing.[91]

Finding 1.5

There is currently no effective tool for measuring social inclusion and participation of people with disability that can be used to determine the effectiveness of the Victorian Government's *State disability plan 2013–16*, related initiatives and efforts, or broader disability policies and legislative frameworks, in advancing the social inclusion of Victorians with disability.

Recommendation 1.2

That the Victorian Government review the range of mechanisms for measuring the social inclusion of people with disability—including local, national and international tools—and identify an appropriate method for determining levels of social inclusion experienced by people with disability in Victoria.

1.3.   Social exclusion and disability

The Committee was asked to inquire into the nature and scale of relative inclusion (exclusion) and participation of Victorians with disability in the economic, social and civil spheres of society. It recognises that Victoria has progressed in its efforts to enhance the social inclusion of people with disability.

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[90]   *Submission S129*, Scope (Vic) Ltd, p.25.
[91]   L. Martin & V. Cobigo (2011) *Definitions matter in understanding social inclusion*, p.281.

However, the Committee heard that current experiences of exclusion and disadvantage are still daily occurrences for many people with disability.

In view of the current limitations in measuring social inclusion outlined in Section 1.2.3, this section considers the experience of social exclusion as expressed by Inquiry participants.

1.3.1. Historical context of social exclusion and disability

Inquiry participants expressed that the ongoing discrimination and exclusion experienced by people with disability relates strongly to historical policies of institutionalisation and segregation. While policies have changed, the Committee heard that approaches relating to segregation are entrenched in the everyday practices of governments, service providers, businesses, community groups and individuals. In her individual submission, Mrs Delia Fisher stated that:

> This unique positioning of people with disability in terms of social inclusion has arisen from a long history of institutionalization in special schools, sheltered workshops. Not only did this model of disability support segregated people with disability from the community, it robbed them of their basic right to make decisions about their lives and to be seen as worthwhile, capable citizens in society rather than objects of charity.[92]

In her submission, Ms Raelene West reviewed literature relating the historical exclusion of Victorians with disability.[93] Research has identified that the institutionalisation of people with disability began in Victoria as early as European settlement in 1788, with the confinement of people with disability in asylums and institutions viewed as a social good for both the individual and their families.[94]

Institutionalisation of people with disability and their segregation from the community remained the dominant response to disability up until the late 1970s. From the 1980s large institutions began to close across the state and community based support and services for people with disability became the dominant policy response to disability in Victoria. The introduction of the *Intellectual Disability Act 1986* and the *Disability Services Act 1991* provided frameworks for the planning, management and administration of community based support services.

Following the implementation of the two Acts, the Victorian Government reduced the number of individuals in institutional care from 4439 in 1976 to 1126 in 1996. The last remaining institutions in Victoria include Sandhurst Residential Services in Bendigo, Colanda Centre in Colac and the Oakleigh Centre in the Melbourne suburb of Oakleigh. The Victorian Government is currently in the process of closing each of these residential facilities and assisting residents to transition into alternative housing and the NDIS.[95]

Some Inquiry participants also drew attention to the current capacity of service providers to deliver effective, individualised and inclusive outcomes for their clients, suggesting they continue to be adversely impacted by the legacy of these historical models. For example, in its submission VALID referred to an

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[92]   *Submission S008*, Mrs Delia Fisher, p.1.
[93]   *Submission S010*, Ms Raelene West.
[94]   *Submission S010*, Ms Raelene West, p.14.
[95]   Premier of Victoria (2 May 2014) *Media release: Oakleigh disability institution to close.* Accessed on 13 May 2014 from http://www.premier.vic.gov.au/media-centre/media-releases/9798-oakleigh-disability-institution-to-close.html.

observation of Inclusion International in its *Global Report on Article 19: the right to live and be included in the community* about the state of disability services internationally:

> Many of the services and support models that governments and communities fund to support people with intellectual disabilities are remnants of institutional, protectionist delivery systems and continue to segregate and isolate people.[96]

Further, in its report, *Disability expectations: Investing in a better life, a stronger Australia*, PricewaterhouseCoopers (PwC) stated:

> The historical experience of people with disability illuminates the current state of disability care and support in Australia. Despite significant changes along the way, there has been limited improvement. In fact, Australia is among the worst performers when it comes to key indicators such as employment and disadvantage of people with disability. Further fuelling this poor performance are societal attitudes towards people, which have evolved only slowly over time.[97]

1.3.2.   Current experiences of social exclusion and disadvantage

Throughout the Inquiry, the Committee received overwhelming evidence regarding the interrelatedness of disability and disadvantage. This is supported by research evidence:

> Disability can be both a cause and consequence of disadvantage. That is, people who experience disadvantage are more likely to become disabled, while people with disability are more likely to experience disadvantage.[98]

People with disability and their families are identified as one of the most disadvantaged groups in Australia, and are typically underrepresented in the economic, civil and social dimensions of life. Inclusion Victoria expressed its view that, 'the inclusion of people with disability in 2014 is varied and patchy.'[99]

Evidence to the Inquiry repeatedly stressed the issues and barriers encountered by people with disability on a daily basis. In particular, the Committee heard that people with disability 'tend to have lower levels of educational attainment, low rates of participation in employment, have difficulty accessing housing and are more likely to be living on social benefits.'[100] These issues are ongoing and continue to prevent people with disability from participating as equal and active members of the community and experiencing social inclusion.

In its submission, the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) outlined the main disability discrimination areas of complaint it received under the Victorian *Equal Opportunity Act 2010* (Vic). The VEOHRC stated that based on the complaints received in 2012–13, disability was the largest attribute of inquiry, and the highest attribute of complaint. Disability discrimination also consistently made up the highest attribute of complaints over several years. Complaints made in 2012–13 were made in relation to education, employment, public transport, and access to social and

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[96]   *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.14.
[97]   PricewaterhouseCoopers (2011) *Disability expectations: Investing in a better life, a stronger Australia*. Canberra, PwC, p.14.
[98]   VicHealth (2012) *Disability and health inequalities in Australia. Research summary*. Carlton South, VicHealth, p.5.
[99]   *Submission S056*, Inclusion Melbourne, p.4.
[100]   *Submission S047*, St Laurence Community Services Inc, p.2.

cultural life. Discrimination in the context of employment represented the greatest percentage of complaints.[101]

In its submission, National Disability Services (NDS) Victoria provided specific evidence regarding poor outcomes of people with disability across a range of areas:

Unemployment—in 2009, an estimated 48 per cent of Victorians with disability aged 15 to 64 with disability were employed compared with 78 per cent of Victorians without disability.

Poverty—estimates of income in 2009 indicate the households including a person with disability are over-represented (28 per cent) in the lowest household income quintile.

Involvement in the criminal justice system—a 2011 Victorian study found that 42 per cent of male prisoners and 33 per cent of female prisoners had an acquired brain injury (ABI); compared with 2 per cent of people with an ABI in the general population.

Isolation—about 15 per cent of people with disability aged 15–59 live alone compared to 6.8 per cent of people without disability.[102]

The evidence reinforced that social exclusion can occur in multiple contexts, and can impact many aspects of a person's life.[103] The Committee heard that the overall health and wellbeing of people with disability is typically worse than other members of the community. This difference in health does not necessarily relate to a specific health condition or impairment but rather is understood to be socially determined.[104] The various and multiple disadvantages that people with disability encounter are major contributors to poor health, and in particular poor psychological health.

The Committee recognises that poor psychological health reflects the seriousness of persistent segregation, exclusion and marginalisation, as well as highlighting the disproportionately high levels of social isolation among people with disability.[105] This was a key finding in *Shut Out: the experience of people with disabilities and their families in Australia*, the National Disability Strategy consultation report:

Few can appreciate the impact of exclusion and profound isolation on the identity and self-esteem of people with disability. Always defined as 'different', always defined by lack—many people spoke movingly of the impact of being defined by others. When identity is always framed by others and always framed in a negative way, it is difficult to develop and maintain a strong positive sense of self and difficult to establish and maintain relationships characterised by equality and mutual support.[106]

The psychological health and wellbeing of people with disability is discussed in greater detail in Chapter 5.

The Committee also heard there is a growing body of research indicating disproportionately high levels of poor health and wellbeing among carers of people with disability, compared with others in the community.[107] This is concerning given that social inclusion is viewed as an interdependent issue for

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[101] *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, pp.6, 9.

[102] *Submission S045*, National Disability Services Victoria, p.3.

[103] *Submission S110*, Catholic Social Services Victoria, p.5.

[104] VicHealth (2012) *Disability and health inequalities in Australia. Research summary*, p.1.

[105] *Submission S081*, Mr Bret Fishley, p.1; *Transcript of Evidence*, Inclusion Melbourne, Melbourne, 20 March 2014, p.2.

[106] National People with Disabilities and Carer Council (2009) *Shut out: The experience of people with disabilities and their families in Australia*, p.52.

[107] *Submission S087*, Carers Victoria, p.6.

people with disability and their carers and family members.[108] Mr Ilsley from Carers Victoria advised that carers can act as a buffer against the socially excluding effects of disability and can facilitate social inclusion. He also highlighted that the opposite can occur if carers and family members are socially excluded.[109]

The Committee identified that key contributing factors to the isolation of people with disability are prevailing social and attitudinal barriers that marginalise and ignore people with disability. This issue was raised by various Inquiry participants, including the Australian Community Support Organisation (ACSO) which referred to research that identified the attitudes of others as being the biggest single barrier to the social inclusion of people with disability. Similarly, Inclusion Melbourne indicated that low expectations of and negative attitudes towards people with disability are key barriers:

> Mistaken or outdated attitudes, knowledge, assumptions, values and paradigms, despite often being coupled with good intentions, lead to exclusion. This is frequently exemplified by community responses to the challenging or misunderstood behaviours of some people with disability.[110]

Chapter 8 discusses attitudes towards disability in further detail.

Finding 1.6

Victorians with disability continue to articulate experiences of social exclusion, lack of belonging and restricted opportunities to participate meaningfully in education, employment and other goals they aspire to. Their reasons include inaccessible environments, community attitudes, financial insecurity, housing issues, and difficulties accessing health and other supports.

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[108] *Transcript of Evidence,* Carers Victoria, p.2.
[109] *Transcript of Evidence,* Carers Victoria, p.2.
[110] *Submission S056*, Inclusion Melbourne, p.4.

Chapter 2
Leading the social inclusion agenda

AT A GLANCE

Background

In recent decades, Victoria has progressed initiatives aimed at increasing the social inclusion of people with disability based on their needs and aspirations. Despite progress, people with disability continue to report experiences of widespread social exclusion. While its focus is specifically on funding and provision of services, the National Disability Insurance Scheme (NDIS) was designed with the intention of increasing social inclusion. The NDIS is a major social reform that is currently being trialled. The full rollout of the NDIS will occur between 2016 and 2019.

Summary of key findings

- Despite legislative and policy reforms that have increased the focus on inclusion, the Committee heard that real and meaningful social inclusion is not reflected in the daily lives of Victorians with disability. Social inclusion requires attitude change, shifts in community culture, and long-term drive and commitment. **(Finding 2.1)**

- A key challenge for governments investing in social inclusion initiatives is that social inclusion is not well defined and there are currently no tools for accurately measuring it. Targeting investment at social inclusion initiatives is difficult to quantify. **(Finding 2.2)**

- Social inclusion is not the responsibility of any one organisation, body or individual—it is a whole of community responsibility. Everyone has responsibility—as a socially responsible citizen or as a responsible corporate entity. **(Finding 2.3)**

- While everyone has responsibility for contributing to socially inclusive communities, governments have a key role in driving this whole-of-community obligation. **(Finding 2.4)**

- The *Disability Act 2006* (Vic) provides a strong legislative framework to increase social inclusion for people with disability and its principles and objectives are broadly supported. **(Finding 2.5)**

- The Victorian Disability Advisory Council undertakes important work and its members do valuable work in advocating for the needs of people with disability, but it is not well known in the general community. **(Finding 2.6)**

- The *State disability plan 2013–16* is broadly supported, and future State Disability Plans will need to complement the National Disability Insurance Scheme and could be reoriented to a disability inclusion plan and strengthened by including specific targets and outcome measures and providing specific strategies relating to building social capital and clearly articulating the role of local government and the Building Inclusive Communities Program. **(Finding 2.7)**

- There are no standards for disability action plans or systems for monitoring their effectiveness, yet imposing additional systems of oversight could pose considerable regulatory burden and not lead to greater effectiveness. **(Finding 2.8)**

AT A GLANCE

- Local government is particularly well positioned to understand:
    - ♦ the diversity of communities and local needs
    - ♦ plan, promote and develop greater inclusiveness and community capacity
    - ♦ influence services across the full range of community infrastructure. **(Finding 2.9)**

- The Building Inclusive Communities Program is a valuable initiative and highly regarded, however, outcomes from the Program are not effectively measured or evaluated and its needs stronger drive internally within the Department of Human Services. **(Finding 2.10)**

- The future of community building and other social inclusion initiatives are linked to Tier 2 of the National Disability Insurance Scheme which is yet to be clarified to determine the nature of supports and funding arrangements. **(Finding 2.11)**

- All interventions that involve people with disability need to be driven and informed by people with disability themselves, and their involvement in the design of elements of the National Disability Insurance Scheme is no different. **(Finding 2.12)**

- There is great potential to forge partnerships across non-government organisations, local government, the Victorian Government and the National Disability Insurance Agency through Building Inclusive Communities Program, Access Officers and Local Area Coordinators, and Community Participation Teams. **(Finding 2.13)**

Recommendations

That the Victorian Government:

- Commence a review of the *Disability Act 2006* (Vic) by 2019 to ensure it aligns with the *National Disability Insurance Scheme Act 2013* (Cth) and reflects the Victorian Government's future involvement in disability. **(Recommendation 2.1)**

- Request the Victorian Auditor-General undertake an audit of the suitability, effectiveness and implementation, and the monitoring and improvement of disability action plans in local government. **(Recommendation 2.3)**

- Work with the National Disability Insurance Agency to clarify the roles and responsibilities of Local Area Coordinators associated with the National Disability Insurance Scheme and Access Officers in the Building Inclusive Communities Program to ensure their social inclusion interventions are complementary. **(Recommendation 2.5)**

That the Minister for Community Services:

- Request that the Victorian Disability Advisory Council (VDAC) develop a strategy to increase its profile and that it will be incumbent on VDAC to implement this strategy. **(Recommendation 2.2)**

- Seek advice from the Victorian Disability Advisory Council (VDAC) on future directions for social inclusion and that it is incumbent on VDAC to ensure it gathers relevant information to be considered in the development of Tier 2 of the National Disability Insurance Scheme. **(Recommendation 2.4)**

Since the 1980s, Victoria and Australia more broadly have introduced policy and legislative reform with the goal of moving away from segregation and improving the lives of people with disability.

While this Inquiry relates specifically to social inclusion, the policy and legislative context of social inclusion and disability in Victoria cannot be considered without taking into account the introduction of the National Disability Insurance Scheme (NDIS). It is the most significant social reform in Australia for 30 years and will transform the disability support system.[1]

In addition to providing people with a severe or profound disability assurance that they will have access to support, the NDIS is also expected to change the way people are treated in the community. The NDIS is currently being trialled in Victoria and other states and territories, and the full rollout will be completed between 2016 and 2019.

In Victoria recent progress towards a social inclusion agenda has been made with the introduction of the *Disability Act 2006* (Vic) and the release of the *State disability plan 2013–16.* In addition, unique to Victoria, the Building Inclusive Communities Program (formerly the Community Building Program) was established in 2002 and has a key objective to increase social inclusion for people with disability.

These interventions have led to the creation of partnerships across local government, state government departments and non-government organisations. While evolving, the Committee considered these partnerships are important beginnings and require ongoing commitment to foster their development and to continue working towards a social inclusion agenda.

2.1.   Progressing disability policy

Progress in disability policy in Victoria and across Australia has largely related to the provision of disability services, including the gradual dismantling of large residential or institutional facilities and introducing person-centred approaches to disability services in the community. In May 2014, the Victorian Government announced its intention to close all remaining institutional facilities.

Through their advocacy efforts people with disability have been at the forefront in influencing reforms to improve their own life and the lives of other people with disability.

Victoria has also made headway in advancing the inclusion of people with disability and has led the way in Australia. The Disability Services Commissioner, Mr Laurie Harkin, stated that 'The fact is we will not be there for a while yet, but what is encouraging, when I look out the window of the car from the back seat, is that I can see we are actually going somewhere, which is a really good thing.'[2]

In the context of social inclusion, the Secretary of the Victorian Department of Human Services (DHS), Ms Gill Callister, expressed her view that 'we have

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[1]   Joint Standing Committee on the National Disability Insurance Scheme (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme*. Canberra, Commonwealth of Australia, p.131.

[2]   *Transcript of Evidence*, Disability Services Commissioner, Melbourne, 3 March 2014, p.4.

come a long way from the time when people with disability were hidden away from their community and institutions, unable to direct their own lives and lived with stigma and exclusion.'[3] Dr Fiona Reidy also explained to the Inquiry that:

> Disability policy, and the experience of people with disability, has shifted significantly from assumptions regarding the philosophies of charity, education, segregation and normalisation.[4]

Reforms aimed at improving the lives of people with disability have been made in the following contexts:

- introducing anti-discrimination legislation at both state and national levels

- dismantling large residential institutions

- moving away from segregated services and activities

- adopting person-centred approaches to service provision

- increasing recognition of the role of informal carers.

Inquiry participants were positive about these reforms and felt they had led to efforts to socialise inclusion for people with disability. For example, the Darebin Disability Advisory Committee stated that in the past 10 years:

> Social inclusion for people with disability has become an ongoing agenda item for the Federal and State Governments with such policies as the impending NDIS, *Disability Act 2006*, National Disability Strategy 2010–2020, ratification of the *United Nations Convention on the Rights of Persons with Disabilities,* National Mental Health and Disability Employment Strategy 2009, the Victorian *State disability plan 2013–16* and the *Carer Recognition Act 2012* (Vic).[5]

Dr Reidy also pointed to the increased attention on social inclusion, stating that has become 'a common international, contemporary philosophy for public policy.'[6]

Despite legislative and policy reforms that have increased the focus on inclusion, the Committee heard that real and meaningful social inclusion is not reflected in the daily lives of Victorians with disability. Social inclusion requires attitude change, shifts in community culture and long-term drive and commitment. Efforts to improve the lives of people with disability tend to prioritise improving disability supports over sustaining momentum on increasing social inclusion in the community. Karingal explained the impact on people with disability and informal carers:

> Even though it has been 60 years since Karingal was founded, every day we still meet families who are fearful about the future of a loved one who has either a congenital or an acquired disability. They can still see that there is a lack of meaningful participation options for them and they worry about their future. Every day we meet persons with disability who still feel shut out of the community.[7]

Chapter 1 outlined that experiences of social exclusion remain all too common for people with disability and that there is considerable progress to be made in

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3   *Transcript of Evidence*, Department of Human Services, Melbourne, 3 March 2014, p.5.
4   *Submission S094*, Dr Fiona Reidy, p.2.
5   *Submission S041*, Darebin Disability Advisory Committee, p.3.
6   *Submission S094*, Dr Fiona Reidy, p.2.
7   *Transcript of Evidence*, Karingal, Melbourne, 26 May 2014, p.2.

the context of inclusive communities. The Committee determined that there is a need for ongoing leadership in driving a social inclusion agenda.

Finding 2.1

Despite legislative and policy reforms that have increased the focus on inclusion, the Committee heard that real and meaningful social inclusion is not reflected in the daily lives of Victorians with disability. Social inclusion requires attitude change, shifts in community culture, and long-term drive and commitment.

Government expenditure on disability demonstrates that the majority of funding is directed towards the provision of disability supports. The Committee requested information from DHS regarding the resources it allocates to foster disability inclusion. In its response, DHS explained that strategies for social inclusion mostly relate to the *State disability plan 2013–16* and that:

> … there is no dedicated budget associated with the plan because the inclusion of people with disability is considered core business for government.[8]

It went on to explain that 'strategies within the plan are budgeted for by individual departments', ensuring responsibility across government.[9] The Committee recognises that a key challenge for governments investing in social inclusion initiatives is that social inclusion is not well defined and there are currently no tools for measuring it. Consequently, targeting investment at social inclusion initiatives is difficult to quantify.

DHS highlighted some of the key initiatives under the *State disability plan 2013–16*, including support provision for aids and equipment and the transition to the NDIS, which includes $25 million over three years for establishment costs in locating the national headquarters of the National Disability Insurance Agency (NDIA) in Geelong. In the context of more specific social inclusion initiatives, it outlined that:

- One of the key funded programs for targeting the social inclusion of people with disability is the *Community Building Program*—funded at $6.95 million in 2012–13.

- Established to provide leadership and support across the Victorian Government, the Office for Disability drives systemic change to reduce and prevent barriers to the mainstream participation and inclusion of people with disability—funded at $5 million in 2012–13.[10]

By 2019, the Victorian Government will increase its funding contribution to disability from $1.2 billion to 'invest an estimated $2.5 billion annually in cash or in-kind services to the NDIS.'[11] This will include 'pay for individualised support packages for scheme participants, Local Area Coordinators and other general supports.'[12] The Australian Government will contribute $2.6 billion amounting to a total of $5.1 billion annually. The Committee recognises that some of this funding will be for social inclusion initiatives, but that the majority

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[8]   *Supplementary evidence*, Response to request for information, Department of Human Services, 27 June 2014.
[9]   *Supplementary evidence*, Response to request for information, Department of Human Services, 27 June 2014.
[10] *Supplementary evidence*, Response to request for information, Department of Human Services, 27 June 2014.
[11] *Supplementary evidence*, Response to request for information, Department of Human Services, 27 June 2014, p.7.
[12] *Supplementary evidence*, Response to request for information, Department of Human Services, 27 June 2014, p.7.

will be for individualised supports for a small percentage of people with severe functioning limitations.

Strategies to increase social inclusion do not need to cost a lot of money and small investments can go a long way. Section 2.5.2 demonstrates how the small investment in the Building Inclusive Communities Program has started to make inroads. These initiatives have the potential to dovetail effectively with the NDIS. But they need a higher profile and ongoing drive and commitment. Social inclusion is difficult to measure and for governments is often considered intangible, but in Victoria steps have been made.

Finding 2.2

A key challenge for governments investing in social inclusion initiatives is that social inclusion is not well defined and there are currently no tools for accurately measuring it. Targeting investment at social inclusion initiatives is difficult to quantify.

2.2.   Social inclusion—whose responsibility?

At the centre of efforts to increase social inclusion are people with disability themselves. At all levels they need to determine their own aspirations. They need to have choice and control in how they pursue their goals, who they connect with to achieve these goals, and the extent to which they actively engage in the process of pursuing them.

Inclusion is a dynamic concept and occurs across networks, connections and relationships. Like all people in the community, people with disability cannot achieve social inclusion without an embracing community.

The Committee heard that social inclusion is not the responsibility of any one organisation, body or individual—it is a whole-of-community responsibility. Everyone has responsibility—as a socially responsible citizen or as a responsible corporate entity.[13] For example, Ms Shaunagh Stevens expressed her view that 'all sectors and sections of the community have a responsibility to take an active role to improve the social inclusion of people with disability.'[14] Annecto similarly told the Inquiry that:

> There is no sector or section of the community that should be absolved from the responsibility to contribute to the continual advancement of an inclusive community and society, or to reduce the incidence and impact of exclusion.[15]

Whitehorse City Council pointed out that 'Legislation articulates that the inclusion of people with disability is the responsibility of all people, organisations, and all levels of government.'[16]

The Committee heard that everyone benefits from an inclusive society. Monash Health highlighted that striving for social inclusion of people with disability is mutually beneficial for communities and people with disability. It stated that the community has a responsibility:

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[13]   *Submission S013*, Centre for Rural Regional Law and Justice, Deakin University, p.14.
[14]   *Submission S090*, Ms Shaunagh Stevens, p.4.
[15]   *Submission S104*, Annecto - the people network, p.11.
[16]   *Submission S097*, Whitehorse City Council, p.21.

> To act as a catalyst, facilitator, enabler and resource provider for disabled people to enjoy as much as humanly possible, the same experience as an able bodied person [which in turn] would also create a richer, more rewarding experience for the whole community.[17]

The City of Boroondara stressed that in view of this shared responsibility, there is a need to promote 'a community where it is everyone's responsibility to remove barriers to inclusion.'[18]

Finding 2.3

Social inclusion is not the responsibility of any one organisation, body or individual—it is a whole- of-community responsibility. Everyone has responsibility—as a socially responsible citizen or as a responsible corporate entity.

2.2.1. Partnerships for inclusion

The Committee heard that the emphasis on 'whole-of-government' and 'whole-of-community' involves collaboration and partnership across all levels of government, the community, and people with disability. For example, in a simplistic sense, at the state level, the Victorian Government facilitates horizontal partnerships across state government departments, and vertical partnerships across local government and the Commonwealth.

Inquiry participants emphasised the value of partnership and collaboration to effectively achieve social inclusion. Yarra City Council stated that rather than operate in isolation or silos:

> Collaboration between all levels of governments, the community sector and people with disability and family/carers, can deliver stronger results.[19]

Brimbank City Council also stressed that collaboration is important, stating that alone 'no single organisation holds the capacity to deliver best practice projects.'[20]

Much of this collaborative effort needs to facilitate social inclusion at the local community level and foster grassroots connections. The Centre for Rural Regional Law and Justice suggested that to achieve greater social inclusion there is a need for governments to:

> … adopt a much more 'bottom up' approach to the challenges of collaboration with rural and regional Victoria—one that is shaped and driven by those differences and that sees government as the instrument of the communities it represents, in all their diversity …[21]

Northern Support Services also told the Inquiry that it is 'grass root connections, whilst seeming small and insignificant, which play a huge role in building a sense of social inclusion for people with disability.'[22]

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[17] *Submission S068*, Monash Health, p.15.
[18] *Submission S048*, City of Boroondara, p.5.
[19] *Submission S118*, Yarra City Council, p.9.
[20] *Submission S086*, Brimbank City Council, p.12.
[21] *Submission S013*, Centre for Rural Regional Law and Justice, Deakin University, p.17.
[22] *Submission S123*, Northern Support Service's My Place-KeyRing Program, p.9.

2.2.2. Role of governments

While everyone has responsibility for contributing to socially inclusive communities, the Committee heard that governments have a key role in driving this whole-of-community obligation. They have a responsibility to provide vision, leadership, strategic direction and to coordinate and drive partnerships across different areas within the community and other levels of government. In Victoria this includes across government departments and relevant programs and initiatives. Section 2.4 discusses existing arrangements for doing this.

Dr Fiona Reidy told the Inquiry that there is an ongoing 'need for leadership and continuing action … to support the implementation of social inclusion.'[23] Marriott Support Services similarly stated that:

> A key role for government should be as a supporter and facilitator of change. This will not deliver any 'quick fix' but it is necessary if sustainable long term change is to be achieved.[24]

The Committee identified that in the context of social inclusion, there are key areas where governments can provide leadership and vision. In addition to providing and funding quality support services, these include:

- accessible environments, buildings and public spaces

- building social connections, social capital and supporting 'supporters' (such as informal carers)

- ensuring strong foundations for social inclusion through health promotion, housing options, and financial security

- providing opportunities to participate in areas such as education, employment, sporting, cultural, and other activities.

In view of multiple responsibilities across communities and governments there is a need for clarity in roles and responsibilities. Whitehorse City Council emphasised the importance of this mutual understanding of roles:

> Greater collaboration between government departments, levels of government, organisations, services and the community sector including the disability service sector will only be improved when there is a shared understanding of roles and responsibilities and when partnerships are forged with mutual respect.[25]

The Committee recognises that governments, mainstream and specialist non-government organisations, and others in the community are operating in a transitional environment with the rollout of the NDIS. In this environment, clarity of roles in the context of building inclusive communities is evolving.

Regardless of the changing context, the Committee considers it is the responsibility of all levels of government to have vision, leadership and to facilitate the necessary networks and partnerships to achieve social inclusion for people with disability. In its 2011 report on *Disability expectations*, PricewaterhouseCoopers (PwC) stated that:

> A well-functioning NDIS will facilitate some of the change necessary, but fundamental change in mainstream services, infrastructure and cultural mores is a job for all

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[23]   *Submission S094*, Dr Fiona Reidy, p.6.
[24]   *Submission S020*, Marriott Support Services, p.2.
[25]   *Submission S097*, Whitehorse City Council, p.23.

governments. In order to achieve true social inclusion and citizenhood for people with disability, a whole-of-government approach is required.[26]

Section 2.7 discusses how the role of the Victorian Government in the context of the introduction of the NDIS.

Finding 2.4

While everyone has responsibility for contributing to socially inclusive communities, governments have a key role in driving this whole of community obligation:

- it is the responsibility of all levels of government to have vision, leadership and to facilitate the necessary networks and partnerships to achieve social inclusion for people with disability

- in view of multiple responsibilities there is a need for clarity in roles and responsibilities.

2.3.   Australian government

The Australian Government has responsibility for providing national leadership and vision in advancing the quality of life of people with disability, particularly in the context of income support through government benefits, employment services, and anti-discrimination.

Since the early 1980s, the Australian Government has introduced policy and legislative reforms aimed at improving the lives of people with disability in the community. These reforms followed the 1975 *Poverty in Australia* report that revealed high levels of poverty among people with disability and the 1981 International Year of the Disabled Person that raised awareness of people with disability.

In 1992, the Australian Government introduced anti-discrimination legislation that aimed to eliminate discrimination against people with disability. The legislation also aimed to ensure equality before the law and to promote acceptance within the community of the fundamental rights of people with disability. In its submission, Maroondah City Council reflected on the importance of the legislation:

> The introduction of the Commonwealth's *Disability Discrimination Act 1992* (the DD Act) represented a fundamental shift in the treatment of people with disability. The DD Act diverged from the traditional medical model of disability, instead adopting a new approach premised on an individual's right to engage in meaningful social and economic experiences.[27]

From the early 1990s until 2013, state governments held agreed responsibility for disability service provision. The Australian Government held responsibility for employment services, income support and some broader reforms that related to social inclusion. In addition to introducing anti-discrimination legislation, these areas of reform included endorsing the rights of people with disability, establishing a National Disability Strategy and increasing recognition of informal carers. Table 2.1 outlines the major policy and legislative initiatives.

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[26] PricewaterhouseCoopers (2011) *Disability expectations: Investing in a better life, a stronger Australia*. Canberra, PwC, p.13.
[27] *Submission S073*, Maroondah City Council, p.5.

Table 2.1: Australian Government—policy and legislation

Year	Policy / legislation
1986	*Disability Services Act 1986* (Cth)
1991	Disability Reform Package • Reformed Commonwealth income support payments for people with disability with a view to encouraging their integration into the workforce to the maximum extent possible. Commonwealth–State Disability Agreement • Aimed to clarify the roles and responsibilities of the respective governments. In essence, the Commonwealth was given responsibility for employment services and the States and Territories were given responsibility for accommodation and other support services.
1992	*Disability Discrimination Act 1992* (Cth) • Social response to disability in Australia providing people with disability a specific legal mechanism to take action against disability-based discrimination in a number of areas including employment, education, and access to premises used by the public, provision of goods, services and facilities.[28]
1994	Commonwealth Disability Strategy • A 10 year framework designed to ensure that people with disability have equal opportunity to access all Commonwealth programs, facilities and services.
1998	Commonwealth–State Disability Agreement.
2002	Commonwealth, State and Territory Disability Agreement 2002 to 2007.
2008	Ratified the United Nations (UN) Convention on the Rights of People with Disabilities (the UN Convention). • The UN Convention does not create any new rights or entitlements but outlines existing rights in the context of their application to people with disability.
2009	National Disability Agreement • High level agreement between the Australian and state and territory governments for the provision of disability services for people with disability.
2010	*National disability strategy 2010–20* • The Strategy reflects a strong social inclusion agenda and is based on the social model of disability, recognising that attitudes and practices can disable people with disability from enjoying economic participation, social inclusion and equality.[29]

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[28]   Australian Human Rights Commission *D.D.A. guide: What areas of life does the D.D.A. cover?* Accessed on 10 July 2014 from https://www.humanrights.gov.au/dda-guide-what-areas-life-does-dda-cover.

[29]   Council of Australian Governments (2011) *2010–2020 National disability strategy*. Canberra, Commonwealth of Australia, p.16.

Year	Policy / legislation
2010	*Carer Recognition Act 2010* (Cth)
	• Recognises the significant contribution made by unpaid or informal carers.
	National carer strategy
	• Six priority areas for action—1) recognition and respect, 2) information and access, 3) economic security, 4) services for carers, 5) education and training, and 6) health and wellbeing.
2013	*National Disability Insurance Act* (Cth)
	• Providing certainty that people with disability will receive the care and support they need over their lifetime by adopting an insurance-based approach to the provision and funding of supports for people with disability.

Source: Compiled by the Family and Community Development Committee.

2.4. Victorian government

A key responsibility for the Victorian Government in disability has been the provision of disability services. In addition, it holds responsibility for providing vision and leadership in other areas of policy that affect the daily lives of people with disability—including health, physical infrastructure, transport, housing, and education.

Since the early 1980s the Victorian Government has introduced legislative and policy changes in an effort to change attitudes towards disability, to increase accessibility of built environments and public spaces, and to create more opportunities for people with disability to participate in the community. These decades also saw a general transition from institutional services toward community orientated service provision, reducing segregation and turning attention to inclusion in the community.

Table 2.2: Victorian Government—policy and legislation

Year	Policy / legislation
1977	*Report of the Victorian committee on mental retardation: Report to the Premier of Victoria* (the Evans Report)
	• Identified that institutions were overcrowded and understaffed, and that they effectively segregated people with disability isolating them from contact with the general community and were a deficient living environment.[30]
1986	*Mental Health Act 1986* (Vic)
	• Repealed and replaced by new legislation in 2014 (see below).

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[30] J. Gardner & L. Glanville (2005) 'New forms of institutionalization in the community'. In Johnson, K. & Traustadottir, R. (Eds.), *Deinstitutionalization and people with intellectual disabilities: In and out of institutions.* United Kingdom, Jessica Kingsley Publishers, p.224.

Year	Policy / legislation
1986	*Intellectually Disabled Persons' Services Act 1986* (Vic) • Repealed and replaced by new legislation in 2006 (see below).
1986	*Guardianship and Administration Board Act 1986* (Vic) • Reviewed in 2014.
1989	*Local Government Act 1989* (Vic) • Requires local council to work towards improving the overall quality of life of people in the local community, promoting appropriate business and employment opportunities, and ensuring that services and facilities provided by the Council are accessible and equitable.
1986	*Equal Opportunity Act 1986* (Vic) • Repealed and replaced by new legislation in 2010 (see below).
1991	*Disability Services Act 1991* (Vic) • To ensure that persons with disability receive the services necessary to enable them to achieve their maximum potential as members of the community. • Repealed and replaced by new legislation in 2006 (see below).
2002	*State disability plan 2002–12* • Outlined a new approach to disability—it had a whole-of-government and whole-of-community approach to disability that aimed to focus on all aspects of life beyond disability supports.
2006	*Disability Act 2006* (Vic) • Increased emphasis on the social inclusion of people with disability, introducing requirements for disability action plans and a statewide disability plan • Led to major reforms in disability service provision, with a greater focus on person centred approaches that give people with disability greater choice, control and rights in the services they use
2006	Charter of Human Rights • Stipulates that all Victorian public authorities are required by law to act compatibly with human rights when making decisions.[31] • Recognises that 'all people are born free and equal in dignity and rights, and that human rights belong to all people without discrimination'.[32]

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[31]   *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.5.
[32]   *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.2.

Year	Policy / legislation
2010	*Equal Opportunity Act 2010* (Vic) • Aims to identify and eliminate individual and systemic discrimination. • Recognises direct and indirect discrimination on the basis of disability as unlawful 'if it occurs in an area of public life including employment, sport, education, provision of goods and services and accommodation'.[33]
2013	*State disability plan 2013–16* • Continues whole-of-government work towards self-directed and flexible disability services that complement accessible and responsive mainstream services such as health, education and transport.
2013	*Victoria's priorities for mental health reform 2013–15*
2014	*Mental Health Act 2014* (Vic)
2014	*Guardianship and Administration Bill 2014* • Proposed changes to the *Guardianship and Administration Act 1986* to provide more flexible powers to customise its orders to the needs of people with impaired decision making capacity and their families.

Source: Compiled by the Family and Community Development Committee.

For the purposes of this Inquiry, the key piece of legislation relating to social inclusion is the Disability Act. The *Mental Health Act 2014* (Vic) has some relevance in the context of social inclusion experienced by people with a severe or enduring mental illness. However, in the context of people with mental illness and social inclusion it is more useful to consider recent policy initiatives that focus more directly on participation and social inclusion than the Mental Health Act.

In 2013, the Victorian Government released *Victoria's priorities for mental health reform 2013–15*. This document outlines an agenda for change with six priorities largely focused on the provision of mental health services and preventative efforts. It highlights the link between services and social inclusion, stating that 'building a stronger system in which long-term recovery and support for overall health and wellbeing, social connectedness and economic participation are paramount.'[34]

In determining its future social inclusion agenda for people with disability, the Victorian Government will need to clarify the extent to which mental illness and disability are considered together or separately. The NDIS will include assessments for people 'with a psychiatric condition who have significant and

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[33] *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.4.
[34] Department of Health (2013) *Victoria's priorities for mental health reform 2013–15*. Melbourne, Department of Health, p.iii.

permanent functional impairment' and will have consequences for how social inclusion initiatives are framed into the future.

The Committee recognises this is a contentious area. For example, the CEO of SANE Australia, Mr Jack Heath, expressed his view to the Inquiry regarding the concept of 'psychiatric disability' and the NDIS:

> … there are some things around that which are problematic. The big push we have had in the past number of years is around a recovery focus, and organisations in Victoria, be it Mind Australia, Neami National or whatever, have taken a really great leadership role. Some of those programs being rolled out by those and other organisations are as good as anywhere in the world in terms of taking that recovery focus. The challenge is that the notion of psychiatric disability actually runs counterthetical to notions of recovery. I am afraid I do not have the easy answer for you on this. In terms of the request, we know that a number of consumers, and carers as well, have issues around the notion of psychiatric disability. I am not sure what is the better way to deal with it in a disability context, other than to take it out of the disability context.[35]

In view of the Terms of Reference for this Inquiry, the Committee focuses specifically on the Disability Act.

2.4.1. Disability and inclusion—the *Disability Act 2006* (Vic)

In 2002 the release of the *State disability plan 2002–12* contributed to an increased focus on participation and social inclusion for people with disability. The Plan committed to a number of reforms aimed to improve the lives of people with disability. Its key purpose was to reform the disability services system and review the *Intellectual Disabled Persons Act 1986* (Vic) and the *Disability Services Act 1991* (Vic). These Acts were repealed and replaced with the *Disability Act 2006* (Vic).

The objectives of the Disability Act demonstrate the intention to build more inclusive communities that enable people with disability to pursue their aspirations. Specifically the Disability Act aims to:

- advance the inclusion and participation in the community of persons with disability

- promote a strategic whole of government approach in supporting the needs and aspirations of persons with disability.[36]

The objective to increase social inclusion for people with disability was supported by the introduction of the Victorian Disability Advisory Council (VDAC) and requirements for public sector bodies to develop disability action plans to reduce barriers for people with disability. Box 2.1 outlines the three key tools legislated by the Disability Act to increase social participation and inclusion.

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[35] *Transcript of Evidence*, SANE Australia, Melbourne, 5 May 2014, p.4.
[36] *Disability Act 2006* (Vic) s.4.

Box 2.1: Social inclusion and the *Disability Act 2006* (Vic)

The Act has three key areas that focus on the inclusion and participation of people with disability in the community.

Victorian Disability Advisory Council

The Victorian Disability Advisory Council (VDAC) provides advice to the Minister for Community Services on issues that affect people with disability across all government services. VDAC is a way for people with disability to have a say in decision making on whole-of-government policy issues. VDAC is comprised by people with disability and:

- provides advice to minister
- raises community awareness
- works with other disability advisory bodies
- monitors implementation of strategy for inclusion and participation
- reports annually to minister.

State Disability Plan

The Act states that the State Disability Plan must be created in 2013 and needs to:

- identify the needs of persons with disability
- establish goals and priorities for the support of persons with disability
- identify objectives and policy priorities for the development and delivery of services for persons with disability
- identify strategies for achieving those objectives and priorities.

Disability Action Plans

In addition, under the Act public sector bodies are required to develop disability action plans that aim to:

- reduce barriers for people with disability to access services, goods, facilities, and employment opportunities
- promote inclusion and participation for people with disability
- address attitudinal barriers that lead to discriminatory practices against people with disability.[37]

Source: Department of Human Services (2007) *About the Disability Act 2006.* Melbourne, DHS. Accessed on 6 August 2014 from
http://www.dhs.vic.gov.au/__data/assets/pdf_file/0008/598940/disability_act_web_print_version.pdf.

In addition to its vision for social inclusion for people with disability, the Disability Act reformed the provision of disability services in Victoria. Its objectives are to:

- facilitate the planning, funding and provision of services, programs and initiatives for persons with disability

- promote and protect the rights of persons accessing disability services

- support the provision of high quality disability services

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37   *Disability Act 2006* (Vic) s.38.

- make disability service providers accountable to persons accessing those disability services

- ensure the efficient and effective use of public funds in the provision of disability services.[38]

The NDIS was introduced in 2013 and is currently being trialled. The full rollout between 2016 and 2019 will change the role of states and territories in the funding and oversight of disability support. This is discussed in Sections 2.6 and 2.7.

The Committee determined that the Victorian Government will need to commence a review of the Disability Act by 2019 to ensure it aligns with the *National Disability Insurance Scheme Act 2013* (Cth) and reflects its changed role in funding and overseeing disability service provision.

Recommendation 2.1

That the Victorian Government commence a review of the *Disability Act 2006* (Vic) by 2019 to ensure it aligns with the *National Disability Insurance Scheme Act 2013* (Cth) and reflects the Victorian Government's future involvement in disability.

Effectiveness of the Disability Act

The Committee heard that the Disability Act has provided a strong legislative framework for social inclusion for people with disability and that its principles and objectives are broadly supported. Despite its strong foundations, a number of Inquiry participants considered that in the context of social inclusion, the legislation is aspirational and that there is still some way to go before inclusion becomes a reality in the lives of people with disability.

Many participants emphasised that the Disability Act had been a critical reform and continues to provide good guidance for how to create a more inclusive Victoria for people with disability. Box 2.2 outlines some of the views shared with the Inquiry.

Box 2.2: Disability Act and social inclusion

- The Disability Services Commissioner acknowledges and supports the aspirations outlined in the principles of the *Disability Act 2006* (the Act). The principles provide clear guidance for the actions we as a community need to take if we are to achieve the creation of an inclusive and welcoming society for Victorian's with disability, including a commitment from all tiers of government and a significant cultural and perceptual change in the community. (*Submission S049,* Disability Services Commissioner, p.3)

- The Victorian *Disability Act 2006* has provided a strong legislative framework that reinforces the rights of people with disability in the community and sets expectations and parameters for disability service provision across the state. *Disability Act 2006* remains relevant to the social inclusion of people with disability in the community. (*Submission S097,* Whitehorse City Council, p.14)

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[38]   *Disability Act 2006* (Vic) s.4.

Box 2.2: Disability Act and social inclusion

- *The Disability Act 2006,* along with the *State Disability Plan 2002–12*, provided a framework for a number of reforms in disability services which promote social inclusion. (Submission S067, Warrnambool City Council, p.16)

- Victoria has made a clear commitment to the full and equal social participation of people with disability in the Victorian *State disability plan 2013–16* and the *Disability Act 2006.* (*Submission S071,* Women's Health West, p.1)

Some Inquiry participants highlighted that the principles in the Victorian legislation are now reflected in the NDIS, demonstrating its strength as a framework for the rights of people with disability. For example the Centre for Rural Regional Law and Justice explained to the Inquiry that it is reassuring to see that Victoria's legislative principles have been picked up by the NDIS:

> It is encouraging to see the platform for such approaches already set out, in a service context, in the launch site of the National Disability Insurance Scheme (NDIS) in Victoria's Barwon Region and, legislatively, in Victoria's *Disability Act 2006.*[39]

The Disability Services Commissioner similarly commented that 'it was pleasing to see that many similar principles were adopted in the *National Disability Insurance Scheme Act 2013* (Cth).'[40]

Yet several participants suggested that while its principles are good, the 'Act is "aspirational" with respect to promoting social inclusion'.[41] The Committee heard that the implementation of the Disability Act is yet to make inclusion a lived reality in the lives of people with disability. For example, Belonging Matters highlighted that the principles of the Disability Act are strong, but approaches to implementation that actually achieve social inclusion have not followed:

> The Disability Act sets out excellent principles for realising justice and inclusion for people with disability. However, difficulties remain with implementation and practice. Individuals, families and services do not necessarily know how to move beyond the slogans of social inclusion and make them a lived reality.[42]

National Disability Services (NDS) Victoria expressed a similar view that 'the policy frameworks are pretty strong and the legislation is pretty strong; it is just a question of making sure that it is actually implemented.'[43]

Other evidence suggested that inadequate data made it difficult to accurately determine how successful the Disability Act has been in achieving its objectives since 2007. For example, in its response to the Committee's question in its Submission Guide regarding the effectiveness of the Disability Act, Annecto stated that 'there are several inspiring success stories, but solid analysis of the extent of inclusion and participation would require group and population data.'[44]

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[39] *Submission S013*, Centre for Rural Regional Law and Justice, Deakin University, p.4.
[40] *Submission S049*, Victorian Disability Services Commissioner, p.3.
[41] *Submission S130*, Health and Community Service Union (HACSU), p.5.
[42] *Submission S030*, Belonging Matters, p.5.
[43] *Transcript of Evidence*, National Disability Services, Melbourne, 3 March 2014, p.6.
[44] *Submission S104*, Annecto - the people network, p.10.

Annecto went on to explain that it 'is unable to comment further as we have no access to this date'.[45]

Some Inquiry participants suggested that the Disability Act is too focused on people with disability as service recipients and that it needed a stronger focus on them as members of the community. For example, Melbourne City Mission highlighted that 'the Disability Act formalised the principles of participation and inclusion' but went on to say that:

> … it has not achieved the fundamental changes that we wanted to see—it is still focused on people being recipients of services, rather than being rights-based.[46]

The Association for Children with a Disability suggested that 'replacing the old system where people with disability and families were passive recipients of care, requires greater investment in encouraging them to participate in all aspects of community life.'[47]

The Committee also heard that the Disability Act could be strengthened to ensure greater accountability. The Disability Services Commissioner, Mr Laurie Harkin, expressed his view that 'legislatively there are deficits' in the Disability Act.[48] In particular, he pointed to the reality that responsibility for social inclusion rests across multiple departments, yet legislative responsibility sits with only one Minister and that only one departmental officer has specific responsibility for undertaking actions. He explained that:

> The act refers only to particular responsibilities being vested with the Minister for Community Services and the other titles that minister may hold, and the secretary is the only person or government official who is nominated as having to do anything about it, leaving aside various other things that are laudably said in the act.[49]

In addition he commented that 'there is no particular regime of arrangements that requires a whole-of-government approach to be adopted; it rests on the goodwill of the government, whomever the government of the day might be.'[50] He went on to express his view that: 'I find it curious that the expectation of government would have it all sit with one minister.'[51] Further, The Disability Services Commissioner stated that:

> My submission to you is this: this is not about human services; this is about society.[52]

There are a number of legislative tools that currently exist in the Disability Act that provide a basis for leading the social inclusion agenda:

- Victorian Disability Advisory Council
- State Disability Plan
- Disability Action Plans.

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45   *Submission S104*, Annecto - the people network, p.10.
46   *Submission S111*, Melbourne City Mission, p.33. See also *Submission S122*, Association for Children with a Disability.
47   *Submission S122*, Association for Children with a Disability, p.4.
48   *Transcript of Evidence,* Disability Services Commissioner, p.3.
49   *Transcript of Evidence,* Disability Services Commissioner, p.3.
50   *Transcript of Evidence,* Disability Services Commissioner, p.3.
51   *Transcript of Evidence,* Disability Services Commissioner, p.3.
52   *Transcript of Evidence,* Disability Services Commissioner, pp.2–3.

> **Finding 2.5**
>
> The *Disability Act 2006* (Vic) provides a strong legislative framework to increase social inclusion for people with disability and its principles and objectives are broadly supported.

Victorian Disability Advisory Council (VDAC)

The Victorian Disability Advisory Council (VDAC) has considerable power under the Disability Act. As outlined in Section 2.4.1, it provides advice to the Minister, works with other disability advisory bodies, and raises community awareness. Under the legislation VDAC has a role in providing the advice to the Minister regarding:

- whole-of-government policy directions and strategic planning and the implementation of initiatives for persons with disability

- the barriers to full inclusion and participation in the community of persons with disability and the strategies for the removal of those barriers

- any matter relating to disability referred to the Victorian Disability Advisory Council by the Minister.[53]

Despite its extensive powers, the Committee heard that VDAC does not exercise them to their full extent. Inquiry participants also suggested VDAC has a low profile in the general community and it is difficult to identify what activities it is undertaking or has undertaken. For example, Whitehorse City Council stated that VDAC has an important role and that its members do valuable work in advocating for the needs of people with disability, but that it 'is not well known in the general community'.[54] It explained that 'VDAC members have undertaken a wide range of roles on various working and advisory groups ensuring the voices of people with disability are heard across state government.'[55]

VDAC holds bi-monthly meetings in rural and metropolitan areas across Victoria. It has sub-committees in areas where people with disability experience barriers to inclusion, such as transport, housing and education. The sub-committees work with local communities, hold discussions with relevant organisations and report back to VDAC on a regular basis.

Areas in which Inquiry participants identified that VDAC could be strengthened included its involvement with disability advisory committees in local government. The Committee heard that:

> Councils have variations of Disability Advisory Committees that inform local policy, developments and initiatives. The Whitehorse Disability Advisory Committee for instance is chaired by an elected Councillor and made up of 12 representative members that include people with disability, parents or carers and service providers.[56]

Whitehorse City Council explained that its disability advisory committee is an advisory committee to the Council and its purpose is to provide 'Council with strategic advice regarding systemic, structural, cultural and social barriers impacting on the lives and opportunities available to people with disability.'[57] It

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[53] *Disability Act 2006* (Vic) s.12.
[54] *Submission S097*, Whitehorse City Council, p.15.
[55] *Submission S097*, Whitehorse City Council, p.15.
[56] *Submission S097*, Whitehorse City Council, p.15.
[57] *Submission S097*, Whitehorse City Council, p.15.

also aims to 'ensure that the Disability Action Plan remains reflective, responsive and relevant to both the community and Council'.[58] Mildura Rural City Council explained that the input of its Disability Access Advisory Committee 'has strengthened the knowledge base and networks of our committee overall.'[59]

Whitehorse City Council told the Inquiry that one key objective of the Whitehorse Disability Advisory Committee is to explore 'greater links between the local advisory committees and VDAC' which:

> … may assist in the identification of emerging issues but also provide an opportunity to share good practice amongst committee members.[60]

Monash City Council highlighted that these linkages are starting to occur. It explained that VDAC recently initiated 'joint meetings with Disability Advisory Committees at local municipalities.' The Council told the Inquiry that 'this initiative provides the opportunity for local DACs [disability advisory committees] and Councils to develop a closer and more meaningful relationship with pivotal advisory structures such as VDAC.'[61]

Whitehorse City Council also suggested that it promoting a 'VDAC portal would assist individuals, Councils and other organisations to connect in with the work and link the work of VDAC back to the community.'[62]

Finding 2.6

The Victorian Disability Advisory Council undertakes important work and its members do valuable work in advocating for the needs of people with disability, but it is not well known in the general community.

Recommendation 2.2

That the Minister for Community Services request that the Victorian Disability Advisory Council (VDAC) develop a strategy to increase its profile and that it will be incumbent on VDAC to implement this strategy.

State Disability Plan

Social inclusion is increasingly central to the Victorian Government's policy response to disability. The current Victorian *State disability plan 2013–16* is the first Plan to be developed under the Disability Act. It articulates an overarching vision to create 'an inclusive Victorian society that enables people with disability, their families and carers to fulfil their potential as equal citizens'.[63]

The Plan is accompanied by an *Implementation plan 2013–14* containing 141 government actions and an interdepartmental committee that meets quarterly

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58   *Submission S097*, Whitehorse City Council, p.15.
59   *Submission S076*, Mildura Rural City Council, p.3.
60   *Submission S097*, Whitehorse City Council, p.15.
61   *Submission S120*, Monash City Council, p.5.
62   *Submission S097*, Whitehorse City Council, p.15.
63   Department of Human Services (2012) *Victorian state disability plan 2013–2016*. Melbourne, DHS, p.11.

to keep the plan on track. It also produced a *Companion document* with statistics relating to the participation of people with disability.

The Plan states that the Victorian Government needs to work across a number of levels to bring about changes that will make a real difference to people with disability. These include removing barriers in the community, supporting the individual and continuing to reform the disability service system. It has four interconnected long-term goals:

- Goal 1—a strong foundation in life

- Goal 2—upholding rights and promoting participation

- Goal 3—accessing information, transport, buildings and places

- Goal 4—a contemporary approach through disability system reform.[64]

Most Inquiry participants that referred to the Plan were positive about its direction, suggesting that it is 'good policy intent' and that it 'has the right frameworks in place'.[65] For example, the Victorian Council of Social Service (VCOSS) considered that the intention behind the Plan is sound and that it provides a strong basis for building a more inclusive Victoria for people with disability. It explained that:

> As an aspirational statement, the Plan is, on the whole, very good. While many may quibble with the particular wording, emphasis, or choice of indicators or strategies, it is generally in line with the community's expectations for what is required for improvements to be made.'[66]

Whitehorse City Council also made reference to its foundations for partnerships in that it 'interacts with other State Government strategic plans.'[67] It expressed its view that:

> The current Plan continues build upon previous work to ensure people with disability participate in decision making that impacts their life and have greater control over all aspects of their lives. There is clear intention to work in partnership with local government, community organisations and the business sector to affect the desired outcomes.[68]

In the context of improving the Plan, a number of Inquiry participants suggested that there is room for a stronger focus on outcomes to ensure it is effectively implemented and evaluated. Box 2.3 outlines some of the views expressed.

Box 2.3: *State disability plan 2013–16*—improving implementation

- We have a view that the state plan is good policy, but the government really does need to focus very heavily on its implementation. (*Transcript of evidence*, National Disability Services, p.3)

- The great weakness of the plan is not its aspiration or direction, but its inability to stipulate any binding targets, impose any requirement for compliance, or definitively recruit any resources to fulfil its goals. Because there are no benchmarks, no one can

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[64] Department of Human Services (2012) *Victorian state disability plan 2013–2016.*
[65] *Transcript of Evidence,* National Disability Services, p.3.
[66] *Submission S126*, Victorian Council of Social Service (VCOSS), p.9.
[67] *Submission S097*, Whitehorse City Council, p.14.
[68] *Submission S097*, Whitehorse City Council, p.14.

Box 2.3: *State disability plan 2013–16*—improving implementation

be held to account for failing to reach them. While the Implementation Plan contains many worthy, if often vague, initiatives, they do not contain any measures of success, and there is no mechanism to determine whether they are sufficient to achieve reasonable progress. (*Submission S126*, Victorian Council of Social Service, p.9)

- The lack of an overt link between plans and shared actions is of concern as funded services look to state strategic plans to provide statewide guidance in relation to target groups and emerging issues. (*Submission S097*, Whitehorse City Council, p.14)

- Addressing the issue of social inclusion requires a multi-pronged approach [including] greater focus on implementation of the state disability plan throughout the community such as infrastructure and building codes. (*Submission S043*, Cerebral Palsy Support Network, p.4)

In its submission, VCOSS went on to recommend that into the future the Victorian Government needs to improve the State Disability Plan process by ensuring all initiatives are funded, but also by including:

- criteria for success of each initiative in the next Implementation Plan

- targets for each indicator in the next State Disability Plan.[69]

The Committee identified that the current Plan has a strong focus on participation. It uses participation indicators rather than indictors of social inclusion to measure its progress and success. Increasing participation levels do not always determine if people feel respected, valued or more included. Also, due to the availability of participation data, some of the actions in the Plan do not have indicators, such as the actions relating to culturally and linguistically diverse communities.

Where used, the participation indicators are based on data and survey information collected by the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW) and others. These bodies use different methodologies for different data and survey collections. Furthermore, there is minimal emphasis on longitudinal data that can inform social inclusion.

Chapter 1 outlined the differences between inclusion and participation in the context of measuring people's experiences. It also emphasised the need to identify a specific tool for effectively measuring social inclusion.

Into the future, the Plan will obviously need to complement the NDIS and any revisions to the Disability Act. The Committee envisages that a future Plan could be reoriented to a disability inclusion plan and be strengthened by:

- broadening its definition of social inclusion as recommended in Chapter 1 and include a stronger focus on identifying and understanding the aspirations of people with disability in the context of social inclusion in the community

- providing specific directions relating to building social connections and social capital for people with disability, as discussed in Chapter 4

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[69] *Submission S126*, Victorian Council of Social Service (VCOSS), p.5.

- clearly articulating the role and work of local government through disability action plans and initiatives for building inclusive communities

- more effectively engaging relevant professional bodies that represent architects, developers, town planners and small business.

Finding 2.7

The *State Disability Plan 2013–16* is broadly supported, and future State Disability Plans will need to complement the NDIS and could be reoriented to a disability inclusion plan and strengthened by:

- including specific targets and outcome measures for its strategies and implementation actions

- providing specific strategies relating to building social capital and clearly articulating the role of local government and the Building Inclusive Communities Program.

Disability Action Plans

The Disability Act encourages public bodies to develop disability action plans that are directly related to increasing the social inclusion of people with disability. This includes identifying and implementing actions to reduce barriers experienced by people with disability, promote inclusion in the community and work towards changing attitudes in the community that discriminate against people with disability.

Inquiry participants highlighted the potential value disability action plans can contribute to increasing social inclusion for people with disability. For example, Geelong City Council Disability Advisory Committee made reference to the requirement for disability action plans introduced under the *Disability Discrimination Act 1992* (Cth) and the Australian Human Rights Commission's view that the plans have 'the capacity to produce the systemic change and strategically change practices which may be discriminatory.'[70]

Despite viewing disability action plans positively, the Committee heard that there is room for strengthening the process to increase their effectiveness. Inquiry participants expressed concern that there are no consequences for public bodies that do not develop a disability action plan. For example, Darebin Disability Advisory Committee stated that:

> … while disability action plans (DAPs) are legislated under the Act, there are no consequences where service providers do not develop a DAP–reinforcing the notion that quality of services and social inclusion is not a priority.[71]

National Disability Services (NDS) Victoria suggested that the Victorian Government needs to 'mandate the development and implementation of disability action plans (DAPs) across all Departments and agencies, including organisations delivering government funded services and programs.'[72] Darebin Disability Advisory Committee also suggested that there needs to be greater accountability for existing disability action plans. While it noted requirements to report on progress, it told the Inquiry there are no reporting standards:

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[70]   *Submission S116*, Geelong City Council Disability Advisory Committee, p.6.
[71]   *Submission S041*, Darebin Disability Advisory Committee, pp.7–8.
[72]   *Submission S045*, National Disability Services Victoria, pp.6–7.

> … there are few mechanisms to monitor actions and standards that have not been completed or implemented. There needs to be greater measures of accountability in monitoring and reviewing how closely sector bodies are meeting their stated objectives through disability action plans and legislated standards of practice.[73]

The Committee also heard that some disability action plans are limited in scope or are not living documents that contribute to real change. For example, Hobsons Bay City Council stated that:

> Despite the introduction of this act however, many people with disability continue to face discrimination, inequalities and barriers to full participation in their community. This is largely due to the limited scope that the disability action plans are including and that it is not a requirement of all organisations to have one.[74]

It suggested that 'further work needs to be done by the state government to raise awareness of the importance for all organisations to have a disability action plan.'[75] Marriott Support Services expressed its view to the Inquiry that the strategies adopted by some public bodies can be ineffective in some plans:

> While local, state and federal governments produce beautifully printed disability action plans, too often these plans fail to incorporate realistic mechanisms and commensurate funding to accomplish their goals.

It went on to explain that 'disjointed plans constructed across different areas of government are often based on insufficient consultation and partnership with those who have the knowledge and expertise which comes from working with people with disability on a daily basis.'[76]

Amendments to the Disability Act in 2012 made it a requirement for local government to report on the progress of disability action plans, but that there is still no consequences for not developing a plan. The Committee considered that there could be a role for the Victorian Auditor-General to undertake an audit of the suitability, effectiveness and implementation, and the monitoring and improvement of disability action plans.

The Committee recognises the value that disability action plans (DAPs) have, but also the regulatory burden that such requirements can have on public bodies, particularly smaller entities. It heard that the capacity of local councils varies considerably. For example, the Municipal Association of Victoria (MAV) told the Inquiry that issues 'for smaller rural councils were keeping the momentum for progress going when councils are facing major sustainability issues and addressing multiple competing priorities including emergency management.'[77]

The MAV also explained that discriminatory attitudes continue to persist in some local councils and communities which affect their levels of commitment to addressing the barriers experienced by people with disability:

> Overt and covert discriminatory attitudes are still evident amongst some areas within councils and the local community and there is lack of understanding about (and sometimes acceptance of) the rights of people with disability to be included and supported to pursue their potential as equal citizens.[78]

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73   *Submission S041*, Darebin Disability Advisory Committee, pp.7–8.
74   *Submission S078*, Hobsons Bay City Council, p.3.
75   *Submission S078*, Hobsons Bay City Council, p.3.
76   *Submission S020*, Marriott Support Services, p.2.
77   *Submission S053*, Municipal Association of Victoria, p.5.
78   *Submission S053*, Municipal Association of Victoria, p.8.

The Committee reviewed the disability action plans referred to by the 25 local councils that provided submissions to the Inquiry. It identified that they vary considerably. Some have moved from referring to their plans as 'disability action plans' to calling them 'access and inclusion plans'. The MAV explained that it had determined that 'many plans demonstrat[e] a strong whole-of-council commitment.'[79] The Committee also identified that a number of the plans are integrated into the broader objectives and goals of the local council.

Some plans have a strong focus on issues relating specifically to accessibility, such as access to the built environment, transport, employment and arts and culture. Others are moving to incorporate a stronger focus on inclusion, such as building communities that are connected and engaged, informed and aware, and supportive and welcoming. A number follow the requirements set out in the Disability Act.

The Committee also heard that there is a wealth of information collected through the disability action planning process about local priorities and local experiences of including people with disability.[80] Participants suggested that this could be used to better inform state policy and action. For example, Whitehorse City Council stated that:

> Outcomes of disability action plans provide a wealth of information regarding local priorities and actions that could be captured and utilised to inform State policy and actions. Resources would be needed to collate priorities and actions across the state. Undertaking this body of work would promote a whole of Victoria approach to increasing the social inclusion of people with disability.[81]

The Committee heard that in 2011 the MAV, in partnership with the Office for Disability in DHS, undertook a pilot project and developed a *Disability access and inclusion strategy* to support local councils in their work to reduce the barriers experienced by people with disability in local communities. The Geelong City Council Disability Advisory Committee explained that this led to the development of a number of resource guides for councils, including:

- *Creating a more inclusive community for people with disability*

- *Local government: Building inclusive communities*

- *Increasing civic participation and improving consultation with people with a disability*

- *Creating employment opportunities for people with a disability.*[82]

The Committee recognises that these guides are valuable, but that in isolation they cannot ensure that local councils use or implement them.

Participants told the Inquiry that local councils tend to be more aware of the value and importance of disability action plans than other public bodies. For example, Whitehorse City Council stated that:

> Knowledge of the Disability Act 2006 requirement to develop disability action plans is believed to be limited. Training opportunities provided by the Office for Disability for

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[79]   *Submission S053*, Municipal Association of Victoria, p.5.
[80]   *Submission S017*, City of Stonnington, p.4; *Submission S097*, Whitehorse City Council, p.15.
[81]   *Submission S097*, Whitehorse City Council, p.15.
[82]   *Submission S116*, Geelong City Council Disability Advisory Committee, pp.6–7.

community and health services highlighted a lack of knowledge surrounding the legislative requirement to develop disability action plans.[83]

It explained that this is also demonstrated by the fact that 'many community and disability service organisations have not developed disability action plans.'[84] It considered there needs to be greater attention to 'creating mechanisms to ensure that all State funded organisations, regardless of sectors, are aware of legislative requirements is critical to achieving and measuring the achievement of social inclusion goals.'[85]

The Committee identified a need for the Office for Disability in DHS to:

- Develop a mechanism for using the information contained in progress reports from disability action plans to inform future policy and directions, including the State Disability Plan.

- Increase its efforts in raising awareness of the value in developing a disability action plan.

- Identify those local councils with persistent discriminatory attitudes and develop a targeted campaign.

Finding 2.8

There are no standards for disability action plans or systems for monitoring their effectiveness, yet imposing additional systems of oversight could pose considerable regulatory burden and not lead to greater effectiveness.

Recommendation 2.3

That the Victorian Government request the Victorian Auditor-General undertake an audit of the suitability, effectiveness and implementation, and the monitoring and improvement of disability action plans in local government.

Other states

The Committee recognises that other states and territories have also been working to create more inclusive communities for people with disability. It considered the range of initiatives that relate to disability inclusion frameworks and plans for service system reform. Like Victoria, some are yet to integrate aspects of their plans to reflect the introduction of the NDIS and, also like Victoria, some have included some specific actions relating to the NDIS. Table 2.3 outlines the broad strategic directions of these plans and frameworks.

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83   *Submission S097*, Whitehorse City Council, p.14.
84   *Submission S097*, Whitehorse City Council, pp.14–15.
85   *Submission S097*, Whitehorse City Council, p.15.

Table 2.3: Disability plans and framework of other Australian jurisdictions

State	Disability plan	Broad strategic directions
Australian Capital Territory	*Future directions: Challenge 2014*	Vision: All people with disability achieve what they want to achieve, live how they choose to live, and are valued as full and equal members of the ACT community. A person with disability should be able to: • be recognised as an individual and for their capabilities • live life like other people their age.
New South Wales	*Stronger together: A new direction for disability services in NSW 2006–2016*	Places efforts on: • Strengthening families (enabling children and young people with disability to grow up in a family and participate in the community). • Count me in … promoting community inclusion (supporting adults with disability to live in and be part of the community). • Improving the system's capacity and accountability (fairer and clearer ways to access services with greater accountability and more opportunities for innovation).
Queensland	*Disability plan 2014–19: Enabling choices and opportunities*	Priorities for change: • Support people with disability and communities to be well informed and confident about what the NDIS means for them. • Support people with disability, families and carers to exercise choice and take up opportunities. • Support non-government disability service providers to operate in a competitive market-based environment. • Develop a skilled and strong workforce. • Prepare Queensland Government departments to transition disability funding and services to the National Disability Insurance Agency. • Enhance mainstream services and facilities to enable genuine choice and participation in all areas, including education, employment, health, justice services and housing. • Promote genuine participation in the community.

State	Disability plan	Broad strategic directions
Tasmania	*Tasmanian disability framework for action 2013–2017*	Guiding principles: • involvement of people with disability • community engagement • simplicity • choice • universal approach. • Life course approach. • Person-centred. • Independent living. • Collaboration.
Western Australia	*Count me in— Disability future directions*	Vision: All people live in welcoming communities that facilitate citizenship, friendship, mutual support and a fair go for everyone. Three future directions: • Personalised supports and services. • Participation and contribution in all aspects of life. • Economics and community foundations.

Source: Compiled by the Family and Community Development Committee.

2.5.   Local government

Local government has regulatory responsibilities in the context of planning and development in local government areas and also delivers a range of human services. It has specific requirements under the Disability Act in regard to developing, implementing and reporting on disability action plans.

In addition, participants told the Inquiry that the *Local Government Act 1989* (Vic) provides an overarching legislative responsibility for local councils to work towards socially inclusive communities for people with disability. For example, Moonee Valley City Council recognised the connection between that legislation and the responsibility of council to people with disability. It stated that:

> The *Local Government Act 1989* (s.3C) requires Councils to pursue a range of 'facilitating objectives', including activities which:
>
> • improve the overall quality of life of people in the local community
>
> • promote appropriate business and employment opportunities
>
> • ensure that services and facilities provided by the Council are accessible and equitable.

> These objectives provide a legislative basis for activities that increase social inclusion for people with disability.[86]

The Committee considered the role of local government in advancing the social inclusion of people with disability. The MAV told the Inquiry that all local councils have disability action plans and expressed its view that many have made progress in creating more socially inclusive communities:

> Local government in Victoria has a significant history of working to address issues of access and inclusion for people with disability, particularly since the Commonwealth *Disability Discrimination Act 1992* which provided the impetus for Australia to more actively address the discrimination experienced by people with disability in many aspects of their lives. The legislation was promoted through the national local government peak body, the Australian Local Government Association, and Victorian councils were early leaders in developing disability action plans.[87]

The MAV has a strategic framework that provides 13 actions to guide local governments in building the capacity of local communities to be more inclusive of people with disability. Table 2.4 outlines these actions.

Table 2.4: Actions in the MAV Strategic framework for local councils to build inclusive communities for people with disability

Actions
• a whole-of-council approach
• incorporate access and inclusion objectives in key strategic documents
• facilitate civic participation and inclusive consultation
• systematically improve the accessibility of council buildings and infrastructure
• inclusive communication and information approaches
• accessible and inclusive council services, programs and events
• strategic use of statutory and regulatory roles
• improve employment opportunities
• influence community attitudes and perceptions
• exercise leadership in advocating to other organisation
• foster partnership and collaboration
• effective accountability practices
• review and evaluate progress.

Source: *Submission S053*, Municipal Association of Victoria, pp.12–13.

Twenty-five local councils across Victoria made submissions to the Inquiry. Each of these local councils acknowledged they have a role in building the capacity of communities to be more socially inclusive. For example, Whittlesea Disability Network suggested that 'local Councils have very powerful potential to promote and foster an inclusive community.'[88] It went on to explain that:

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[86]   *Submission S052*, Moonee Valley City Council, pp.4–5.
[87]   *Submission S053*, Municipal Association of Victoria, p.3.
[88]   *Submission S037*, Whittlesea Disability Network, p.6.

> Our local Council is well placed to garner support for social inclusion from people and organisations across the municipality, including local businesses, State and Federal government departments, service providers, sporting clubs and community organisations.[89]

In its submission, Warrnambool City Council explained that communities need to be 'engaged in the change process and equipped with skills and capacity to support the aspirations of people with disability.'[90]

Moonee Valley City Council suggested that there are six key areas of responsibility that sit with local government and that relate to increasing social inclusion for people with disability. One relates to service provision—local governments provide a range of services funded under the Home and Community Care Program, including personal care, respite activities, planned activity groups, community meals and home maintenance. The other areas relate to infrastructure, leadership, partnerships, coordination and capacity building.

Box 2.4 outlines the views of some local councils regarding the role that local governments can play in the context of building inclusive communities.

Box 2.4: Role of local government in building inclusive communities

- The role of Local Government is critical, providing clearly defined population catchments and geographic boundaries to facilitate effective area based planning and service development. (*Submission S103*, Maribyrnong City Council, p.5)

- Services and initiatives tailored for major rural locations such as Benalla, Wangaratta, Shepparton are also not always relevant to smaller local communities such as Mansfield, where the demographics and issues can be very different. (*Submission S057*, Mansfield Shire Council, p.3)

- Council has an important role in designing and developing the type of environments— social, built, economic and natural—that support and enhance the health and wellbeing of all people in the municipality. Council is also conduit for connecting people to a range of community based services and resources that meet their individual needs and aspirations. (*Submission S097*, Whitehorse City Council, p.18)

- Local Government provides the environment and capacity to support and nurture key relationships in the community and an avenue to further support partnership work. No single organisation holds the capacity to deliver best practice projects. Local Government … is a key partner in building capacity of people and places. (*Submission S086*, Brimbank City Council, p.12)

Non-government organisations also emphasised the valuable role that local government has in building inclusive communities. For example, Ms Annette Gill, Policy and Research Manager at Karingal, told the Inquiry that:

> I actually think local government holds some responsibilities in this area. Part of their role is to develop community capital and bring together and coordinate resources within the community. Most local governments—not all local governments—would have a disability action plan for themselves and a disability plan for the community, and certainly the City of Greater Geelong has those things in place.[91]

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89   *Submission S037*, Whittlesea Disability Network, p.6.
90   *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.9.
91   *Transcript of Evidence,* Karingal, p.10.

Ms Gill expressed her view that 'it is incumbent upon any civic leader to be looking at how their organisation role models for the community in terms of their own strategies for disability and employment and how they run inclusive events for the community.'[92]

Victoria is not alone in identifying the need to focus on local communities in working towards more inclusive communities. In other countries there is an increasing focus on identifying new and innovative approaches in building inclusive communities at the local level. For example, in its most recent strategy for people with disability, *Fulfilling potential*, the United Kingdom (UK) Government has emphasised the need to focus on building inclusive communities at the local level.[93]

As pointed out by the Centre for Rural Regional Law and Justice, social inclusion needs to happen 'as part of the natural internal fabric of the community rather than through externally facilitated processes.'[94] The Committee considered that local governments are well positioned to promote social inclusion. They have grassroots connections to local communities, their activities can contribute to inclusive communities and they have established disability action plans and often a disability advisory committee.

2.5.1.   Understanding local communities and building partnerships

One key advantage that most local councils possess is their capacity to understand the unique and diverse needs of local communities. Communities are diverse—they each have their own strengths, characteristics and needs.[95] 'Community' means different things to different people. It is broad and includes 'its citizens, its volunteers, its networks both formal and informal'[96] such as 'business, sporting clubs, neighbourhoods, schools, hospitals.'[97]

The Centre for Rural Regional Law and Justice suggested to the Inquiry that 'the ways people participate, connect and interact … happens differently in different contexts and in different communities.'[98] In the context of rural and regional communities, the Centre highlighted that many rural communities have a strong foundation from which they can build social inclusion for people with disability:

> Regional and rural communities can sometimes be incredibly rich in social capital. That is, there is often already a strong sense of community working together in regional and rural areas and of people being prepared to 'chip in' to make their communities thrive. Volunteerism is typically strong.[99]

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[92]   *Transcript of Evidence,* Karingal, p.10.
[93]   Department for Work and Pensions (2012) *Fulfilling potential: Next steps.* London, (UK) Office for Disability Issues, DWP p.21.
[94]   *Submission S013*, Centre for Rural Regional Law and Justice, Deakin University, p.6.
[95]   *Submission S013*, Centre for Rural Regional Law and Justice, Deakin University, p.2.
[96]   *Submission S013*, Centre for Rural Regional Law and Justice, Deakin University, p.15.
[97]   *Submission S117*, Psychiatric Disability Services of Victoria (VICSERV), p.3.
[98]   *Submission S013*, Centre for Rural Regional Law and Justice, Deakin University, p.4.
[99]   *Submission S013*, Centre for Rural Regional Law and Justice, Deakin University, p.14.

Yet it also cautioned against stereotyping rural communities. It explained that:

> … we have to be so careful that we do not stereotype all regional communities as these sort of lovely extended families. Sometimes that is the case in some of those communities, but it is certainly not always the case.[100]

The Committee recognises that local councils will vary in their capacity to achieve social inclusion for people with disability.

The MAV highlighted that not all local councils are making the same level of progress and that strategies to engage them in community capacity building needs to take this into account:

> Local government in Victoria now has a significant history of working to address issues of access and inclusion for people with disability. While there is still variability in the way individual councils approach this issue, all councils are progressively addressing issues that present barriers to access and inclusion for people with disability within their municipality. Councils across Victoria now have a sound understanding of the ongoing efforts required to enable people with disability to fulfil their potential as equal citizens.[101]

Whitehorse City Council also emphasised that it is important to bear in mind that 'the capacity of local governments to meet community needs and address priority areas varies greatly between metropolitan Councils and between metropolitan and rural Councils.'[102] For example, Whittlesea Disability Network highlighted that Whittlesea is a rapidly growing outer-suburban community and that its services need to stretch at an equally fast pace.[103]

In view of the diversity of communities, the Committee determined that local government is particularly well positioned to understand local needs and to identify strategies to build greater inclusiveness and community capacity. MetroAccess Southern Division commented that:

> Local expertise and understanding is crucial to the ongoing development of the disability services sector, and to addressing social inclusion for people in their own communities.[104]

Mansfield Shire Council also explained the success local councils can have, stating that in its community, 'local initiatives and solutions developed by local people have been far more relevant and effective in improving social inclusion in the community context.'[105]

Many local councils emphasised to the Inquiry that they have capacity to support initiatives and solutions at a local level that can potentially build inclusive communities. In particular, the Committee heard the strengths lie in their capacity to build local partnerships across many contexts. Monash City Council explained how this can work:

> A strength of Councils is to facilitate relationships at the local level and building partnerships with local community groups, agencies, service providers and individuals that supports the provision of meaningful services and programs and advocacy at other levels of government.

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100 *Transcript of Evidence*, Centre for Rural Regional Law and Justice, Deakin University, Melbourne, 6 March 2014, p.7.
101 *Submission S053*, Municipal Association of Victoria, p.5.
102 *Submission S097*, Whitehorse City Council, p.18.
103 *Submission S037*, Whittlesea Disability Network, p.3.
104 *Submission S131*, MetroAccess South Division: Bayside Peninsula & Southern Melbourne, p.2.
105 *Submission S057*, Mansfield Shire Council, p.3.

It is believed that the community development and facilitation roles of Councils are one of their great strengths that should be supported and strengthened.[106]

Brimbank City Council also expressed a view that facilitating partnership is a key contribution that local government can make in building inclusive communities:

Local Government facilitates place based partnerships that have a clear direction; purpose and goal are effective in achieving results. Partnerships that engage local government, community members and disability organisations have the advantage of delivering a whole of community approach to inclusion.[107]

Finding 2.9

Local government is particularly well positioned to:

- understand the diversity of communities and local needs

- plan, promote and develop greater inclusiveness and community capacity

- influence services across the full range of community infrastructure.

2.5.2.   Building inclusive communities—the Access initiatives

The Disability Services section of the Department of Human Services (DHS) developed the Building Inclusive Communities Program (formerly known as the Community Building Program) with the intention of building inclusive communities. It is based on a partnership with local government (in most instances). The initiative was developed in response to the 'limited community membership opportunities available to some people with disability'.[108] Research had identified that 'while people with disability were living in the community, they were not necessarily regarded as members of their communities'.[109]

In its information about the program, DHS explained the rationale behind the program:

As people choose more individualised lifestyles and participate in their community more, the community sometimes needs support to be inclusive and welcoming.[110]

Northern Support Services emphasised the risks in not supporting communities to be inclusive of people with disability, and explained that its experience is that:

… the community needs to be supported to do this and being left with full responsibility can leave them feeling overburdened and concerned or at worse risks alienating the supports.[111]

In evidence to the Inquiry, the DHS Secretary, Ms Gill Callister stressed the significance of the program in the context of the Department's efforts to increase social inclusion:

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[106]   *Submission S120*, Monash City Council, p.4.

[107]   *Submission S086*, Brimbank City Council, p.13.

[108]   Department of Human Services (2010) *Disability services community building program: Introduction to the program*. Melbourne, DHS, p.4.

[109]   Department of Human Services (2010) *Disability services community building program: Introduction to the program*, p.4.

[110]   Department of Human Services *What is the community building program? Tip sheet 1*. Linking self-direction and community building series, DHS, p.1. Accessed on 15 April 2014 from http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/linking-self-direction-and-community-building-tip-sheets.

[111]   *Submission S123*, Northern Support Service's My Place-KeyRing Program, p.9.

> The community building program is our key program targeted at social inclusion for a disability. It is located in local government … with an investment of $6.95 million this financial year.[112]

DHS told the Inquiry that the program currently 'supports a range of targeted programs that work specifically with mainstream services, other areas of government, disability services and people with disability to facilitate a more socially inclusive Victoria.'[113] These are known as MetroAccess, RuralAccess, and deafaccess. Table 2.5 provides an overview of the objectives of the program.

Table 2.5: Building inclusive communities—MetroAccess, RuralAccess, deafaccess

Objectives
• mobilise and support people with disability to optimise participation in the life of their local community
• build and strengthen the community's capacity to provide support to people with disability and their families
• facilitate integrated local community planning and co-ordination which engages and involves people with disability and their families, disability service providers and community organisations
• work with existing disability service providers to enhance their capacity to provide relevant and appropriate supports in the community
• improve access to information about relevant services and community activities available to people with disability in their communities.

Source: *Supplementary evidence*, Response to request for information, Department of Human Services, 28 July 2014.

There are three avenues in which the Building Inclusive Communities Program is delivered:

• RuralAccess—there are 26 councils and community health services in rural and regional Victoria that implement RuralAccess. Many cover more than one local government area.

• MetroAccess—each of the 31 councils across metropolitan Melbourne now implement MetroAccess.

• Deafaccess—there are five organisations (one per non metropolitan region) which auspice deafaccess.

Warrnambool City Council commended the program, stating that it sets Victoria apart from other states and territories:

> Victoria is unlike any other state in Australia in that the State government has made a strong commitment to the development of community building infrastructure through the funding of the RuralAccess, MetroAccess and the DeafAccess initiatives. This places Victoria in a unique position to engage in community development activity which responds to the needs and aspirations of people with disability.[114]

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[112] *Transcript of Evidence,* Department of Human Services, p.5.
[113] *Transcript of Evidence,* Department of Human Services, p.5.
[114] *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.16.

Warrnambool City Council explained that 'the program was designed by DHS to develop strong partnerships between State and local government, specialist disability supports and mainstream community services and organisations.'[115] It went on to outline that:

> The program recognises the potential for local government to lead and facilitate change in local communities by planning and engaging mainstream community organisations and services across the full range of community infrastructure (education, employment, transport, sport and recreation, arts and cultural development, tourism, etc) and building their capacity to include people with disability.[116]

It also highlighted that building partnerships is 'critical to expanding the terms of community membership available to people with disability and opening up opportunities for them to participate in all aspects of community life.'[117]

Darebin Disability Advisory Committee explained to the Inquiry that MetroAccess assists the community to include people with disability and their families and carers by bringing 'together the strengths, resources and creativity of individuals, communities and government to work in partnership to build longterm, sustainable change in local communities.'[118]

Mr Paul Dunn, a consultant with TR Concepts, expressed his view to the Inquiry:

> The community building programs recognise the important role that Local Councils play in planning, promoting and developing inclusive communities. Councils have an ability to influence services across the full range of community infrastructure and can provide leadership to local community providers and organisations so that they can open up their services to people with disability.[119]

Section 2.7.3 discusses local government, the NDIS and how the Access initiatives provide opportunities to increase social inclusion.

Community development approach—Access initiatives

The Building Inclusive Communities Program is based on a community development approach that involves collective action and collective ownership. It is about 'people working together to make a difference to address their shared needs.'[120] The approach is based on 'assets-based community development' (ABCD), which emphasises the following features:

- it starts from a position of understanding the strengths of a community, rather than the issues and needs in a community

- it stresses the importance of local investment and control

- it relies on the building of relationships between local people and organisations.[121]

In Victoria, the Building Inclusive Communities Program has a comprehensive Practice Guide which state that the program 'aims to increase the opportunities

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[115] *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.1.

[116] *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.1.

[117] *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.1.

[118] *Submission S041*, Darebin Disability Advisory Committee, pp.8–9.

[119] *Supplementary evidence*, Response to request for information, Mr Paul Dunn, 23 May 2014, p.1.

[120] Department of Human Services (2010) *Disability services community building program: Practice guide*. Melbourne, DHS, p.16.

[121] Department of Human Services (2010) *Disability services community building program: Practice guide*, p.17.

for people with disability to be seen as valued and contributing citizens in their local communities.'[122] It contains considerable resources to assist Access Officers in the program.

The Practice Guide also highlights a community building cycle to support Access Officers in understanding their role. Table 2.6 briefly summarises the four components of the cycle. Section 2.7.3 discusses the future role of the Building Inclusive Communities Program in the changed landscape emerging with the rollout of the NDIS.

Table 2.6: Components of the capacity building cycle

Component	Description
Community mapping	Community mapping should consider: • The existing assets or resources of the community, including the current service provision for people with disability, and also the potential opportunities for inclusion and participation which may be derived from an analysis of community assets. • The diversity of experiences and backgrounds of local people with disability. • The strategic connections able to be built in the local community which may result in increased inclusion and participation.
Planning	Using the information collected in the ongoing community mapping process as an evidence base, the community building plan will: • describe the priorities for the program locally • set some specific goals • propose some strategies to be undertaken by the Community Building Program [Building Inclusive Communities] auspice organisation to meet the objectives of the program.
Strategies—the doing phase	The Community Building Program [Building Inclusive Communities] takes a multi-faceted community capacity building approach to enabling communities to plan and respond to key issues in the lives of people with disability. Three overlapping capacity-building strategy types form the foundation of the Community Building Program [Building Inclusive Communities] approach: • Community capacity—build the capacity of the local community to include people with disability and remove barriers to access and inclusion. • Individual capacity— build the capacity of individuals to be able to have more choice and control in their lives and their communities. • Service capacity— build the capacity of service providers to provide flexible, self-directed supports.
Reflection and evaluation	Through reflection the understanding of the local community (ie mapping), the work needed (ie planning) and the way the work is

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[122]   Department of Human Services (2010) *Disability services community building program: Practice guide*, p.19.

Component	Description
	undertaken (ie strategies), is re-visited. There are a range of dimensions to reflection:
	• Personal reflection—evaluates the professional contribution by an individual officer to the program.
	• Process evaluation—measures the effectiveness of specific strategies.
	• Impact evaluation—measures progress towards the program objectives.
	• Dissemination—shares the knowledge developed through the program.

Source: Adapted from the Department of Human Services (2010) *Disability services community building program: Practice guide.* Melbourne, DHS.

Strengthening the Building Inclusive Community Program

The Committee considered the ongoing role of local councils in supporting communities to be socially inclusive. In view of the long history in working towards access and social inclusion, the Committee determined the gains made should not be lost (particularly in a context in which change is notoriously slow).

Many councils emphasised the successes of the Building Inclusive Communities Program. For example, Wellington (Local Government Area) Community stated that 'RuralAccess, MetroAccess, deafaccess has had a significant impact on communities' and went on to explain that:

> Organisations/programs such as Rural Access and Deaf Access create strong links between people with disability and opportunities within their community. Without the support of organisations such as these two, many events/programs/projects would not be happening. Rural Access has been a great partner to many individuals and organisations to create sustainable programs and events, promoting social inclusion within the community and ongoing participation opportunities for everyone.[123]

Brimbank City Council told the Inquiry that 'since the inception of MetroAccess there have been major projects that have increased Social Inclusion and supported infrastructure and environment initiatives to support community connectedness.'[124] Maribyrnong City Council also stated that 'as a community building initiative MetroAccess complements and adds value to [the Disability Action] Plan by working across the full range of community infrastructure to build capacity and effect change in communities.'[125]

Warrnambool City Council listed a number of benefits it considered the community building initiatives had contributed to furthering the social inclusion of people with disability:

• disability action plans developed in every council in Victoria

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[123]   *Submission S083*, Wellington (Local Government Area) Community, p.5.
[124]   *Submission S086*, Brimbank City Council, p.15.
[125]   *Submission S103*, Maribyrnong City Council, p.6.

- stronger partnerships between state and local government in relation to community planning and capacity building

- stronger planning across a range of local government department program areas in relation to planning developing services for people with disability

- a coherent and consistent approach to planning and project development across Victoria, focusing on a number of areas of community infrastructure and service delivery—built environment, community awareness raising, sport and recreation, the arts, health, education and training, employment, transport, tourism, etc.[126]

The City of Melbourne Disability Advisory Committee also emphasised the value of the program, stating that it had 'local government to plan, develop and implement local capacity building and community development projects, which mobilise and support people with disability to optimise participation in the life of their local community.'[127]

In addition to the benefits of access, coordination and planning, Maribyrnong City Council explained to the Inquiry that:

> MetroAccess achieves good practise by working to increase community awareness about the needs and aspirations of people with disability.[128]

Frankston City Council expressed its view that the value of the community building initiatives lies in their flexibility, their place based nature, and their contribution to collaboration across local and state governments:

- Place-based approach—a significant factor in the success of the MetroAccess Program is that it is place-based in nature. This allows the MetroAccess Program to identify local needs and the required responses.

- Flexibility in program guidelines—another significant factor in the success of the MetroAccess Program is the flexible program guidelines which allow responses to needs through a planned and opportunistic approach.

- Collaboration between levels of government—the MetroAccess Program provides an example of effective collaboration between state and local government. The program is funded by the Victorian Government and administered by local government.[129]

Warrnambool City Council commended the initiatives stating that it sets Victoria apart and puts it in 'a unique position to engage in community development activity which responds to the needs and aspirations of people with disability.'[130] It further explained that 'for this work to be continued and strengthened the funding of the RuralAccess and MetroAccess Programs needs to be sustained at least at current levels.'[131]

The Committee heard there is scope to further strengthen the program, particularly at a statewide level. The MAV suggested to the Inquiry that while an

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[126] *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.15.
[127] *Submission S077*, City of Melbourne Disability Advisory Committee, p.4.
[128] *Submission S103*, Maribyrnong City Council, p.6.
[129] *Submission S106*, Frankston City Council, p.3.
[130] *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.16.
[131] *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.16.

effective initiative, the program would benefit from greater opportunities to share information and develop innovative approaches. It suggested that:

> The MAV has played a significant role in providing a strategic framework which both reflects and leads councils in their role. Greater gains could be made by minimal investment by strengthening the Community Building Program [Building Inclusive Communities] by supporting the sharing of information, the development of further forums to push the boundaries and in supporting existing networks to extend their knowledge and advocacy approaches.[132]

Several local councils supported this position. The Committee heard that there are areas in which the program could be strengthened. For example, several Inquiry participants identified a need for improved opportunity to share information to avoid 'reinventing the wheel'. In its submission, Whitehorse City Council explained this:

> The ability to build upon the work of other organisations or across Council areas has been limited by a lack of access to outcome and evaluation reports. The State Government's CBPARS [Community Building Project Achievement Reporting System], an Access Database originally used in the Community Building Program [Building Inclusive Communities] to share projects and outcomes has not been operational for approximately 2 years. This has impacted on the program's ability to share information and resources across the state.[133]

Others expressed similar views. Hobsons Bay City Council expressed its view that 'Community Building has had some great successes however there is limited documentation at the state level to identify and share achievements and best practice to ensure we are continuing to build on and strengthen the disability work across the state.'[134] Mansfield Shire Council also told the Inquiry that 'in regard to measuring and reporting on social inclusion initiatives there is some concern in the Mansfield community that this is becoming more complex and can be a barrier to participation and volunteering in this field.'[135] Notably the Council went on to explain that:

> There is also a concern from those currently with requirements for reporting that there is a lack of feedback about their reports and how the reports and data are influencing the future development of programs.[136]

The Committee identified that since the DHS restructure in 2012 and the reassignment of internal staff, the CBPARS is no longer operational. DHS did not provide a response regarding why the database is not operating. In 2010, extensive guidelines were prepared for planning and reporting on community building initiatives. This was intended to strengthen the reporting processes for the program and to make local councils more accountable.

Non-government organisations were also supportive of the role played by the Building Inclusive Communities Program. For example, Karingal told the Inquiry that:

> … the Rural Access, Metro Access and Deaf Access groups have done a fantastic job in supporting the community and also really engaging with people with disability. Their committees are equally represented, with people who can speak about their own lives and be role models.[137]

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[132] *Submission S053*, Municipal Association of Victoria, p.10.
[133] *Submission S097*, Whitehorse City Council, p.7.
[134] *Submission S078*, Hobsons Bay City Council, p.4.
[135] *Submission S057*, Mansfield Shire Council, p.3.
[136] *Submission S057*, Mansfield Shire Council, p.3.
[137] *Transcript of Evidence,* Karingal, p.8.

Others non-government organisations were less positive. Some expressed that they had difficulties engaging local Access officers on specific issues. Disability Media Australia, for example, stated that it found them difficult to engage on disability access issues.[138] Inclusion Melbourne expressed its view that the outcomes for the programs should be more thoroughly measured, audited and reviewed annually. It suggested to the Inquiry:

> Outcomes for local government and MetroAccess/RuralAccess programs should be measured, audited, and reviewed annually. The funding for MetroAccess/RuralAccess programs provides a powerful lever and we would suggest that this funding be conditional on achieving tangible local outcomes.[139]

As mentioned, the CBPARS database had been intended to strengthen reporting and increase accountability, but it is no longer operational. Inclusion Melbourne suggested that where local councils do not achieve advancements in social inclusion, the 'funding should be put up for competitive tendering and opened up to the community sector.'[140]

While the Committee recognises that councils vary in their capacity to deliver social inclusion and community strengthening initiatives, it believes local government has a unique role in building community capacity. This rests partly in the legislative obligations of local governments outlined in earlier in this section, but also in their role as elected representatives of local communities. The Committee considers those local councils not delivering need support to strengthen their approach.

Of the three programs, only the RuralAccess initiative was subject to an evaluation. In 2006, HDG Consulting Group reported on the evaluation that DHS engaged it to undertake. DHS was unable to provide the Committee with a copy of the report from the evaluation to assist in understanding the methodology used for the evaluation. However, the Committee was provided with a copy of the DHS document titled *The next steps for RuralAccess* released in October 2006.[141] This document provided an overview of the evaluation, the eight recommendations, and the DHS intended actions in response to the recommendations.

Importantly, the HDG Consulting Group evaluation identified that the RuralAccess Program had been successful in its objectives. It stated that:

> Since its inception, RuralAccess has been instrumental in changing the way that communities respond to people with disability with over 500 local community projects developed across the full range of community infrastructure. These projects include transport initiatives, improvements to the build environment, arts and cultural development programs, and a range of other work across the areas of education, health, youth, community awareness and sport and recreation.[142]

The evaluation 'confirmed that the overall direction of Disability Services community building initiatives and demonstrated that the work of RuralAccess has made a significant contribution to strengthening the capacity of Victorian communities to be more inclusive.'[143] A number of resources and guides were developed in response to the evaluation.

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138   *Submission S025*, Disability Media Australia, p.2.
139   *Submission S056*, Inclusion Melbourne, p.8.
140   *Submission S056*, Inclusion Melbourne, p.8.
141   *Supplementary evidence*, Response to request for information, Warrnambool City Council, 6 June 2014.
142   Department of Human Services (2006) *The next steps for RuralAccess*. Melbourne, DHS, p.1.
143   Department of Human Services (2006) *The next steps for RuralAccess*, p.4.

Table 2.7: Evaluation of RuralAccess Program—2006

Recommendations
• continue to strengthen and support the RuralAcess Program
• clarify role and responsibilities
• strengthen links with the disability services sector
• develop quality project planning methods and tools
• develop a culture of evaluation
• develop a cost adjusted resource formula to support Program expansion
• develop a promotional strategy
• implement evaluation findings.

Source: Adapted from the Department of Human Services (2006) *The next steps for RuralAccess.* Melbourne, DHS.

The Committee considered information provided by Mr Paul Dunn, a consultant from TR Concepts. Mr Dunn has a comprehensive understanding of the Building Inclusive Communities Program and Melba Support Services encouraged the Committee to make contact with Mr Dunn, explaining that:

> We recommend that Mr Paul Dunn of TR Concepts be invited to give evidence at a Committee hearing on the efficacy of these programs. Mr Dunn was closely involved in the establishment of the RuralAccess program and has a long history in community development within the disability sector.[144]

Mr Dunn from TR Concepts provided his personal insights regarding the programs, stating that his response should be seen in the context of the submission from Warrnambool City Council, which he assisted in preparing. Mr Dunn provided useful insights into the internal operations of the Building Inclusive Communities Program within the statewide Department of Human Services. These insights are outlined in Box 2.5.

Box 2.5: Insights into DHS internal management of the Building Inclusive Communities Program [formerly Community Building Program]
Prior to the introduction of the DHS Community Building Program [Building Inclusive Communities], Disability Services had a poor record of engaging and working with Local Government Authorities (LGAs) and until RuralAccess and MetroAccess were developed, had very few effective partnerships with councils across Victoria …
DHS struggled to understand the potential impact of community development as a complementary practice in its suite of programs which together with individualised planning, specialist support and advocacy could be integrated within local areas to help plan and build inclusive communities. As a result, it has struggled to market and manage the community building programs effectively …
The recent restructures in DHS and the development of cross program teams working within smaller regional areas provides a great opportunity to partner more effectively with LGAs …
Recent reports from MetroAccess and RuralAccess Officers now indicate that this coordination and partnership with DHS may happen at the local level but appears it is more

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[144] *Submission S080*, Melba Support Services Inc, p.4.

Box 2.5: Insights into DHS internal management of the Building Inclusive Communities Program [formerly Community Building Program]

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by means of good luck than good management and is dependent on the commitment of their [Community Participation Officer].

There is now a sense that there is limited commitment to the program centrally, with the responsibility for its management given to officers/managers who it is perceived have no understanding of the program and no commitment to their local work. Local officers report that they have no idea who the central office rep is nor do they know what is going on there. There is no feedback from anyone at DHS in relation to the 6 month reporting process required of the program which has been set up to enable DHS to compile 2 statewide reports per year …

There is a feeling that all of this represents a missed opportunity given the NDIS reforms, where DHS could be drawing on the strategic role of RuralAccess and MetroAccess to engage local government across Victoria as one of the key players in building the capacity of mainstream community organisations to support the social inclusion of people with disability.

To address the issues identified above, I feel management for the program should be shifted to the Office for Disability who have a much stronger mandate to work across government and a greater capacity to develop partnerships with local government. They also have a team that understands and values the role that community building can play in promoting social inclusion.

Source: *Supplementary evidence*, Response to request for information, Mr Paul Dunn, 23 May 2014.

The Building Inclusive Communities Program has a specific focus on disability and is currently embedded in the Community and Economic Participation Branch within DHS. Community Participation relates to a range of activities that support the social and economic participation of Victorian communities, particularly vulnerable populations and priority places. This includes the Neighbourhood House Coordination Program, Men's Sheds, Community Renewal and Community Finance initiatives.

The Committee considered that in the context of the transition to the NDIS there would be value in the Office for Disability (or its equivalent) providing leadership of the program in partnership with the MAV.

Finding 2.10

The Building Inclusive Communities Program is a valuable initiative and highly regarded, however:

- outcomes from the Building Inclusive Communities Program are not effectively measured or evaluated

- its internal location within the Department of Human Services has prevented it from providing the focus the program needs to effectively coordinate with the Municipal Association of Victoria and local councils.

2.6. The National Disability Insurance Scheme

It is not possible to talk about social inclusion and disability without considering the changes that will occur with the introduction of the National Disability Insurance Scheme (NDIS). The NDIS 'is the most significant social reform in Australia for 30 years'[145] and is intended to transform the disability support system. The Committee heard that:

> The disability landscape in Victoria and across the nation is changing profoundly.[146]

While a major reform, it is important to be mindful that the NDIS addresses one specific policy area of six contained in the *National disability strategy 2010–20*. Social inclusion is relevant to all policy areas outlined in the Strategy, which are:

- inclusive and accessible communities
- rights protection, justice and legislation
- economic security
- personal and community support
- learning and skills
- health and wellbeing.

The NDIS addresses the policy area relating to 'personal and community support'. Critically, however, it intersects with other policy areas, particularly when considered in the context of the intention behind the Productivity Commission's proposed scheme. Furthermore, the provision of support is essential for many people with disability who seek to participate in the community.

In March 2013, the Australian Government introduced legislation to establish a national disability insurance scheme—the *National Disability Insurance Scheme Act 2013* (Cth).

2.6.1. What is the NDIS?

In February 2010, the Australian Government requested the Productivity Commission inquire into the long-term care and support of people with disability. A major driving force related to ongoing concerns about the capacity of the disability service system to provide adequate support for people with disability to live a quality life in the community.

In 2011, the Productivity Commission reported that the 'existing disability support "system" is unsustainable on multiple grounds'.[147] It went on to explain that:

> Current disability support arrangements are inequitable, underfunded, fragmented, and inefficient and give people with disability little choice. They provide no certainty that people will be able to access appropriate supports when needed. While some governments have performed much better than others, and there are pockets of success, overall, no

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[145] Joint Standing Committee on the National Disability Insurance Scheme (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme*, p.131.

[146] *Submission S072*, Youngcare, p.5.

[147] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*. Canberra, Commonwealth of Australia, p.5.

> disability support arrangements in any jurisdiction are working well in all of the areas where change is required.[148]

The Productivity Commission determined that there would be greater cost in doing nothing in response to its expressed concerns about the service system. It predicted that while the initial fiscal cost of its proposed NDIS would be high, from an economic perspective the long term benefits would exceed the costs.[149]

The scheme proposed by the Productivity Commission consisted of three tiers. While essentially a new scheme for funding and providing disability support, the proposed NDIS was also intended to minimise the impact of disability, to raise awareness of disability, and to increase social inclusion by stimulating social capital. Box 2.6 outlines the NDIS tiers.

Box 2.6: NDIS tiers

Tier 1—Everyone

The NDIS is for all Australians in that it will provide insurance against the costs of support in the event that they, or a family member, acquire a significant disability. Insurance is valuable even if someone makes no claim.

The NDIS is intended to minimise the impacts of disability. This includes:

- promoting opportunities for people with disability

- creating awareness by the general community of the issues that affect people with disability, and the advantages of inclusion

- drawing on data and research capabilities to engage with other agencies to improve public health and safety.

Tier 2—People with or affected by disability

Anyone with, or affected by, a disability will be able to approach the scheme for information and referral services (as distinct from funded support). The scheme is also intended to provide general information about the most effective care and support options.

An important role for the NDIS in both Tiers 1 and 2 is intended to strengthen voluntary links between the community and people with disability — to stimulate 'social capital'. The goal is to increase, rather than crowd out existing formal and informal arrangements.

Tier 3—Access to funded individualised supports

Tier 3 is targeted at the much smaller group of people with significant care and support needs. A person getting funded support from the NDIS will have a disability that is, or is likely to be, permanent. In addition, people have to meet at least one of the following conditions:

- have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support

- be in an early intervention group for whom there was good evidence that the intervention would be safe, significantly improve outcomes and would be cost-effective (such as autism, acquired brain injury, cerebral palsy and sensory impairments, multiple sclerosis and Parkinson's disease).

Source: Productivity Commission (2011) *Disability care and support. Volume 1, report no.54*. Canberra, Commonwealth of Australia, pp.10–14.

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[148] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.5.
[149] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.7.

Bilateral agreements and NDIS trial

The initial launch of the NDIS in July 2013 has focused on trialling the scheme in five trial sites across Australia. Prior to the passage of the legislation, the Victorian Government lodged an expression of interest (EOI) to host the first stage of the NDIS and proposed the Barwon region as a trial site. This covers the local government areas of City of Greater Geelong, the Colac-Otway Shire, the Borough of Queenscliffe and the Surf Coast Shire.

The EOI was successful and in December 2012, the Victorian and Australian Governments signed a Bilateral Agreement for the NDIS launch. The launch was anticipated to cover around 5,000 people based on the number of people in the Barwon region who were less than 65 years of age and who had a need for assistance in one (or more) activities of daily living, excluding those funded by other schemes (such as the Transport Accident Commission or WorkSafe Victoria).

On 1 July 2013, the Barwon site started its trial of the NDIS. The launch included services that are related to what was referred to as 'Tier 3' services. The Committee recognises that in the first stage of the NDIS trial, the initial design of Tier 2 is yet to be negotiated across the three levels of government.

In August 2014, the Chairman of the National Disability Insurance Agency (NDIA), Mr Bruce Bonyhady, drew attention to the reality that the rollout of the NDIS inevitably involves some fluidity and ongoing learning. In reference to the progress of the launch he explained that:

> Implementing a cautious and staged approach by learning from our experiences will continue.
>
> The Productivity Commission designed NDIS 1.0.
>
> We started with NDIS 2.0.
>
> Operational changes by the Agency led to NDIS 2.1 and 2.2.
>
> NDIS 2.2 was introduced on 1 July [2014] and includes many important changes, including that supports are now packaged into three key categories: capital, capacity building and core supports. This 'rolled up' package model provides more opportunities for participants to exercise control and choice and so drive the best arrangements for them.[150]

Clarifying Tier 2

Many services that relate to social inclusion fall within the category that is generally referred to as 'Tier 2'. How these types of services will be defined or funded is currently under consideration by the NDIA. Generally, these services include community building initiatives, individual capacity building programs and some mainstream supports such as travel, education and health initiatives.

In the context of a *Review of the optimal approach to transition to the full NDIS*, in July 2014 KPMG released an *Interim report* prepared for the NDIA Board. It identified that if the NDIS is to be effective as a reform, a number of issues need to be resolved relatively quickly, including the design of Tier 2. It commented that 'clarity on how Tier 2 will be designed, including how it will link to the

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[150] B. Bonyhady (2014) 'The NDIS vision: Delivering the Plan' (Speech delivered at St Laurence National Conference: The NDIS one year on, Deakin University, Geelong, 11–12 August 2014).

broader human services sector within each jurisdiction, is critical.'[151] In its *Progress report* released on 31 July 2014, the Joint Standing Committee on the NDIS (the Joint Committee) also pointed to the need for Tier 2 supports to be better articulated. In the context of Tier 2 supports it explained that eligibility for Tier 3 supports is a key consideration:

> As of 31 March 2014, the NDIS had 8,021 access requests. Of this number, only 5,401 people have received a package. This leaves approximately 2,620 people who felt sufficiently incapacitated to seek assistance but were ineligible for a package.[152]

At June 2014, these figures had altered slightly with approximately 23 per cent of people assessed as eligible.[153] While there is ongoing fluidity during the trial phase, KPMG advised that in the context of ineligibility 'the development of Tier 2 is required as soon as possible to ensure that appropriate supports are in place for those not eligible for Tier 3.'[154]

KPMG also emphasised that clarifying the design of Tier 2 and its interface with Tier 3 will assist in 'mitigating the potential adverse impacts of price inflation.'[155] It also stressed that the development and management of Tier 2 'will be critical in underpinning the effectiveness and sustainability of Tier 3.'[156]

In its *Progress report* the Joint Committee reported that one consequence of the delay in negotiating Tier 2 arrangements is the effect on the availability of some mainstream services. It found that some NDIS participants had lost access to mainstream supports during the transition. The NDIA advised the Joint Committee that:

> … under the intergovernmental agreement the states and territories are required to maintain tier 2 services during the trial phase, up until full speed. But you are right, we are seeing withdrawal of those services.[157]

In evidence to this Inquiry, participants expressed concern about the ongoing funding of programs designed to build social inclusion and strengthen communities. For example, NDS Victoria stated that:

> One area of particular concern relates to community development activities, particularly those extending the social inclusion of people with disability. It is acknowledged that the National Disability Insurance Agency (NDIA) is currently considering the possible block funding of some programs. However, it is unlikely that such moves will adequately fund the place based community development activities which lead to real inclusion of people in their local communities.[158]

The Committee recognises that further work to clarify support types and how they are funded is necessary. Dr Fiona Reidy explained to the Inquiry that there needs to be a systemic framework to ensure accessible and ongoing mainstream services and programs that aim to strengthen community capacity. She stated that:

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[151] KPMG (2014) *Interim report: Review of the optimal approach to transition to the full NDIS*. KPMG, p.8.
[152] Joint Standing Committee on the National Disability Insurance Scheme (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme*, p.150.
[153] National Disability Insurance Agency (31 July 2014) *30 June 2014: Quarterly report to COAG Disability Reform Council*. National Disability Insurance Scheme (NDIS), p.23. Accessed on 3 September 2014 from http://www.ndis.gov.au/sites/default/files/documents/report_to_disability_reform_council_june_2014.pdf.
[154] KPMG (2014) *Interim report: Review of the optimal approach to transition to the full NDIS*, p.8.
[155] KPMG (2014) *Interim report: Review of the optimal approach to transition to the full NDIS*, p.14.
[156] KPMG (2014) *Interim report: Review of the optimal approach to transition to the full NDIS*, p.15.
[157] Joint Standing Committee on the National Disability Insurance Scheme (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme*, p.150.
[158] *Submission S045*, National Disability Services Victoria, pp.10–11.

> The NDIS may fund packages of care that can provide aids and equipment, personal care and support that positions a person with disability to engage with the social, economic, built and natural aspects of their local community but if a systematic framework has not been implemented to ensure that mainstream health and community services, sporting and recreational clubs and activities, transport and education are accessible then social inclusion will remain challenging.[159]

In its *Progress report*, the Joint Committee made reference to the South Australian approach to Tier 2 supports and its contingency plans for funding these supports. The South Australian Government has set in place arrangements to ensure that all government departments responsible for supports and services relevant to Tier 2 (education, health, transport) are required to report the removal of any relevant services. The Joint Committee recommended that:

> … the Ministerial Disability Reform Council expedite roles and responsibilities and any funding arrangements for Tier 2 services. The committee commends the attitude and direction that the South Australian Government is taking in its involvement with Tier 2 and the sector, and recommends that states and territories adopt this approach.[160]

The NDIA is currently developing a proposed approach for the Council of Australian Governments (COAG) to ensure the key design features that drive the scheme are assessed, including Tier 2 and Local Area Coordinators (LACs). Section 2.7.3 discusses the role of the LACs further. The Committee notes that the NDIA intends to provide a final report to the COAG Disability Reform Council by September 2014.[161]

Finding 2.11

The future of community building and other social inclusion initiatives are linked to Tier 2 of the National Disability Insurance Scheme which is yet to be clarified to determine the nature of supports and funding arrangements.

Employment participation and links to NDIS success

In its 2011 report, the Productivity Commission stressed the importance of increasing employment opportunities for people with disability to enable the NDIS to work effectively. Taking into account an assumed increase in employment and additional employment, it estimated considerable benefits for the economy through the implementation of the NDIS:

> By 2050, the collective impact of these two employment gains would be around a one per cent increase in GDP above its counterfactual level, translating to around $32 billion in additional GDP (in constant price terms) in that year alone.[162]

In 2011, Deloitte Access Economics undertook economic modelling to determine what benefits the proposed scheme would have for the Australian economy if employment participation increased for people with disability. It reached similar conclusions to the Productivity Commission:

> The economic modelling presented in this report suggests that closing the gap between labour market participation rates and unemployment rates for people with and without

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[159] *Submission S094*, Dr Fiona Reidy, p.5.
[160] Joint Standing Committee on the National Disability Insurance Scheme (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme*, p.151.
[161] Joint Standing Committee on the National Disability Insurance Scheme (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme*, p.146.
[162] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.55.

disabilities by one-third would result in a cumulative $43 billion increase in Australia's GDP over the next decade in real dollar terms. The modelling also suggests that GDP will be around 0.85 per cent higher over the longer term, which is equivalent to an increase in GDP in 2011 of $12 billion.[163]

Deloitte based its figures on a conservative increase in employment participation, highlighting that other countries have already surpassed those levels of employment by people with disability. It explained that its estimate of an increase in GDP 'implies an increase in the participation rate for people with disability from 54 per cent to 64 per cent and a reduction in the unemployment rate from 7.8 per cent to 6.9 per cent.'[164]

In its submission to the Inquiry, WISE Employment referred to the emphasis on employment in the NDIS:

> The NDIS and the National Disability Strategy are a developmental investment by government because of the Productivity Commission's report and its prima facie evidence of essential facts in relation to the economic gains by increasing the workforce participation rates of people with disability.[165]

The Committee recognises the critical role that employment can contribute to social inclusion from an economic and social perspective. It acknowledges the emphasis that DHS places on workforce participation for improving the lives of people with disability. The Secretary of DHS, Ms Gill Callister, stated that:

> Workforce participation reinforces the key elements of disability service provision … It builds greater connection with the community, and it strengthens individuals' capacity for choice and control over their own lives.[166]

Disability Employment Australia expressed its view that 'the opportunity afforded this nation through the National Disability Insurance Scheme is a once-in-a-generation opportunity and that every state and territory, and of course the commonwealth, needs to put its shoulder to the wheel in relation to supporting the National Disability Insurance Scheme.'[167]

NDIS and eligibility

The Committee estimated that about 10 per cent of people with disability in Victoria will receive funding as participants of the NDIS. In 2012 about 6.4 per cent of Victorians with disability received specialist disability supports. In 2013, about 1.5 per cent received an Individual Support Package.[168] The NDIS will contribute to a substantial increase in support for people with a profound disability.

For the remaining 90 per cent of people with disability in Victoria, those who require assistance to engage in the community are anticipated to receive support from informal carers and mainstream services. In its submission to the Inquiry, NDS Victoria outlined its calculations:

> Whilst the NDIS presents a tremendous opportunity to ensure that over 100,000 Victorians with a serious and permanent disability receive a decent level of support, there are about

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[163] Deloitte Access Economics (2011) *The economic benefits of increasing employment for people with disability*. Sydney, Access Economics Pty Ltd, p.ii.

[164] Deloitte Access Economics (2011) *The economic benefits of increasing employment for people with disability*, p.ii.

[165] *Submission S044*, WISE Employment, p.6.

[166] *Transcript of Evidence,* Department of Human Services, p.5.

[167] *Transcript of Evidence*, Disability Employment Australia, Melbourne, 20 March 2014, p.2.

[168] 63 168 Victorians received disability supports in 2012. *Transcript of Evidence,* Department of Human Services, p.3. In 2011 the population of Victorians with disability was approximately 990 000.

> one million Victorians with disability (18.4 per cent of the population) and 338,200 Victorians living with profound or severe disability (6.2 per cent). This means that some 900,000 Victorians with disability will not qualify for the NDIS and will still require access to mainstream services such as transport, housing, education, health, justice and mental health.[169]

The Committee reviewed the Productivity Commission estimations and population data and considered this is a reasonable estimate of the number of Victorians who will be eligible for Tier 3 supports.

DHS itself recognises that the majority of people with disability will not access services as participants of the NDIS and emphasised that 'we must also keep an eye on the many people with disability who do not require specialist services but for whom the barriers within society are the primary disabling factor.'[170] Similarly, Karingal told the Inquiry that:

> … only a percentage of people are going to be eligible for the NDIS. If we do not build the social capital, those on the fringes will just keep missing out, and they will continue to be excluded and will not be fulfilling their potential either.[171]

2.6.2. NDIS and social inclusion

Despite the emphasis on workforce participation, the extent to which social inclusion will be addressed by the NDIS is currently unknown. The Committee heard that Tier 2 is expected to address some aspects relating to social inclusion. However, Inquiry participants expressed concerns about how the NDIS will address social inclusion in a practical sense, particularly for those not eligible for Tier 3 funding. A substantial amount of evidence provided to the Inquiry emphasised the need for caution. Many participants stressed that while the NDIS 'will bring about positive change, it will not be a panacea for all the barriers people with disability face.'[172]

Recent reviews on the transition to the NDIS have emphasised the importance of Tier 2 supports. For example, in its July 2014 *Interim report* on the NDIS, KPMG stated that 'Tier 2 was identified as key to achieving scheme sustainability as it is the gateway to effective diversion from specialist supports.'[173] To date, reference to Tier 2 focuses particularly on access to and the availability of mainstream supports. There has been less emphasis on engaging the community in ways envisaged by the Productivity Commission.

It is useful to revisit the 2011 report titled *Disability care and support* to understand the Productivity Commission's original intention regarding Tiers 1 and 2.

Social inclusion and the Productivity Commission report

In its 2011 report on disability care and support, the Productivity Commission envisaged that changes to the provision and funding of disability supports needed to be accompanied by increased opportunities for social inclusion and changed community attitudes towards disability:

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169   *Submission S045*, National Disability Services Victoria, p.5.
170   *Transcript of Evidence,* Department of Human Services, p.5.
171   *Transcript of Evidence,* Karingal, p.8.
172   *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.2.
173   KPMG (2014) *Interim report: Review of the optimal approach to transition to the full NDIS*, p.8.

> An important role for the NDIS in both tiers 1 and 2 would be to strengthen voluntary links between the community and people with disability — to stimulate 'social capital'. The goal would be to increase, rather than crowd out existing formal and informal arrangements.[174]

The Productivity Commission provided some insights on how increased social inclusion would relate to its proposed new scheme. In its overview to the report, it explained that in the NDIS:

- local area coordinators could link people to community groups

- not-for-profit organisations would take the lead in community capacity building

- all governments would continue to support a range of community and carer support services, largely through block-funding with some limited user charges.[175]

Notably the Productivity Commission placed a strong emphasis on non-government organisations building capacity in the community. Yet it also acknowledged that additional community strengthening efforts are integral to the success of the NDIS. It highlighted that there are 'numerous state and territory government as well as local government initiatives' contributing to community capacity building.[176]

The Productivity Commission considered that all governments would have responsibility for funding and driving social inclusion, stating that it 'envisages that these government initiatives will continue and complement the NDIS.'[177] It highlighted the Community Building Program in Victoria (now known as the Building Inclusive Communities Program) as an example of capacity building initiatives located in local government aimed at increasing social inclusion for people with disability. This Program is discussed in depth in Sections 2.5.2 and 2.7.3.

Critically, the Productivity Commission emphasised the need for ongoing consultation with states and territories around existing initiatives to strengthen community capacity and increase social inclusion. It recognised that the proposed NDIA would not be in a position to undertake all elements of Tier 2:

> In considering which actions it should take, the NDIA must be mindful of the myriad of Australian, state and territory, and local government 'community capacity building' and 'social inclusion' initiatives (as well as a broader range of HACC services) in order to avoid unnecessary overlap and adding to the paper work burden of not-for-profit organisations, and to avoid displacing funding. Accordingly, an important first step would be for the NDIA to consult with not-for-profit organisations and relevant government agencies and, if necessary, negotiate with them a memorandum of understanding.[178]

The Productivity Commission considered it important that the 'NDIS should retain the valuable contribution of not-for-profit organisations in terms of community engagement, common sense and grass roots contact.'[179] It also suggested that their 'their broader activities in the community (tiers 1 and 2 of

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[174]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.13.
[175]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.13.
[176]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.214.
[177]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.214.
[178]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.223.
[179]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.201.

the NDIS) can reduce the need for more costly individually-funded services and supports.'[180]

Box 2.7 outlines the Productivity Commission's recommendations in the context of building community capacity and the ongoing role of non-government organisations and local government.

Box 2.7: Productivity Commission—community capacity building

Recommendation 4.1

The NDIA should improve engagement of the general community and people with disability by:

- forming a 'compact' with not-for-profit disability service providers that would:

  ♦ use the voluntary and philanthropic resources freed up by the creation of a properly funded NDIS for activities that promote community engagement and employment for people with disability

  ♦ clarify their new roles in the system.

- Undertaking local initiatives, including improving access to buildings and public spaces, to address disability issues within the community.

- Offering modest grants that leverage engagement by community clubs and associations with people with disability and that would be likely to yield social or economic benefits consistent with the size of the grant. The effectiveness of such financial incentives should be independently evaluated after a reasonable period.

- Specifying roles for local area coordinators and disability support organisations to connect NDIS participants with the local community and to build the capacity of the community for such interaction.

Recommendation 4.2

Prior to implementing recommendation 4.1, the NDIA should consult with not-for-profit organisations and relevant government agencies on the best arrangements for 'community capacity building' or 'social inclusion' initiatives to ensure that any overlap or paperwork burden, or displacement of funding, is kept to a minimum.

Source: Productivity Commission (2011) *Disability care and support. Volume 1, report no.54.* Canberra, Commonwealth of Australia, p.224.

2.6.3.   Not a panacea—the NDIS

Many Inquiry participants expressed the need to be cautious when considering how the NDIS will affect the social inclusion of people with disability during the transition from 2016 until 2019. Several stated that the impact of the NDIS on social inclusion should not be over-estimated.

The Committee received a resounding message from Inquiry participants that in the context of social inclusion, the NDIS is not a cure-all and needs to be considered within the limitations of what it provides or is intended to provide. For example, Dr Fiona Reidy told the Inquiry that:

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[180]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.201.

> The introduction of the NDIS should not be viewed as a panacea for achieving social inclusion for people with disability. It is just one of many reforms that will contribute and does not dilute the need for collaboration between government departments, organisations, services and the community sector.[181]

Box 2.8 outlines some of the many views expressed in the evidence the Committee received.

Box 2.8: 'Not a panacea'—NDIS and social inclusion

- … the NDIS alone is not the panacea. There is a clear role for the State Government in enhancing social inclusion for Victorians with disability. (*Submission S045,* National Disability Services Victoria, p.5)

- The NDIS is not a panacea for these issues but rather serves to illuminate the issues faced by people with disability. (*Submission S047,* St Laurence Community Services, p.2)

- Increased social inclusion will not be accomplished solely through reforms such as the NDIS. Instead it requires acknowledgement and understanding of the issues across all Government services and initiatives; followed by rigorous planning that incorporates participation, inclusion and feedback from people with disability. (*Submission S041,* Darebin Disability Advisory Committee, p.12)

- Overcoming infrastructure public barriers is not a major focus of the National Disability Insurance Scheme, with only limited discretionary funding available for modifications beyond an individual support package. (*Submission S089,* The Able Movement, p.14)

- … our members report that they sometimes encounter the view that once the NDIS is in operation, 'disability is done'. This could not be further from the truth. The NDIS intends to provide basic services for people with more extensive disabilities. It does not reduce discrimination, create accessible places, provide jobs or change attitudes, for those are not its role. (*Submission S126,* Victorian Council of Social Services, p.11)

- … the NDIS is only part of the solution. Whilst it is a much-welcomed investment, it is not, in itself, a panacea. (*Submission S111,* Melbourne City Mission, p.26)

- I don't think the NDIS can or will provide what it takes to make social inclusion happen. (*Submission S051,* Contributor to Women with Disabilities Victoria, p.25)

- The NDIS, I think, is a great social reform. It is also a great economic reform … but it has also provided a great big get-out-of-jail-free card for state and local governments. (*Transcript of Evidence*, Inclusion Melbourne, p.9)

- The NDIS is seen as the big solution to all things that impact on the lives of people with disability, which is simply not the case. To ensure that people with disability and their families are aware of the scope and limitations of the NDIS there needs to be ongoing promotion and education opportunities. (*Submission S097,* Whitehorse City Council, p.23)

As outlined in Section 2.6.1, the success of the NDIS is interlinked with the achievement of increased social inclusion for people with disability. The Committee heard similar opinions from Inquiry participants. For example, Warrnambool City Council expressed its view that in addition to the readiness of

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[181]   *Submission S094*, Dr Fiona Reidy, p.6.

mainstream services, communities need to be strengthened if the benefits of the NDIS are to be fully realised. Specifically it stated that:

> … whilst the NDIS heralds significant change which empowers people with disability and aims to give them more control over the nature of their supports and how they live their lives, there is still some concern that these changes will be merely cosmetic unless communities are engaged in the change process and equipped with skills and capacity to support the aspirations of people with disability.[182]

In its submission, Women with Disabilities Victoria (WDV) also emphasised the limitations of the NDIS in the context of social inclusion:

> The NDIS is designed to be an individualised disability service, a baseline for resource provision. While the NDIS Charter of Service claims to be 'designed to enhance the quality of life and increase economic and social participation for people with disability,' it does not articulate how this would be achieved.
>
> The NDIS Act does not empower the NDIA to engage in addressing structural, systemic barriers to social inclusion.[183]

The Able Movement explained to the Inquiry that there are two pathways for achieving social inclusion for people with disability:

> To create a smooth life pathway for people with disability, and increase social inclusion, reform needs to focus on two objectives: 1) to prepare people with disability practically and emotionally to be ready to participate in society, and 2) to prepare our community to welcome the participation of people with disability at a practical and cultural level.[184]

It went on to explain that to achieve these objectives 'we need an "inclusion roadmap" laying out the elements of individual and community support that each person needs to identify missing elements and links.'[185] In the context of the NDIS, The Able Movement explained that the focus is largely on the individual:

> Many aspects of this 'roadmap' are also reflected in the goal based planning and assessment under the National Disability Insurance Scheme. However, the primary purpose of the NDIS is on the first objective described above: to prepare people with disability with the practical supports and life skills they need to face the world. We are concerned that the Australian community may conclude that the significant investment in the NDIS is enough to close the participation gap without further efforts to prepare the community to be 'participation ready'.[186]

Inclusion Melbourne similarly explained to the Inquiry that 'the provision of individualised supports in the NDIS is dependent on the community itself being more inclusive and recognising that there are community development activities that need to occur to offset the costs of the NDIS.'[187] It went on to provide an example:

> … if there are five people living in a rural town and they each go to the bank to do their banking one day per week and there are four steps in front of that bank, the NDIS will quite happily provide for them to have 2 or 3 hours of attendant care to pick them up from their rural location, drive them, carry them up the four steps into the bank to do their banking and then take them back home again, which will cost us hundreds of thousands of dollars over these people's lifetimes, versus someone going, 'You know what? $5000 for a ramp would fix this'.[188]

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182   *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.9.
183   *Submission S051*, Women with Disabilities Victoria, p.24.
184   *Submission S089*, The Able Movement, p.9.
185   *Submission S089*, The Able Movement, p.9.
186   *Submission S089*, The Able Movement, p.9.
187   *Transcript of Evidence*, Inclusion Melbourne, Melbourne, 20 March 2014, p.9.
188   *Transcript of Evidence,* Inclusion Melbourne, pp.9–10.

Much of the evidence the Committee received suggested that a market driven approach to service delivery can potentially improve services, but the market cannot drive social inclusion.

While its primary focus is on reforming the disability support system, several Inquiry participants highlighted the potential for the reform to be capitalised on to drive a social inclusion agenda. For example, in its submission The Able Movement expressed its view about the opportunity the NDIS offers:

> The establishment of the National Disability Insurance Scheme and its focus on individual goal-based support offers a paradigm shift in the delivery of disability services in Australia. Now is the time to capitalise on the groundswell of support and genuine belief in reform to bring about a dramatic uplift in the social inclusion and participation of Victorians.[189]

2.6.4.   NDIS and people with disability

As reflected throughout this report, all interventions that involve people with disability need to be driven and informed by people with disability themselves. Their involvement in the design of elements of the NDIS is no different. The Committee considered that during the transition phase through until 2019, the Victorian Government has a role in providing a forum for people with disability to contribute to the co-design process.

The Committee recognises that there are some existing mechanisms to ensure the experiences of people with disability are considered and that they inform the ongoing learning and development of the scheme. The NDIA itself has a process in place for surveying the satisfaction of participants with their experience of the NDIS and the NDIA.

The Victorian Government has also taken steps to support people with disability to provide feedback about their experiences of the NDIS and contribute to its future development. This initiative is known as *Leading, educating and advocating for disability* (LEAD) and is auspiced by the Committee for Geelong. Box 2.9 outlines the initiative.

Box 2.9: LEAD—*Leading, Educating and Advocating for Disability*

The experiences of participants and their families and carers will be fundamental to the success and future development of the NDIS.

In December 2013, the LEAD Barwon initiative was providing 22 individuals—participants of NDIS, parents and carers of people with disability—with training and support so that they can develop skills as advocates and leaders and publicly share their experience of the NDIS. Over the longer term, the initiative aims to help ensure the NDIS is the best possible system for Victorians with disability, their carers and families.

Participants are being guided through a number of program phases to develop their communication, advocacy and leadership skills with a focus on increasing individuals' confidence and ability to communicate publicly about the NDIS. They are learning new skills while sharing their needs and knowledge about the NDIS. It involves a monthly whole group workshop followed by small group workshops and individual coaching. Diverse workshops are offered to meet the varying goals, needs and capabilities of participants.

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[189]   *Submission S089*, The Able Movement, p.18.

Box 2.9: LEAD—*Leading, Educating and Advocating for Disability*

From the knowledge and experienced gained to date, indications are that the LEAD participants will continue to develop networks, skills and opportunities to become leaders in the Barwon area.

The program has successfully raised the profile and issue of inclusiveness for people with disability.

Source: *Supplementary evidence*, Request for information, Department of Human Services, *Mid-point project report*; Victorian Government *National Disability Insurance Scheme: Victorian e-bulletin July 2013.* Department of Human Services, pp.1–2. Accessed on 14 August 2014 from http://www.dhs.vic.gov.au/about-the-department/plans,-programs-and-projects/projects-and-initiatives/disability-services/national-disability-insurance-scheme.

The Committee considers this is a valuable initiative for people with disability in the Barwon trial site for highlighting the positive and challenging experiences of NDIS participants, and assisting in further improvements to the scheme.

In addition to this initiative for providing feedback about experiences of the NDIS, the Committee considered there is scope for greater input of people with disability into the design of Tier 2 and ways that the NDIS can effectively intersect with existing program operating in local communities.

The Committee believes the Victorian Disability Advisory Council (VDAC) could play a key role advising the Victorian Government on social inclusion issues relevant to the design of Tier 2. As outlined in Section 2.4.1, VDAC has a legislated role in advising the Minister for Community Services on policy issues. It also works with other disability advisory groups in advocating for the needs of people with disability across all of state government. VDAC would be well positioned to provide intelligence gathered through its work to inform the Minister on issues relevant to people with disability in the context of social inclusion that need to be considered in the design of Tier 2 of the NDIS.

Finding 2.12

All interventions that involve people with disability need to be driven and informed by people with disability themselves, and their involvement in the design of elements of the National Disability Insurance Scheme is no different:

- there are some existing mechanisms to ensure the experiences of people with disability are considered and that they inform the ongoing learning and development of the scheme

- the Victorian Government has a role in providing a forum for people with disability to contribute to their experience and knowledge to the development of the National Disability Insurance Scheme.

Recommendation 2.4

That the Minister for Community Services seek advice from the Victorian Disability Advisory Council (VDAC) on future directions for social inclusion and that it is incumbent on VDAC to ensure it gathers relevant information to be considered in the development of Tier 2 of the National Disability Insurance Scheme.

2.7. NDIS, Victoria and social inclusion

In comparison with disability service provision, initiatives to increase social inclusion for people with disability are relatively new. As a goal social inclusion is less tangible than service provision. Achieving social inclusion is an ongoing process that requires sustained effort across multiple areas within communities. It involves cultural change in communities and long-term commitment to sustain the level of drive to identify new and innovative approaches.

Inquiry participants emphasised the need for a whole-of-government and whole-of-community approach to improve experiences of social inclusion. For example, Karingal told the Inquiry that it is aligned to the view that 'takes a whole-of-government approach and a whole-of-community engagement approach to make a difference.'[190] To effectively pursue this approach to creating socially inclusive communities, it is critical that all governments provide vision and leadership, and facilitate the necessary networks and partnerships.

In the context of the transition to the NDIS, the Victorian Government is well positioned to turn its attention from the provision of disability support to leading a social inclusion agenda. In addition to steering a successful transition to the NDIS, the Committee considers the Victorian Government has an ongoing role in supporting community capacity building, funding self-advocacy groups, and coordinating efforts to strengthen communities.

Many supports, programs and initiatives that aim to increase social inclusion are funded by state and territory governments and in the future many will be funded through Tier 2 of the NDIS. As outlined, Tier 2 is currently being negotiated across the Commonwealth, state and territory governments. In the context of Tier 2 the Victorian Government told the Joint Committee on the NDIS that it 'recognised the complexity of this issue and … it is ongoing work.'[191]

The Secretary of DHS, Ms Gill Callister, explained to the Inquiry that 'while the NDIS focuses on meeting the support needs of people with disability, it also focuses on reducing the lifetime costs of disability by giving people the support they need to participate and contribute both socially and economically.'[192]

2.7.1. NDIS co-design and social inclusion

The Victorian Government has a role in co-designing the trial of the NDIS, including the development and implementation of the scheme. DHS told the Inquiry that 'since the scheme's inception the Victorian Government has played a leading role in the development and implementation of the NDIS.'[193]

The structure of the NDIA was designed to ensure that governance of the NDIS is a shared responsibility across the Commonwealth, states and territories. In its *Interim report*, KPMG drew attention to the fact that:

190 *Transcript of Evidence,* Karingal, p.3.
191 Joint Standing Committee on the National Disability Insurance Scheme (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme*, p.151.
192 *Transcript of Evidence,* Department of Human Services, p.4.
193 *Transcript of Evidence,* Department of Human Services, p.4.

> The Commonwealth has agreed with States and Territories to share oversight of the NDIS through the Standing Council of Disability Reform. This means that governance is a shared responsibility which is reflected in the terms of the NDIS Act and the current Inter Governmental Agreements (IGAs).[194]

The Standing Council of Disability Reform is a ministerial council that consists of ministers of the Commonwealth, states and territories and has been designated with responsibilities relating to the NDIS. The NDIS Act outlines that the functions of the Standing Council of Disability Reform are to:

> (a) consider policy matters that relate to the National Disability Insurance Scheme or arise under this Act; and
>
> (b) advise the Minister [for Social Services] about such matters; and
>
> (c) make recommendations to COAG about such matters.[195]

KPMG recommended that a more formal co-design process be developed to complement the legislative arrangements and the inter-governmental agreements to ensure the ongoing development and implementation of the NDIS is informed by the expertise of states and territories. It suggested that 'introducing a more formal process of co-design that leverages existing expertise and infrastructure within States and Territories would reduce the risks to the full Scheme design.'[196]

The Committee heard that it is critical the Victorian Government and the NDIA engage communities in the change process and avoid a top-down approach to transition. Inquiry participants expressed concern that 'changes will be merely cosmetic unless communities are engaged in the change process and equipped with skills and capacity to support the aspirations of people with disability.'[197] To assist in this process, the City of Melbourne Disability Advisory Committee suggested to the Inquiry that 'the Community Building Program [Building Inclusive Communities] can also play a key role in ensuring a smooth roll-out of the National Disability Insurance Scheme.'[198] The Building Inclusive Communities Program is discussed in Sections 2.5.2 and 2.7.3.

2.7.2. Victorian Government—social inclusion and Tier 2

Evidence to the Inquiry emphasised the importance of all governments taking responsibility for increasing opportunities for people with disability to be socially included. For example, in its submission, Whitehorse City Council stated that:

> Legislation articulates that the inclusion of people with disability is the responsibility of all people, organisations, and all levels of government. Stronger all of government leadership that is respectful of roles and responsibilities of partnering organisations, services and other levels of government and government departments would serve to enhance the social inclusion of people with disability.[199]

The Committee heard an overwhelming message that the Victorian Government has an ongoing role in leading a social inclusion agenda for people with disability in Victoria. For example, the Victorian Council of Social Service

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[194] KPMG (2014) *Interim report: Review of the optimal approach to transition to the full NDIS*, p.12.
[195] *National Disability Insurance Scheme Act 2013* (Cth) s.12.
[196] KPMG (2014) *Interim report: Review of the optimal approach to transition to the full NDIS*, p.12.
[197] *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.9.
[198] *Submission S077*, City of Melbourne Disability Advisory Committee, p.6.
[199] *Submission S097*, Whitehorse City Council, p.21.

(VCOSS) highlighted the ongoing role of the Victorian Government in disability, stating that it 'should steer a successful transition to the NDIS, while recognising that action for social inclusion extends far beyond the disability service system.'[200]

Other Inquiry participants agreed that the Victorian Government needs to commit to a social inclusion agenda beyond the full rollout of the NDIS in 2019. The Victorian Advocacy League for Individuals with Disability (VALID) expressed its view that:

> … there will continue to be little progress unless Government decides to provide effective leadership. In areas where the State Government has shown leadership, we have seen the kinds of major transformations that can occur.[201]

WDV also considered there is an ongoing role for state government, commenting that 'women consulted saw an important role for the Victorian government in providing leadership for better social inclusion'.[202]

Many other Inquiry participants expressed their views that the Victorian Government has an ongoing role in the context of social inclusion work and Tier 2 supports. Box 2.10 provides examples of some of these views.

Box 2.10: Role of the Victorian Government in social inclusion and disability

- The State Government has shown great leadership in influencing the design of the NDIS and is working hard to ensure its successful introduction in Barwon. It now must also compliment these efforts through the implementation of the [State Disability] Plan to ensure Victoria is a truly accessible, inclusive and liveable community for people with disability. (*Submission S045*, National Disability Services Victoria, p.7)

- The challenge for social inclusion for people with disability over the next 20 years heralded by the introduction of the NDIS is how Victoria continues to promote and extend social inclusion in conjunction with the NDIS rollout. How can a systematic framework, implemented by government and community, which involve deliberate intersectoral partnership and intergovernmental collaboration based on robust population and service data continue to evolve beside an individualised social insurance scheme? (*Submission S094*, Dr Fiona Reidy, p.4)

- … the scheme will fundamentally change the relationship between government, service providers and community in the provision of supports. However, whilst this relationship evolves there remains a significant role for the Victorian government in 1) continued development of the mainstream sector and whole of government policy to insure an inclusive and accessible Victorian community and 2) Victoria's preparedness for the scheme.' (*Submission S049*, Victorian Disability Services Commissioner, p.10)

- But the issue is where disability sits within government? Who is prepared to own it and who is prepared to work at these issues? We can talk about the Department of Human Services but I think we want to talk about a greater understanding. What is the role of the Department of Education and Early Childhood Development in this? (*Submission S056*, Inclusion Melbourne, p.6)

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[200] *Submission S126*, Victorian Council of Social Service (VCOSS), p.4.
[201] *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.15.
[202] *Submission S051*, Women with Disabilities Victoria, p.24.

Box 2.10: Role of the Victorian Government in social inclusion and disability

- State government is needed for coordinating local government's Access Officers—funding disability advocacy organisations—creating laws and policies. All are essential and should be continued. The NDIS won't do any of these things. (*Submission S051*, Women with Disabilities Victoria, p.24)

- Currently, State Governments largely fund inclusion work (which encompasses community capacity building, disability awareness training and attitude change initiatives). In the transition to the NDIS the critical questions for both the NDIA and State Governments are 'who pays for inclusion work at a community and system level?' and 'how do we ensure we don't lose successful programs during the transition to the NDIS?' If these questions are not appropriately answered there is a real risk that the work on social inclusion will be set back by years. There is the risk that current highly successful programs that target social inclusion will be dismantled. There is the risk that the NDIA and State Governments will miss important opportunities to ensure there are community-level and system-level strategies to complement the better-and more-targeted funding of individuals that is currently being put in place. (*Submission S129*, Scope (Vic) Ltd, p.29)

Despite views that the Victorian Government has an ongoing role, a number of Inquiry participants stated that they were unclear about how the Victorian Government considers its future role in the context of Tier 2 supports and community engagement. For example, Karingal told the Inquiry that 'we have not yet been able to get a vision of how that is going to work through for those people who are not eligible for direct supports and planning or how that next tier is going to work.'[203]

The Committee determined that the Victorian Government needs to take a role in leading a social inclusion agenda. In making such a commitment, the Victorian Government could provide critical leadership in the following areas:

- Reorienting the next State Disability Plan in 2016 to a disability inclusion plan (see Section 2.4.1).

- Facilitating partnerships across all levels of governments and across state government departments and relevant peak bodies.

- Strengthening the Building Inclusive Communities Program, self-advocacy programs and other community capacity building initiatives to ensure they align with the NDIS and effectively contribute to increased social inclusion.

The Committee observed that many programs that aim to improve opportunities for social inclusion do not require the same levels of investment that is required for the provision of disability support. Small investments can go a long way in the context of strengthening communities and building capacity. Often these types of initiatives rely extensively on volunteers and initiatives that enable community strengthening to occur 'naturally' within communities.

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[203]   *Transcript of Evidence,* Karingal, p.8.

The funding required for such initiatives often relates to resourcing ongoing coordination, networking and building the capacity of individuals and communities. Examples of cost effective initiatives include the KeyRing model discussed in Section 5.3.4 of Chapter 5, self-advocacy mentoring programs discussed in Section 4.5.1 of Chapter 4, and the Building Inclusive Communities Program discussed in Sections 2.5.2 and 2.7.3 in this chapter.

Inquiry participants emphasised the importance of the Victorian Government in facilitating partnerships to progress a whole of government and whole-of-community approach to social inclusion. For example, Whitehorse City Council:

> It is important that the partnerships between Local and State Governments continue to be strengthened to ensure that communities have the capacity and resources to be inclusive of and respond to the needs of people with disability and their families.[204]

Monash City Council made the point that the right mechanisms need to be established to ensure effective partnerships:

> It is important for State Government departments to have the right mechanisms in place that enables them to communicate effectively with local Councils and other key community organisations at the local level.[205]

The Committee acknowledges that the processes the Victorian Government has established to implement the *State disability plan, 2013–16* are steps in the right direction, including its interdepartmental committee and the DHS restructure that aligns specific areas of the Department's work with local government areas (discussed in Section 2.5.2).

2.7.3.   NDIS and local government

Local government is well positioned to have an ongoing role in building inclusive communities. Many have well established programs that are increasingly contributing to greater social inclusion for people with disability. In particular, local government can support a social inclusion agenda by continuing to:

- facilitate grassroots efforts in community capacity building

- increase understanding of the strengths and needs of their individual community

- build partnerships across the diverse individuals, organisations and others in local communities.

Darebin Disability Advisory Committee told the Inquiry that 'the role of local government will still be an integral one following the introduction of the NDIS'.[206] Many local councils pointed to the reality that the NDIS will focus on the needs of individuals more so than on community needs. For example, Yarra City Council expressed its view that:

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[204]   *Submission S097*, Whitehorse City Council, p.1.
[205]   *Submission S120*, Monash City Council, p.5.
[206]   *Submission S041*, Darebin Disability Advisory Committee, p.10.

> Local Governments have focus on accessibility and inclusion of all of their communities, whereas the NDIS will focus on supporting the individual to make choices which meet their need.[207]

The Committee agrees that local council will have an important, ongoing responsibility in the new landscape of the NDIS.

In the context of the NDIS trial, the Local Area Coordination model is anticipated to be the key driver of Tier 2 supports. The model is based on a similar approach that is operated in Western Australia (WA) and it is different from the community building initiative in Victoria.

It is important to distinguish between Local Area Coordinators (LACs) and Access Officers involved with the Building Inclusive Communities Program in Victoria. Local Area Coordination is focused on the individual and provides a case management approach to support individuals to integrate into the community. The Building Inclusive Communities Program, on the other hand, has a community focus that includes facilitating partnerships across community groups, building community capacity to include people with disability and disability inclusion initiatives across local government programs. They are both important roles. Table 2.8 outlines the objectives of the Building Inclusive Communities Program and Local Area Coordination.

Table 2.8: Differences between NDIS Local Area Coordinators and Access Officers in local councils

NDIS Local Area Coordinators	Local government Community Building Program [Building Inclusive Communities]
Build and maintain effective working relationships	Helping people and organisations work together more effectively.
Provide accurate and timely information	Improving community understanding about the needs and aspirations of people with disability.
Provide support and assistance to identify goals, strengths and needs	
Promote self-advocacy and provide advocacy support when necessary	Developing and implementing responses to community priorities.
Help develop personal and local community networks that provide ways to meet goals and needs	Ensuring that the needs of people with disability are the focus of community planning.
Help access supports and services to meet goals and needs	Supporting service providers to assist people with disability to live the sort of life they choose.
Build inclusive communities through partnerships and collaboration	Developing easy ways for people to access the information they need about services, community activities and consultation opportunities.

Source: Government of Western Australia, Disability Services Commission (2013) *Local area coordination: Family, friends, community—a good life.* West Perth, DSC; Department of Human Services *How the community building program works.* DHS. Accessed on 7 August 2014 from http://www.dhs.vic.gov.au/for-individuals/disability/community-life-and-jobs/community-involvement.

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207 *Submission S118*, Yarra City Council, p.13.

The Committee determined that Access Officers in local councils will need to work closely with LACs when the NDIS is rolled out. In the transition to the NDIS there also needs to be clarity of roles and responsibility across the two program areas.

The Committee heard that to build inclusive communities it is important to focus on the needs of communities and not just individuals. For example, the Association for Children with a Disability commented that:

> Community capacity building needs to occur rather than purely focussing on support for the funded participant, as well as retaining programs that previously supported families in their caring role. Retaining programs that build individual and family capacity should be a priority as should programs which previously supported social inclusion.[208]

LACs have a stronger focus on the individual with some emphasis on building inclusive communities. On the other hand, the Building Inclusive Communities Program in Victoria has a more comprehensive focus on building the capacity of communities through partnership, collaboration and facilitation. The Committee considers that there is considerable scope for LACs and Access Officers to undertake complimentary and collaborative efforts to achieve social inclusion.

In considering the differences between LACs and Access Officers, the Committee considered information provided by Mr Paul Dunn. Mr Dunn has a comprehensive understanding of both models and, as mentioned, Melba Support Services encouraged the Committee to make contact with Mr Dunn.

Mr Dunn suggested to the Inquiry that 'the Victoria Community Building Programs are unique—there is nothing like them anywhere in Australia.' He emphasised that 'they are very different to the Local Area Coordination model developed in Western Australia.'[209]

Mr Dunn told the Inquiry that in developing the Building Inclusive Communities Program, the WA Local Area Coordination model was explored and considered as a possible approach for Victoria. The DHS Practice Guide to the Building Inclusive Communities Program also identifies that this model was explored when developing the program. Yet Victoria did not adopt the WA model in its entirety, opting for a different emphasis on community capacity building. Mr Dunn stated that:

> We reviewed this model when we designed the Victorian programs and found that it lacked the key emphasis on freeing up workers to engage and work with communities to promote change by engaging directly with local mainstream community organisations.[210]

He also explained further that:

> We also felt that it lacked the engagement with Local Government whereby councils could be positioned as leaders in the disability reforms and community building processes and thereby representing members of their community who have a disability. It was our understanding that Local Area Coordinators would still be given a case load which they would be responsible for.[211]

Mr Dunn expressed his personal view that 'the individualised programs struggled because there was no time (or expertise in community development)

208   *Submission S122*, Association for Children with a Disability, p.8.
209   *Supplementary evidence*, Response to request for information, Mr Paul Dunn, 23 May 2014.
210   *Supplementary evidence*, Response to request for information, Mr Paul Dunn, 23 May 2014.
211   *Supplementary evidence*, Response to request for information, Mr Paul Dunn, 23 May 2014.

for case managers and facilitators to do the community planning and awareness raising critical to opening up mainstream services to people with disability.'[212]

The Committee considers that there is substantial potential for these two roles to complement each other and provide greater scope for the inclusion of people with disability. Some local councils suggested they could adopt a role in which they have direct contact with NDIS participants. For example, Warrnambool City Council told the Inquiry:

> This could include meeting and liaising with people who are eligible for NDIS packages to find out what their needs are and what it is they would like to do. Having gathered this information, councils are well-placed to have a much stronger understanding of the collective aspirations of people with disability in their communities and are potentially poised to plan and develop a response to these aspirations. This response would include opening up access to a broad range of community services by using the RuralAccess Program to engage mainstream services in capacity-building and disability awareness-raising activity.[213]

The Committee considered that this type of approach and willingness by local government to engage with participants in the NDIS provides considerable potential for liaison and networking between LACs and Access Officers.

In addition, in 2012 DHS restructured the department and created new Community Participation Teams in Local Connections Units across 17 areas in Victoria. They have specific responsibility for leading, developing and implementing a range of community development, social and economic participation and social inclusion initiatives in specified local government areas across Victoria. While not specifically disability related, these teams have been working closely with Access Officers in local government. They also have a responsibility to work in partnership with area-based Agency Connections Teams to involve non-government organisations in community-based initiatives.

The Committee considered that there is great potential for partnerships to be forged at the local level across non-government organisations, local government, the Victorian Government and the NDIA through these three key positions— LACs in NDIA, Access Officers in local government, and Community Participation Officers in state government.

Comprehensive guidelines exist for the Building Inclusive Communities Program and DHS advised the Inquiry that these guidelines are 'still relevant but due to be refreshed and updated' to reflect the DHS restructure.[214]

In the context of the NDIS, the Committee considers there is considerable potential for an ongoing role for local government. In the development of Tier 2, the current contribution from local government to community building initiatives across Victoria needs to be considered. Inquiry participants highlighted the potential value that local government can provide to the NDIS. For example, Monash City Council stated that:

> It has also been suggested that within the context of the implementation of the National Disability Insurance Scheme (NDIS), a Scheme that is primarily focused on the individual

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[212] *Supplementary evidence*, Response to request for information, Mr Paul Dunn, 23 May 2014.
[213] *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.10.
[214] *Supplementary evidence*, Response to request for information, Department of Human Services, 28 July 2014.

and not on the community, Councils are well placed to continue to play a role in identifying local community needs and advocating on how best to address these.[215]

Warrnambool City Council also provided its perspective on the ongoing role of local councils, including the Municipal Association of Victoria (MAV), in getting the reach across local, grassroots communities:

> The potential for partnership between the State government, the NDIS and the MAV to ensure coordination across all three levels of government which facilitates greater reach to grassroots community effort is an extremely positive outcome associated with Victoria's community building programs.[216]

Warrnambool City Council also suggested that 'RuralAccess can play a critical role in supporting the reforms associated with the NDIS.' It explained that:

> This includes strong leadership by local government in the support and rollout of the NDIS across Victoria. RuralAccess/local government can play an important consultative role with people with disability and their families and carers living in their local area.[217]

Mr Dunn told the Inquiry that 'Victoria is well placed to develop an area based placed framework that could see communities responding to the aspirations identified through individualised plans.'[218] He stated that:

> The potential to collect data by local government area based on the aspirations of people with disability, and to plan and build responses to those aspirations, is increased with a strong Community Building Program [Building Inclusive Communities] in place in this state and the proposed NDIS reforms.[219]

The Committee concluded that there is scope to achieve greater social inclusion for people with disability if Access Officers were effectively integrated into the NDIS transition. Section 2.5.2 considers how the Building Inclusive Communities Program can be strengthened.

Finding 2.13

There is great potential to forge partnerships across non-government organisations, local Government, the Victorian Government and the National Disability Insurance Agency that could be effective in furthering social inclusion initiatives:

- Local government has a valuable role in implementing the Building Inclusive Communities Program—which is unique to Victoria.
- Access Officers in the Building Inclusive Communities Program have substantial potential to complement the work of Local Area Coordinators in the National Disability Insurance Scheme.
- Community participation teams in the Department of Human Services are expected to work closely with local government, Access Officers and non-government organisations.

Recommendation 2.5

That the Victorian Government work with the National Disability Insurance Agency to clarify the roles and responsibilities of Local Area Coordinators associated with the National Disability Insurance Scheme and Access Officers in the Building Inclusive Communities Program to ensure their social inclusion interventions are complementary.

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215   *Submission S120*, Monash City Council, p.5.
216   *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.16.
217   *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.10.
218   *Supplementary evidence*, Response to request for information, Mr Paul Dunn, 23 May 2014.
219   *Supplementary evidence*, Response to request for information, Mr Paul Dunn, 23 May 2014.

2.7.4. Current NDIS trial

In its *Progress report*, the Joint Committee on the NDIS identified both achievements and challenges of the NDIS in the four trial sites during its first year. Some of its achievements demonstrate how it can potentially change the lives of people with disability into the future and the overlaps with social inclusion. For example, Ms Simone Stevens is a participant in the Barwon trial site in Victoria and she relayed a very positive experience to the Joint Committee, which is outlined in Box 2.11.

Box 2.11: The NDIS and increased social inclusion—Ms Simone Stevens

I am on a very good package at the moment with the NDIA. I was getting 21.1 hours before, and now I am getting 42 hours. I am doing a lot more. I can be more flexible. I work up in Melbourne ... It has given me great flexibility and good insight with carers and my coordinator, and now we can just do that, because I can do more. Without the NDIA, I would not be able to do that. I am just amazed at how great things are at the moment.

It is incredible. I cannot believe it. I cannot believe how incredibly happy I am at the moment, so it is great … I am getting a new manual wheelchair too, thanks to the NDIA, so it is really good.

The goals were what I wanted to achieve in my life. I am actually quite blessed. I got in contact with my friend who I had not seen in 19 years, and so now I spend—I think it is— every month up in Camperdown. I am able to go up and visit her, whereas before I was not able to because the funding would not allow it. But now I can go up and see her. That has really helped. I think that is the most important part of the goals. The other part of the goals was the work side of it. I am very work related. I love to do whatever I can to work whenever

I can. If I am not working, if I am sitting around at home, I get very annoyed very quickly, so I have got to be up and around and moving, going up to Melbourne, working in Geelong, doing whatever. But I have got to be moving all the time. Without the NDIA and without the goals, I think I would be very stuck.

Source: Joint Standing Committee on the National Disability Insurance Scheme (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme*. Canberra, Commonwealth of Australia, pp.18–19.

Yet there have also been challenges in the transition, with some participants having less positive experiences. The Joint Committee identified a number of challenges during the rollout phase. In addition to some specific concerns about the culture of the NDIA and the composition of staff appointed by the NDIA, issues with the planning process were identified. These included:

- lack of flexibility in plans

- incorrect and inconsistent plans

- losing supports in the transition to the NDIS from Individualised Support Packages provided under the Disability Act in Victoria.

Chapter 5 discusses the importance of quality support services to the social inclusion of people with disability.

NDIS and the changing role of service providers

With the move to a market driven approach to service delivery in specialist disability supports, a number of Inquiry participants raised concerns about the transition. These related to gaps in services, the challenges in moving to a business model, and changes to service provision that support risk-taking.

In its 2014 *Interim report* KPMG also identified a number of these issues, including pricing models, choice and control across market segments, interface with mainstream service provision and access to housing. Inclusion Melbourne expressed its view that there is a need to address 'the weakest links in the national disability insurance scheme engagement process for people who are beginning their engagement in the NDIS, particularly in choice making.'[220]

The Productivity Commission recognised that for some organisations the transition to the NDIS could result in changes to the composition of the non-government sector:

> The community—particularly, not-for-profit organisations—will play a vital role across all tiers of the NDIS, and across a wide range of activities from specialised disability service provision to community participation and inclusion. The NDIS will create new opportunities for not-for-profit organisations, but it will also present particular challenges to those who are disability service providers.[221]

The Commission went on to explain that:

> Many not-for-profit disability service providers will continue to provide specialised services and supports for people with disability funded by the NDIS (Tier 3). Providing these services and supports is their mission. They are well-positioned to provide these services and supports (they have a strong client base, capital investments, a skilled workforce, and expertise). However, with the shift away from block-funding to largely consumer-driven funding of Tier 3 services and supports, there will be pressure on these organisations to become more attuned and responsive to the needs of participants in the NDIS and to use their resources more effectively.[222]

Some members raised concerns about how innovative service models will continue to evolve in the context of the NDIS. Northern Support Services, for example, stated that:

> … with KeyRing you need a number of people to start it up; you need resources to get it going. In a sense it is a resource-sharing model to that extent. Geographically, in terms of getting things started, you need more than one person to start a KeyRing. I think individual support packages are fantastic because they provide people with choice, but on the other hand you need some innovative service models for people to choose from.[223]

Other organisations commented on the consequences for people with disability if services stopped operating due to a market driven approach. For example, the Executive Director of Action on Disability in Ethnic Communities (ADEC), Mr Keith Hitchen, stated that 'I truly believe in the concept of the NDIS in the sense that people will have their individual packages, they will be able to design them around what they believe, as they need, and all those sorts of things.'[224]

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[220] *Transcript of Evidence,* Inclusion Melbourne, p.3.
[221] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.219.
[222] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.219.
[223] *Transcript of Evidence*, Northern Support Services, Melbourne, 20 March 2014, p.7.
[224] *Transcript of Evidence*, Action on Disability within Ethnic Communities Inc, Melbourne, 6 March 2014, p.6.

But he emphasised the challenge within the model and provided the following scenario:

> I am a CEO of a service, and I provide a service. I provide services to a variety of people, and 5 of them want one service and 300 want another service. As a CEO, I am going to say, 'I will work with those 300 people. I cannot afford to work with the five people, and I cannot provide that service to them. Go somewhere else'.
>
> If there are only five people in a rural area or a country area who want that service, they are not going to get it under that concept, because an organisation is not going to turn around and say, 'well, I will put staff on to provide that service for five or six people'.[225]

He went on to explain that there is a risk that:

> Because it is a market-driven process, as a CEO I have to look at where the bulk of the money is going to come from. It is going to come from those people who all want this generic service. What I call boutique services or those specific little services will start to drop off.[226]

The Committee also heard that there will potentially be challenges for non-government organisations as they adjust the way they do business. The Victorian Council of Social Service (VCOSS) stated that 'the transition to an NDIS deeply affects the services provided by VCOSS members.'[227] It explained that:

> As the NDIS is primarily a market-driven system, this requires disability services to radically change they way they operate, with new costs and competencies such as individualised fee-for-service billing, marketing and advertising, and often complete service re-design. Ultimately, this is hoped to produce services that are individually tailored for people with disability. It is of little benefit, however, if services simply flounder or collapse, leading to disruptions in service provision for people with disability, severance of long-established personal relationships, and loss of expertise and skills from the sector.[228]

VCOSS suggested that the Victorian Government needs to support sector readiness for the NDIS.

The Committee recognises that the Victorian Government has provided funding to NDS Victoria to support non-government organisations to become NDIS ready. In addition the NDIA has stated that:

> We are deeply committed to working with disability service providers and we are prepared to use the Sector Development Fund to support this work, but we do not want to be in the business of picking winners.'[229]

Non-government organisations and social inclusion

The Committee considered that disability support services and other non-government organisations have a role in contributing to the social inclusion of people with disability. These organisations do not provide services in a vacuum and are continually supporting the people they provide supports to in their aspirations to participate in the community. Those that participated in the Inquiry stated they consider they have a key role.

Local councils also emphasised the important role of non-government organisations in building community capacity to increase the social inclusion of

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[225]   *Transcript of Evidence,* Action on Disability within Ethnic Communities Inc, p.6.
[226]   *Transcript of Evidence,* Action on Disability within Ethnic Communities Inc, pp.6–7.
[227]   *Submission S126*, Victorian Council of Social Service (VCOSS), p.10.
[228]   *Submission S126*, Victorian Council of Social Service (VCOSS), p.10.
[229]   B. Bonyhady (2014) *The NDIS vision: Delivering the Plan.*

people with disability. Brimbank City Council expressed its view on the role of non-government organisations:

> Community services are a vital part of Australia's social and economic infrastructure and are used by most Australians at some point in their lives. Community services not only support individuals and families, but also build social cohesion, enhance equity, give voice to the needs of disadvantaged groups, mobilise voluntary effort and philanthropy and achieve systemic change. They are one of the key mechanisms by which strong, effective communities are fostered and maintained.[230]

Karingal emphasised the importance of partnership in undertaking social inclusion initiatives and transition to the NDIS:

> We have the GRAND, which is the Geelong Regional Action Network for Disability. That has been around for I think about 10 years. It is a consortium of different agencies that come together and that helped NDIS in getting into the community. I guess that is a great example of a partnership where the agencies work together.[231]

COTA Victoria told the Inquiry that the NDIS presents challenges for non-government organisations in their ongoing role in building community capacity. It stated that organisations have already been effected through the 'the "buying" of the community sector—whereby not-for-profit and community-based organisations compete for funding through a top-down model of tendering for grant funds—has fundamentally altered social inclusion for those dependent on the services they offer.'[232] It went on to state that:

> With this reliance on competitive funding, the community sector seems to move further away from (once embedded) community networks and subsequently jeopardize their ability to be responsive to the changing needs of these communities. Prioritization of the imperatives of funding contracts takes precedence.[233]

Workforce development

The Committee heard concerns about the ongoing workforce development needs of non-government organisations providing disability support services. Box 2.12 outlines some of the views that were expressed.

Box 2.12: NDIS tiers

- The disability support sector workforce must have the capabilities to take a holistic approach to an individual's support needs and social inclusion goals. This is an essential precondition to the individualised goal based planning and assessment process and the aspirations for choice and control of the National Disability Insurance Scheme. (*Submission S089,* Able Movement, p.11)

- The emerging issues for Victorians with disability over the next 20 years affecting social inclusion will be the strain on the workforce with the introduction of the NDIS. If the NDIS is rolled out as promised, there will be a massive increase of demand for services providing access and technology needs… there is a need to ensure that the workforce is supported, grows steadily and is monitored for quality assurance. (*Submission S007*, Deaf Victoria, p.3)

- At present there are not enough disability support workers with appropriate skills, qualifications and experience in Victoria to support the number of people requiring

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230 *Submission S086*, Brimbank City Council, pp.5–6.
231 *Transcript of Evidence,* Karingal, p.4.
232 *Submission S060*, COTA Victoria, p.7.
233 *Submission S060*, COTA Victoria, p.7.

Box 2.12: NDIS tiers

assistance. The NDIS is likely to exacerbate the shortage of available support workers because of the greater numbers of people with disability who have access to funding and seek support workers. Centrelink is currently encouraging large numbers of people with inadequate skills to become disability support workers. This will mean that many people with disability may not receive adequate levels of support through the NDIS in future. (*Submission S033*, Ablelink, p.8)

As outlined in Section 4.5 of Chapter 4, the Committee heard volunteers provide great value to many initiatives that increase opportunities for social connections and social inclusion. Participants told the Inquiry that the future arrangements for supporting volunteers are uncertain. For example, Extended Families Australia stated that:

> Although the NDIS literature appears to promote the role of volunteers in community capacity building it is not clear how services predicated on volunteers will fare under the NDIS system. A major component of volunteer management is the recruitment, training and assessment of the potential volunteers. This all occurs prior to there being a match with an identified child / young person. Extended Families sets a high standard of training and assessment as it is essential that the volunteers that we accredit will be able to carry out their role in a safe and competent manner. The screening out of unsuitable volunteers is a complex and time consuming process but pivotal to us providing a service to families that is safe and that they can trust. Volunteers for various reasons may cease in that role, or not be available for a period of time, they cannot be easily replaced as a paid worker may be.[234]

Inclusion Melbourne explained the benefits that volunteers provide in the work that they do:

> We invest heavily in volunteering because we know the relationships that are created as a result of time that is freely given and from the motivation of someone who chooses to give their time and talents to someone else lead to far better and far different outcomes than those involving individuals who are getting paid close to a minimum wage.[235]

Extended Families Australia told the Inquiry that 'the positive outcomes for authentic social inclusion that can be achieved with volunteers are enormous, the work needed to make this happen must be recognised and volunteers not seen as cheap labour.'

However, the Committee heard that to continue investing in volunteers, non-government organisations need to fund the coordination, recruitment and training of volunteers. For example, Extended Families Australia explained that:

> It is difficult to envisage how to operate our volunteer program purely on a brokerage model. Families are unlikely to wish to use their funds to purchase the recruitment, training and assessment phase of volunteer management particularly as this would not guarantee them a volunteer match… the viability of the social inclusion programs at Extended Families requires that there remain some block funding to enable our recruitment and accreditation functions to continue at the current high standard.[236]

Inclusion Melbourne also stated that:

> We induct our volunteers in the same way that we would induct and recruit staff, and there is a cost associated with all of that. We run monthly volunteer training sessions to provide skills to volunteers to be able to do the work that they do on areas such as human relations, how to deal with awkward questions that might arise—because, 'suddenly for the first time

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[234] *Submission S063*, Extended Families Australia, p.8.
[235] *Transcript of Evidence*, Inclusion Melbourne, p.3.
[236] *Submission S063*, Extended Families Australia, p.8.

> someone is speaking to me and I tell them that I love them' and our volunteers find that a bit uncomfortable.[237]

The Joint Committee on the NDIS identified that there will be workforce issues to resolve in the transition to the NDIS, particularly a likely shortfall of skilled workers. It highlighted that the NDIA is currently developing a national workforce strategy for consideration by the Council of Australian Governments (COAG) in early 2015.[238]

Safeguards

Many Inquiry participants highlighted the need for national safeguards in the context of the NDIS. For example, the Disability Services Commissioner stated that these are:

> … fundamental questions about Victoria's role in preparing both the disability and community sector for a full scheme NDIS. Whilst we recognise that it is only one component of this preparedness, it is our observation that to date there has been insufficient attention and conversation around the development of a national approach to the issues of safeguards for people with disability participating in the NDIS. We understand the responsibility for safeguards during the NDIS trials falls to existing States and Territories; however, it is critical that a national approach is adopted.[239]

In its Bilateral Agreement with the Australian Government, the Victorian Government has agreed that it will continue to ensure the same levels of safeguards for people accessing disability services until 2019. In the interim, the NDIA is currently working with states and territories to develop a national approach to quality and safeguards. COAG is scheduled to consult on this between December 2014 and March 2015. The decision is to be considered by the Disability Reform Council in mid–2016.

DHS informed the Inquiry that the Disability Act currently provides a framework for practice and service delivery to be monitored and audited by a range of statutory authorities who have the legal right in circumstances defined by their governing legislation to:

- scrutinise individual staff actions

- investigate service delivery and adverse events

- recommend policy and practice change.

For example for accommodation services delivered by DHS these include:

- The Ombudsman

- The Auditor General

- The Public Advocate, including the Community Visitor Program

- The Disability Services Commissioner

- The Senior Practitioner

- The Coroner

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[237] *Transcript of Evidence,* Inclusion Melbourne, p.10.

[238] Joint Standing Committee on the National Disability Insurance Scheme (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme*, p.146.

[239] *Submission S049*, Victorian Disability Services Commissioner, pp.10–11.

Chapter 3
Identifying and achieving aspirations

AT A GLANCE

Background

The aspirations of people with disability are strongly connected to their experience of social inclusion. To identify what social inclusion means for people with disability, exploring their hopes and aspirations is necessary, whether this is striving to achieve goals to change and improve their life or to maintain the life they have.

Key findings

- The goals and aspirations of people with disability are no different and equally as unique as the aspirations of others in the community. Like all people, their goals fluctuate and vary over time and include having social connections and relationships, a meaningful job, holidays and living in a home environment of their choice. **(Finding 3.1)**

- Most people with disability know their life aspirations and pursue them independently. However, those with severe or profound disability, including communication difficulties, often require support to identify and articulate their goals, and will generally need some support to pursue these aspirations. **(Finding 3.2)**

- Understanding what people with disability aspire to achieve, what they are capable of and how they want to live their lives, can inform the planning efforts of local communities and society more broadly. **(Finding 3.3)**

- The aspirations of people with disability can be positively and negatively influenced by their personal characteristics, important people in their lives, societal attitudes and access to the environment. **(Finding 3.4)**

- Pathways for young people with disability tend to be different than for other young people in the community. This is not generally due to lower aspirations or potential, but due to low expectations in the community and as a consequence of assumptions relating to their disability. **(Finding 3.5)**

- Key life transitions can have an enormous influence on the aspirations and goals of people with disability and are valuable opportunities to make plans achieving goals and, if necessary, to be supported in pursuing them. **(Finding 3.6)**

- The Committee found that people with disability in disability supported accommodation can experience limitations in their daily activities due to the attitudes and approaches of disability service providers. The provision of supports in disability accommodation will transition to the National Disability Insurance Scheme in 2019. The Victorian Government has a responsibility to ensure that people with disability in their care are afforded social inclusion opportunities during the transition to the National Disability Insurance Scheme. **(Finding 3.7)**

- In pursuing aspirations, the journey is central to the experience (regardless of whether the goal is achieved) and, like others in the community, people with disability want dignity of risk and to drive their own decision making. For many people with disability, the journey is more challenging than for other community members and the activities they engage and participate in do not always reflect their broader aspirations. **(Finding 3.8)**

AT A GLANCE

Recommendation

That the Victorian Government:

- Consider how the aspirations of people with disability have changed as a consequence of legislative and policy changes, specifically the *Disability Act 2006* (Vic), by undertaking a follow-up survey to the 2000 study—*The aspirations of people with a disability within an inclusive Victorian community*.

- Work in partnership with local councils to develop an agreed approach to identifying the aspirations of people with disability in their local communities to be included in disability action plans and the work undertaken by Access Officers. **(Recommendation 3.1)**

To understand the social inclusion of people with disability, a key starting point is to consider the aspirations people have in their life and how these relate to inclusion. Not surprisingly, the goals and dreams of people with disability are no different from other people in the community and are equally as unique for each individual. Like most people they want to choose their own living arrangements, to secure meaningful employment, to engage in recreational activities they enjoy, and have social connections and relationships with others.

The journey of pursuing a goal or dream contributes to people's growth, their ideas, and the shaping of their future aspirations. Yet the challenges in pursuing aspirations are often greater for people with disability than for other members of the community. Often community expectations are lower than the actual capabilities of people with disability and their desire to achieve their ambitions.

Attitudes, fears and preconceived views about the capabilities of people with disability to aspire towards employment, social connection and other forms of social inclusion can influence the individual aspirations of people with disability themselves. Negative experiences can also reduce the aspirations of people with disability and decrease their opportunities for social inclusion.

The Committee identified that to improve social inclusion, there is a need to ensure that people with disability can have the highest of aspirations, opportunities to fulfil their goals, and access to communities and the support they provide to pursue their hopes and goals.

3.1. Aspiration and social inclusion

The aspirations of people with disability are strongly connected to their social inclusion. Chapter 1 outlined that a socially inclusive society is one in which everyone feels valued, their differences are respected and their basic needs are met so that they can live in dignity.

Many aspirations held by people with disability relate to social inclusion—such as moving to a housing arrangement of their choice, achieving financial security, and experiencing meaningful connections with others in the community. Limitations placed on participation can result in diminished aspirations and, consequently, lower levels of social inclusion.[1]

> **Aspiration**—*a hope or ambition of achieving something in the future.*

The Whittlesea Disability Network expressed the importance of aspirations to the social inclusion of people with disability:

> Inclusion is about having the opportunity to fulfill our goals, our aspirations, our dreams and to live in and contribute to a community where these are acknowledged and supported as our rights as equal human beings.[2]

In its submission to the Inquiry, the Disability Services Commissioner pointed to the link between social inclusion and aspirations. The Commissioner stated that when people with disability 'have their ideas, opinions and aspirations respected and heard' one key step towards 'true social inclusion' will be achieved.[3]

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[1] DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community. Summary report.* Melbourne, DisAbility Services Victoria, DHS, p.31.
[2] *Submission S037*, Whittlesea Disability Network, p.1.
[3] *Submission S049*, Victorian Disability Services Commissioner, pp.7–8.

Research evidence has also pointed to the link between aspirations and social inclusion outcomes, such as participating in the community. Figure 3.1 captures this relationship in the context of education and employment aspirations.

Figure 3.1: Framework for understanding aspirations and outcomes
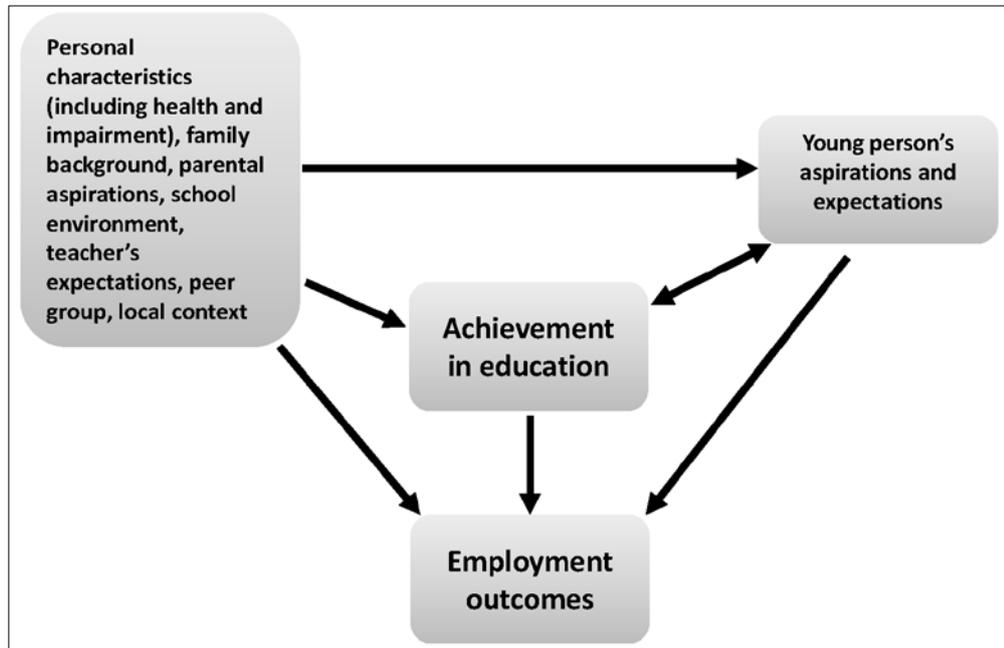
Source: Adapted from Burchardt, T. (2004) 'Aiming high: The educational and occupational aspirations of young disabled people'. *Support for Learning*, Vol.19, No.4, p.183.

Some Inquiry participants suggested a link between aspirations, human capital and social inclusion. Human capital refers to the 'unique set of abilities and acquired skills' that each person possesses and that is of value to others in the community.[4] The concept is often used in the context of skills gained through education and a person's increased employability. It is also has relevance to disability. A variety of personal attributes, abilities and skills will determine the human capital of a person with disability and their potential to be socially included.

Aspirations are a driver of human capital. Having goals and the desire to pursue them are contributing factors in successfully achieving them. One research study suggests that 'aspiration capital' is a form of human capital and that 'ambition plays an important role, in part influenced by environmental factors (eg real opportunities) and by personal traits.'[5]

> **Human capital**—*the collective skills, knowledge, or other intangible assets of individuals that can be used to create value for the individuals, their employers, or their community.*

In 2005, the Policy Research Initiative in Canada identified the value of human capital in building the capacity of people to achieve their aspirations, stating that:

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[4] N. Gao, K. Gill, L. Schmidt et al. (2010) 'The application of human capital theory in vocational rehabilitation for individuals with mental illness'. *Journal of Vocational Rehabilitation*, Vol. 32, No. 1 (25–33), p.25.

[5] J. Douglass (2010) 'Creating a culture of aspiration: Higher education, human capital and social change'. *Procedia Social and Behavioral Sciences 2*, Vol. 2, No. 5 (6981–95), p.6985.

> … through recognizing the value of human capital and other assets, including social capital, the state can help equip its citizens with the capabilities to participate fully in the social and economic life of the country.[6]

In its submission, Annecto stated that there are not only benefits for people with disability in raising their aspirations but for society more broadly:

> By raising the expectations that all people are able to participate in meaningful ways, the value of human capital across Victoria will be raised.[7]

3.1.1.   Aspirations

People's aspirations can provide insights into what social inclusion might mean for them, what is meaningful in their life and what makes them feel valued. As outlined in Chapter 1, social inclusion is a unique experience for every person, and this chapter identifies that aspirations are equally unique.

People's goals in life vary enormously and continuously evolve. Some are hopes and dreams that may not be realistically achieved. Many, however, are attainable and relate to the basic elements of life—such as living in a home environment of choice, having relationships and social connections, or securing a meaningful job.

People in the general community are encouraged to have aspirations and goals for their future, particularly young people. Associate Professor Paul Ramcharan, from RMIT University, emphasised that for the majority of people in the community 'what makes life meaningful is that we are pursuing our aims, dreams, wishes and aspirations.'[8] Similarly, Marriott Support Services made the point that young people in the community are encouraged to have aspirations:

> In our youth most of us, encouraged by parents and family, wanted to try for a life that we perceived as somehow 'better'. We wanted to be valued and to be valuable members of a caring, just society. To pursue opportunities and aspirations and to be accepted as positive contributors to our community.[9]

Research into aspirations is not extensive, but studies that have been conducted have determined that aspirations give life meaning, contribute to wellbeing and provide a sense of connection to society for most community members. Achieving goals, committing to goals and resolving conflicts between goals 'have been found to be important parameters in explaining levels of wellbeing.'[10]

Aspirations are also interconnected with a person's identity and sense of who they are. For example, often employment provides a sense of identity—'I'm a doctor', 'I'm a plumber', 'I'm a receptionist'. So too do relationships—'I'm married', 'I'm a parent', 'I'm a friend'. Research in this area is evolving:

[6]   Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*. Government of Canada, p.1.

[7]   *Submission S104*, Annecto - the people network, p.13.

[8]   *Transcript of Evidence*, Associate Professor Paul Ramcharan, Centre for Applied Social Research, RMIT University, Melbourne, 3 March 2014, p.4.

[9]   *Submission S020*, Marriott Support Services, p.8.

[10] E. Romero, J. Gómez-Fraguela, & P. Villar (2012) 'Life aspirations, personality traits and subjective well-being in a spanish sample'. *European Journal of Personality*, Vol. 26, No. 1 (45–55), p.45. See alsoR. Emmons (1986) 'Personal strivings: An approach to personality and subjective well-being'. *Journal of Personality and Social Psychology*, Vol. 51, No. 5 (1058–68); P. Schmuck (2001) 'Intrinsic and extrinsic life goals preferences as measured via inventories and via priming methodologies: Mean differences and relations with well-being'. In Schmuck, P. & Sheldon, K. (Eds.), *Life goals and well-being: Towards a positive psychology of human striving.* Göttingen, Germany, Hogrefe & Huber.

> Goals are now considered key factors in the regulation of behaviour and integration of personality, and their role in the determination of multiple behavioural and emotional outcomes has been repeatedly underlined by personality psychologists.[11]

Aspirations fluctuate, change and evolve over time. This was emphasised by some Inquiry participants such as the Office of the Public Advocate (OPA), which expressed its view that a 'person's opportunities for participation and inclusion should vary according to their developing and changing aspirations, interests, inclinations and relationships.'[12]

For people in the community, many of these goals relating to employment, family or owning a home are realistic and achievable. What is achievable for the general population, however, is often not attainable for people with disability. Not achieving the basic aspirations in life can result in experiences of social exclusion and isolation.

3.1.2.   The aspirations of people with disability

As for all people in the community, the aspirations of people with disability and the pursuit of these goals inform the directions of their lives.

Participants repeatedly told the Inquiry that the community needs to understand that people with disability have aspirations that are no different to the general population and are equally as unique to every individual. In the words of one Inquiry participant, Mr Kevin Boyce, just like all Victorians people with disability:

> … have the same 'needs and wants' as everybody else, their money they spend helps keep business till's ringing and the employment opportunities they create for Carers, equipment suppliers … is huge. [People with disability] like anybody else tells bad jokes, might drive a Holden or barrack for Collingwood, laugh and cry, are married, single, GLBT, or just wish for the odd bonk! Yes they are inclusive when allowed.[13]

Hobsons Bay City Council echoed this view, stating that through its consultations in the community:

> People with disability in Hobsons Bay have told the Council that they want the things that everyone else in the community takes for granted. They want to go to school and work, get married, go on holidays, and have access to shops and restaurants. Most importantly people with disability in Hobsons Bay want to be accepted and want the opportunity to be spontaneous. They want the chance to participate in and contribute to community life, and require others in the community to share their vision.[14]

More specifically, the Victorian Advocacy League for Individuals with Disability (VALID) informed the Inquiry that most people with intellectual disability 'share the dreams and aspirations—along with the disappointments and frustrations—of people across the world.'[15] The Summer Foundation stated that for people with disability 'their main expressed aspiration is the chance to experience what everyone else does in their regular lives.'[16]

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[11]   E. Romero, J. Gómez-Fraguela, & P. Villar (2012) *Life aspirations, personality traits and subjective well-being in a spanish sample*, p.45. See also B.R. Little, K. Salmela-Aro, & S.D. Phillips (Eds.) (2007) *Personal project pursuit. Goals, action, and human flourishing*. Mahwah, NJ, Erlbaum.

[12]   *Submission S012*, Office of the Public Advocate, p.10.

[13]   *Submission S005*, Mr Kevin Boyce, p.1.

[14]   *Submission S078*, Hobsons Bay City Council, p.2.

[15]   *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.8.

[16]   *Submission S121*, Summer Foundation Ltd, p.24.

The Secretary of the Victorian Department of Human Services (DHS), Ms Gill Callister, also pointed to the normality of the life aspirations of people with disability and their connections to social inclusion. She explained that:

> … people with disability have consistently told us they want to be included in community life. They want to live, work and socialise in the same way as everyone else, and importantly, just as everyone does, people with disability have told us they need support and skills—from education and training to health care and safe and reliable transport—to really access and participate in community life.[17]

Inquiry participants also emphasised the importance of acknowledging that people with a severe or profound disability have aspirations and future goals to work towards that give their life meaning. In a public hearing, for example, AMAZE stated that 'even for someone with quite complex needs what they would like with social inclusion is to have friendships and to have imaginative capacity.'[18]

The evidence the Committee received about the nature of the hopes and goals of people with disability is supported by research undertaken into the aspirations of people with disability. Their goals are unique to the individual and specific to their interests, personality, values and identity.

While dated, the findings of a comprehensive study undertaken in 2000 still provide insights into the specific aspirations of people with disability in Victoria. In partnership with DHS, Millward Brown Australia (MBA) undertook the research on aspirations. It considered what people with disability are doing, what the barriers are, what they want for the future and how they see themselves getting there. It explored the aspirations of people with varying levels of functioning and types of disability. The study identified that:

> Like all members of the community, people with disability aspire to have close and loving relationships, to be valued as members of their community and to experience physical and material wellbeing.[19]

These types of aspirations have strong links to social inclusion. Over 50 goals or types of aspirations were mentioned by the study participants. The most frequent three related to goals associated with work, recreation and holiday travel. While the study did not specifically identify social connections, such as friendships, the importance of close relationships was evident. Many of the aspirations related to connecting with others through social and interactive activities.

No differently from other community members, the aspirations of people with disability were found to vary enormously. Some people felt more challenged than others by their individual circumstances—sometimes those challenges related to their disability and sometimes they related to other factors:

> For some, the horizons are wide, whether due to their own personal outlook or to the supports and plans that are in place for them. For others, barriers and limitations exist to such a degree that, at worst, they have difficulty thinking about next week let alone next year or a few years hence.[20]

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[17] *Transcript of Evidence*, Department of Human Services, Melbourne, 3 March 2014, p.2.

[18] *Transcript of Evidence*, AMAZE, Melbourne, 17 March 2014, p.7.

[19] DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community. Summary report*, p.9.

[20] DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community. Summary report*, p.21.

These barriers and limitations on aspirations—personal outlook, supports or plans—are similar to those that can influence social inclusion.

Broadly, the types of aspiration for those people participating in the study related to goals associated with:

- living arrangements

- work and employment

- socialising and relationships

- participating in cultural and recreations activities (holidays, sport, cultural)

- contributing to social change.

A key finding of the research study was that:

> … the more secure people feel in terms of control over their life, the more concretely they interpret 'aspirations'. The less confident tend to use words like 'wishes' or 'hopes' when discussing aspirations, the more confident refer to 'goals', 'aims' and 'directions'.

Importantly, the researchers highlighted that 'notwithstanding these attitudes, however, all people agree that it is vital to have aspirations—without them life would have no meaning.'[21]

Finding 3.1

The goals and aspirations of people with disability are no different and equally as unique as the aspirations of others in the community. Like all people, their goals fluctuate and vary over time and include having social connections and relationships, a meaningful job, holidays and living in a home environment of their choice.

3.1.3.   Identifying and understanding aspirations

Many who provided evidence to the Inquiry emphasised the importance of effectively identifying and understanding the aspirations of people with disability. This is largely to ensure that these aspirations can be met through supporting individuals, but also to enable communities to be adequately equipped to facilitate and, where necessary, support the aspirations of people with disability.

Individual aspirations—people with a severe or profound disability

Most people with disability are fully capable of identifying and articulating their own aspirations and goals, and they may or may not require additional support to attain these goals. However, understanding the aspirations of someone with a severe or profound disability who cannot easily communicate their views and feelings, on the other hand, is more complex. Importantly, many will have goals for their future that provide meaning in their life.

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[21]   DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community. Summary report*, p.21.

Understanding the aspirations of people with a severe or profound disability generally requires professional, specialist skills, extensive familiarity with the person, and a strong understanding of their disability and requirements for day to day living.[22]

Mrs Mary Nolan AM provided the Inquiry with an example of a personalised approach to identifying the aspirations of her son, Mr Chris Nolan, who suffered a severe brain injury in 1996. Mrs Nolan AM explained that:

> People with very severe neuro trauma usually have a lifelong narrow margin of health … which means they are dependent on others for good clinical care and acute observation and accurate interpretation of subtle signs …
>
> Despite being unable to speak, move, or see much and medically vulnerable, Chris communicates non verbally with facial expressions.[23]

Mrs Nolan AM informed the Inquiry that a process was undertaken to identify and understand her son's personal goals which were then articulated in a proactive plan to inform how they would be pursued. Box 3.1 outlines the stages used to identify Mr Nolan's aspirations.

Box 3.1: Mr Chris Nolan—aspirations and goals

Identifying his aspirations and goals, strategies and evaluation have been part of his life and participation.

1. A vital first step is identifying a person's hopes, dreams, what really gives him/her meaning. Many young people with ABI [Acquired Brain Injury] become 'blank slates' isolated with no one who knows them, their likes, dislikes and history.
   For example Chris had an amazing capacity for people and friendship, loved the land, music, sport, making a difference and fun. He still does and 'Getting on with Life' is a 2 page synthesis of his Goals and aspirations 2004–2013 and reflects what gives him meaning, his interests, and goals and aspirations. Developed with Chris by WDCW [what does Chris want] group in 2013.

2. Then identify with people who know the person (and the person) one or few interests, preferences, set goals and strategies–time limited and review. Document and ensure everyone knows what is aimed for and involve the person. Some of the enjoyment of something any of us look forward to is anticipation and planning and then looking back and reflecting on the experience–the laughs, up and downsides. That should also be a given for people who are non verbal.

3. Preparation is essential. 'Scoping' actual physical access, knowing booking agencies disability access booking details, having access to options etc. And with high care needs, identify and set up emergency procedures (what to do, who to call, if …) education of carers/family to cope with. We've had everything from minor bus breakdowns, wheel chair breakdowns, seizures, Peg tube falling out, RACV unable to find us for 2 hours in breakdown on freeway on Easter weekend.

4. Observe, evaluate, review and either do more of same or something else as is no 1.

Source: *Submission 128*, Mrs Mary Nolan AM, p.8. [Emphasis removed from original]

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[22] A. Hillman, M. Donelly, L. Whitaker et al. (2012) 'Experiencing rights within positive, person-centred support networks of people with intellectual disability in Australia'. *Journal of Intellectual Disability Research*, Vol. 56, No. 11 (1065–75), p.1073.

[23] *Submission S128*, Mrs Mary Nolan AM, pp.4–5. [emphasis removed]

For people with intellectual disability, conceptualising future goals can also require some assistance. In the 2000 study on aspirations mentioned in Section 3.1.2, the researchers pointed out that:

> People with intellectual disability found it more difficult to articulate the importance of having aspirations. Lively discussion around the things they'd like to be doing in the future, as well as some of their fears for the future, underlined the importance attached to the concept …[24]

In the context of the goals and aspirations of people who use disability services in Victoria, the *Disability Act 2006* (Vic) sets out specific requirements for providers of services relating to aspirations. Most people who access disability support do not have the capacity to live independently and require support for daily activities. A key principle of the Disability Act is to ensure that people with disability can achieve their individual aspirations. To do this, services are required under the legislation to provide individualised planning that will:

> … advance the inclusion and participation in the community of the person with disability with the aim of achieving their individual aspirations.[25]

When a person is approved to receive an Individual Support Package (ISP) in the disability service system, they undergo a facilitation process which includes identifying their goals and aspirations.[26]

Since 2007, DHS has provided a resource kit to assist service providers in this process to identify the goals, needs and aspirations of a person who has an ISP. The elements of this process involve:

- finding out about the person

- learning what is important

- balancing risk and happiness

- exploring culture and spirituality

- building relationships

- community links and participation opportunities

- exploring accommodation options.[27]

In its submission, the OPA stated that depending on the skills or attitudes of the supporting organisation, this process can head in one of two directions:

> At their best, these individual support plans are part of a meaningful process and are a living document that incorporates the person's aspirations and works as an effective tool for ensuring that everyone is working towards the realisation and review of these personal goals. At the other extreme, when this process does not work well, it might mean that last year's plan is got out from the draw where it has sat for 12 months so the date can be changed. The variability largely depends on organisational capacity and the skills and attitudes of the staff working on developing and implementing the plan.[28]

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[24] DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community*. Melbourne, DisAbility Services Victoria, DHS, p.44.

[25] *Disability Act 2006* (Vic) s.5.

[26] See Glossary for meaning of Individual Support Package and Individual Support Plan.

[27] Department of Human Services (2007) *Planning for individuals. A resource kit and implementation guide for disability service providers*. Melbourne, DHS, Disability Services Division, pp.27–42.

[28] *Submission S012*, Office of the Public Advocate, pp.27–28.

To date, the Victorian Government has held responsibility for workforce development and consistency in planning processes. With the introduction of the National Disability Insurance Scheme (NDIS), planners and Local Area Coordinators (LACs) will be responsible for considering the aspirations of eligible participants in the scheme. Chapter 2 discusses the development of a national workforce strategy.

The NDIS will continue to emphasise goals and aspirations. The *National Disability Insurance Act (2013)* (Cth) makes it a requirement to include a statement of goals and aspirations in the plans of participants in the Scheme. The NDIS approach is outlined in operational guidelines:

> The participant's statement of goals and aspirations is the crucial first step in preparing the participant's plan and provides the foundation for the subsequent selection of supports. The NDIA [National Disability Insurance Agency] provides a 'planning kit', including a suggested template, to all participants ready to enter the planning stages.[29]

Some Inquiry participants expressed concern about the level of support people with cognitive disability might receive through this planning process.[30] The Committee recognises, however, that state governments and the NDIA are in a process of co-design as the NDIS is trialled and that matters relating to direct service provision are being negotiated progressively from now until 2014.

Finding 3.2

Most people with disability know their life aspirations and pursue them independently. However, those with severe or profound disability, including communication difficulties, often require support to identify and articulate their goals, and will generally need some support to pursue these aspirations.

Community understanding of aspirations and disability

Many Inquiry participants stressed the need for greater understanding in the community that people with disability are no different from anyone else in what they aspire to in life.

In her submission, Ms Leanne Robson, a service manager in a disability service, stated there is a need to 'promote the ordinariness of people with disability as it is then recognised that they have the same aspirations and [the] will to be part of society.'[31] The Victorian Council of Social Service (VCOSS) expressed that society needs to 'recognise the diversity of people and their aspirations for a meaningful life.'[32] In its submission, Belonging Matters made a similar point, stating that 'given the uniqueness of each person's needs and aspirations it's impossible to assume that all needs can be met through the same means.'[33]

Understanding what people with disability aspire to achieve, what they are capable of and how they want to live their lives, can inform the planning efforts

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[29] National Disability Insurance Scheme (16 January 2014) *Operational guideline — planning and assessment — facilitating the participant's statements of goals and aspirations* NDIS, p.2. Accessed on 3 June 2014 from http://www.ndis.gov.au/document/325.

[30] *Submission S012*, Office of the Public Advocate, p.31.

[31] *Submission S022*, Ms Leanne Robson, Yooralla Service Manager, p.4.

[32] *Submission S126*, Victorian Council of Social Service (VCOSS), p.4.

[33] *Submission S030*, Belonging Matters, p.5.

of local communities. For example, such knowledge can contribute to planning for more accessible environments and infrastructure. In turn, this enables people with disability to achieve their aspirations such as meeting a friend for coffee, securing and maintaining a job, or going on a holiday.

Ms Robson provided her opinion to the Inquiry that in planning new infrastructure it is essential people with disability have their 'needs and aspirations … considered and included from the beginning' of any such process, including an understanding of 'what is holding them back from fulfilling their aspirations.'[34] This knowledge can provide valuable insights for communities regarding changes needed to achieve greater social inclusion for people with disability.

Role of local government

Inquiry participants identified a role for local government authorities (LGAs) in improving community understanding of the needs and aspirations of people with disability. The role of LGAs in identifying aspirations is important to briefly consider here. Chapter 2 discusses local councils and community capacity building on issues relating to disability in greater depth.

In evidence to the Inquiry, two local councils acknowledged the need for greater community responsiveness to the aspirations of people with disability in order to increase their social inclusion. For example, Whitehorse City Council stated that:

> Efforts to increase the social inclusion of people with disability require an approach that listens to and responds to the needs and aspirations of the individual, their family and carers. Social inclusion also requires working with the community to ensure that it has the resources and the capacity to respond to the needs and aspirations of the individual, their family and carers.[35]

Warrnambool City Council explained that 'poor community awareness of disability … impacts on the capacity for community organisations to plan and respond effectively to the needs and aspirations of people with disability.'[36]

Both councils had views about the importance of LGAs playing a role in increasing community understanding of the goals and ambitions that people with disability may have. Whitehorse City Council explained that local councils are 'uniquely placed to capture knowledge, identify the needs and priorities of the local community.'[37] Complementing this view, Warrnambool City Council stated that:

> … councils are well-placed to have a much stronger understanding of the collective aspirations of people with disability in their communities and are potentially poised to plan and develop a response to these aspirations.[38]

Whitehorse City Council also pointed to the facilitative role that councils can provide in the context of people's aspirations:

> Council is also conduit for connecting people to a range of community based services and resources that meet their individual needs and aspirations. Local government hosts,

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[34]   *Submission S022*, Ms Leanne Robson, Yooralla Service Manager, p.5.
[35]   *Submission S097*, Whitehorse City Council, p.4.
[36]   *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.9.
[37]   *Submission S097*, Whitehorse City Council, p.18.
[38]   *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.10.

administers and delivers a range of state initiatives that contribute to the social inclusion of people with disability.[39]

In this context, planning by LGAs in communities is the focus of ongoing investment and financial resourcing. In view of this, Scope (Vic) suggested that:

> Inclusion requires identified investment that is long term and based on identified aspirations and areas of need.[40]

At a broader statewide level, the 2000 study into aspirations is one of the few research projects undertaken to specifically identify and understand the aspirations of people with disability. This study is 14 years old and while it still has some relevance, many policy and legislative changes have occurred in the field of disability since it was conducted.

The Committee considered there would be value in conducting a follow-up study on how the aspirations of people with disability have been influenced by legislative and policy changes, resulting in the introduction of the Disability Act and the NDIS.

Finding 3.3

Understanding what people with disability aspire to achieve, what they are capable of and how they want to live their lives, can inform the planning efforts of local communities and society more broadly.

Recommendation 3.1

That the Victorian Government:

- Consider how the aspirations of people with disability have changed as a consequence of legislative and policy changes, specifically the *Disability Act 2006* (Vic), by undertaking a follow-up survey to the 2000 study—*The aspirations of people with a disability within an inclusive Victorian community*.

- Work in partnership with local councils to develop an agreed approach to identifying the aspirations of people with disability in their local communities to be included in disability action plans and the work undertaken by Access Officers.

3.2.   What influences aspirations?

Multiple factors can influence the aspirations of all people in the community. This is no different for people with disability. These can be individual factors, such as personal characteristics, diversity and health status. Aspirations can also be affected by external factors, such as support from family and friends, or societal expectations.

For people with disability, external influences can be more challenging for people with disability than for other community members. Many of these factors

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[39]   *Submission S097*, Whitehorse City Council, p.18.
[40]   *Submission S129*, Scope (Vic) Ltd, p.29.

are discussed in other chapters, particularly Chapters 4, 7 and 8. But they are briefly discussed here in the context of how they can positively or negatively influence the aspirations of people with disability.

Furthermore, the Committee also considers how some of the life transitions people with disability experience can influence their aspirations in ways that are similar and also different from others in the general community.

Finding 3.4

The aspirations of people with disability can be positively and negatively influenced by their personal characteristics, important people in their lives, societal attitudes and access to the environment.

3.2.1. Individual factors influencing aspirations

There are multiple personal factors that can influence the aspirations of people with disability. These include personal identity, personal characteristics, health status, capacity, diversity, and social and economic disadvantage.

The self-belief to aspire to achieve goals and the willingness to accept encouragement from others are both connected to the potential for people with disability to experience social inclusion. Similarly, an individual's perception of the barriers and the challenges in achieving their aspirations can influence whether they will pursue their ambitions.[41] Section 3.3 goes into greater detail about the journey of pursuing goals.

In its submission, Monash Health emphasised the diversity of people with disability, stating that they:

> … need to be treated as individuals with varying likes, dislikes, experiences, education, expectations, resilience, endurance, employment prospects, hopes, desires, support and internal fortitude.[42]

Table 3.1 outlines some of the individual factors that influence the nature and scale of the aspirations of people with disability.

Table 3.1: Individual factors influencing the aspirations of people with disability

Individual factors	Description
Personal characteristics	• Personal characteristics can influence the nature of aspirations people will have. These include levels of motivation, confidence, drive, self-esteem, an internal 'locus of control'[43] and resilience. • It is unrealistic to expect all people to share the same level of drive and ambition.[44]

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[41] DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community*, p.52.

[42] *Submission S068*, Monash Health, p.5.

[43] A locus of control orientation is a belief about whether the outcomes of our actions are contingent on what we do (internal control orientation) or on events outside our personal control (external control orientation).

[44] DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community. Summary report*, p.12.

Individual factors	Description
Health status	• Good physical and mental health contributes to greater independence, diminishes barriers and increases people's ability to realise choices in life.
	• People with disability are more likely to experience physical and mental health problems than others in the community.
Capacity and capability	• The aspirations of people with disability can be influenced by their level of functioning.
Diversity	• People with disability are extremely diverse and this can influence their aspirations—including their gender, age, level of disability, ethnic background, where they live (rural, metropolitan), their social and economic background.

Source: Compiled by the Family and Community Development Committee.

As mentioned, aspirations and personal identity are strongly interconnected. Studies specific to people with disability have reflected on the importance of identity, stating that:

> People with disability strive to maintain their identity as a person first, not to wear a label that says 'disability'. Identity and self-esteem also relate to family and acceptance in the community, as well as ability to participate in community life.[45]

Empowering people with disability to achieve their goals can assist in building the self-esteem to identify and pursue goals that are suitable to them and their personal identity.

Empowerment and achieving a culture of aspiration

It has been established that having aspirations contributes to meaning in life. There will always be people who are satisfied with the life they have now and not want to strive for future goals or people with disability who are well-equipped to identify and pursue their own aspirations. But for others, it may be difficult to visualise what aspirations they could have or they may feel it is too challenging to pursue their hopes and goals. In these circumstances the community needs to create a culture of aspiration to enable people with disability to have aspirations and the freedom to decide how they will pursue those goals. Chapter 2 discusses strategies focused on building inclusive and welcoming communities.

> **Culture of aspiration**—*the sense that an individual has the freedom and the means to better themselves, to advance their knowledge, skills, and position in society.*

While many people with disability are resilient and determined in their lives, the Committee heard that building self-belief is not always easy for people whose experience in the community can often be negative. The Able Movement suggested that:

> Capacity building for Victorians with disability requires concerted effort. The legacy of low expectations is difficult to overcome.[46]

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[45] DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community. Summary report*, p.17.

Strategies provided to the Inquiry for empowering people included a focus on capabilities, self-advocacy programs and external coaching.

The Committee identified a cycle in which empowerment, aspiration and social inclusion each influences the other. The more empowered a person is, the higher their aspirations and the greater their experience of social inclusion, which in turn leads to increased empowerment and raised aspirations.

Key factors that contribute to empowerment for people with disability include autonomy, choice, control and stability. Empowerment is also influenced by capability, support and opportunity.

> **Empowerment**—*the process of enhancing the capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes.*[47]

In the context of choice and control, many Inquiry participants referred to the importance of 'independence' or 'autonomy'. Mr Bil Hurley, an Ambassador with the Summer Foundation, made the following statement when he gave evidence to the Inquiry:

> The word I am going to use is freedom. I need the ability to run my own life. If I do make a mistake, I only want myself to blame. Not having complete control of my choices makes me feel not quite human, so to me, social inclusion is about freedom.[48]

Monash Health stated that for people with disability to feel valued and empowered it means feeling 'that they have choices and are supported to make these choices.'[49] In its submission to the Inquiry, The Able Movement identified the need for:

> A culture that understands that the most disabling thing of all for every human being is a feeling that their own lives are not within their control, and they are in effect 'second class citizens'.[50]

Empowerment incorporates the following components:

- Empowerment is the process of increasing the assets and capabilities of individuals or groups to make purposive choices and to transform those choices into desired actions and outcomes.

- Empowered people have freedom of choice and action. This in turn enables them to better influence the course of their lives and the decisions which affect them.

- Empowerment speaks to self-determined change.[51]

In a practical sense, achieving empowerment involves focusing on capabilities and building capacity. Associate Professor Paul Ramcharan emphasised that 'the capabilities perspective … is hugely important… It is based on the idea of fulfilling a person's potentiality.'[52]

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46 *Submission S089*, The Able Movement, p.12.
47 The World Bank *What is empowerment?* Overview. Accessed on 10 June 2014 from http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTPOVERTY/EXTEMPOWERMENT/0,,contentMDK: 20272299~pagePK:210058~piPK:210062~theSitePK:486411,00.html.
48 *Transcript of Evidence*, Summer Foundation Ltd, Melbourne, 17 March 2014, p.4.
49 *Submission S068*, Monash Health, p.6.
50 *Submission S089*, The Able Movement, p.8.
51 The World Bank *What is empowerment?* From http://web.worldbank.org.
52 *Transcript of Evidence,* Associate Professor Paul Ramcharan, p.4.

The Committee heard that building the capacity of people to self–advocate is essential to social inclusion and to raising aspirations. The Darebin Disability Advisory Committee expressed its view about the value of skills in advocating for oneself:

> Self-advocacy can empower people with disability to be more active participants in their own life and a more active citizen in their community. Self-advocacy skills can give a person more confidence to ask for what they need and want, and to make life decisions. Most importantly good self-advocacy skills equip people to know what their rights and responsibilities are and what options they have to realise their rights.[53]

VALID made a similar point about the benefits of self–advocacy, stating that:

> For people with intellectual disability, that process of empowering them to make those choices is what we call self-advocacy—learning to be a strong self-advocate and speak up for yourself. Our experience is that when a person starts to take control of their life they start to develop self-confidence and self-esteem …[54]

The Able Movement also highlighted the value that a culture of aspiration can have on the aspirations of individuals and communities more broadly:

> Building an individual's capabilities based on their existing strengths and aspirations can help them to:
>
> • self-manage wherever possible, and be in the system only when needed
>
> • be connected to their community
>
> • participate in the economy.[55]

Another strategy for empowering people with disability involved external coaching or role models. Some Inquiry participants suggested coaching can be a valuable way for people with disability to identify and work towards their goals. Research supports these views. For example, the 2000 study on aspirations made the point that:

> External coaching appears to have a marked influence on attitudes to future possibilities. In this study, examples of coaching by self-advocacy facilitators, 'role model' graduates from special schools, parents, providers of disability-specific services, teachers and siblings were cited. Coaching can help to expand the horizons of some and illustrates to others that there are, indeed, horizons. In particular, coaching builds and reinforces confidence.[56]

The CEO of Inclusion Melbourne, Mr Daniel Leighton, also made reference to the value of role models in the context of aspirations:

> … if you are 15 and your parents are now seeing that there are role models of other young adults with autism engaging in the workplace with appropriate supports, you set your horizon far higher.[57]

One example of the use of role modelling or external coaching is the approach adopted by Extended Families Australia. It has developed a program that uses volunteer mentors and role models, particularly for children and young people. Extended Families explained that it accredits volunteers who:

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[53] *Submission S041*, Darebin Disability Advisory Committee, p.11.
[54] *Transcript of Evidence*, VALID (Victorian Advocacy League for Individuals with Disability Inc), Melbourne, 3 March 2014, pp.2–3.
[55] *Submission S089*, The Able Movement, p.12.
[56] DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community*, p.16.
[57] *Transcript of Evidence*, Inclusion Melbourne, Melbourne, 20 March 2014, p.9.

> … take on the role of mentoring, friendship and inclusion support with the children and young people and in so doing provide support to families who are able to experience their hopes and aspirations for their child being realised.[58]

Its submission provides a number of examples of the program's success the in the lives of the children and young people involved in the mentoring scheme. Chapter 4 discusses this and similar programs in greater detail.

3.2.2.   Aspirations and life transitions

Identifying and understanding aspirations at key life transition stages can help to maintain or increase social inclusion for people with disability. These stages can include transitions through education, into employment or into retirement. Other periods of change might include starting a new relationship, becoming a parent, or experiencing a major health incident. This is no different from members of the general community.

Key points of transition in a person's lifetime have considerable influence on their aspirations and subsequently the extent to which they are socially included in specific communities (such as in school, work environments, recreation groups) and the broader community. Effective support for those who would benefit is important at these key stages. This might include identifying needs and planning through transitions to enable people with disability to consider their future goals and opportunities for social inclusion.

In its submission to the Inquiry, Marriott Support Services identified the importance of life transition periods, stating that:

> People with disability should transition through life's phases (school, work, retirement) with genuine support and community involvement. Achieving this requires commitment to a process of positive culture change.[59]

It emphasised the importance of planning and involving people with disability in decision making at times of transition:

> People with disability, with families and carers as appropriate, need to be given the resources and supports to enable realistic planning and decision making about their future.[60]

The Victorian Equal Opportunity and Human Rights Commission (VEOHRC), however, has suggested there is a need to improve how the disability support system does this work. In Appendix 1 of its submission, the VEOHRC makes the following comment in a 2013 report on disability:

> The disability service system deals very poorly with life transitions. This translates to increased pressure on families at transition points, such as adolescence. Family life does not always progress in a neat linear fashion, although service responses appear largely designed in this way.[61]

The Committee identified that the Victorian Government's focus on transition points in the lives of people with disability is sporadic. With the transition to the NDIS, responsibility at the service system level will rest with the Australian Government. Yet many people with disability are not engaged with the disability

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[58]   *Submission S063*, Extended Families Australia, p.1.
[59]   *Submission S020*, Marriott Support Services, p.2.
[60]   *Submission S020*, Marriott Support Services, p.2.
[61]   *Submission S115*, Victorian Equal Opportunity and Human Rights Commission. Appendix 1, p.31.

service system but may still require support in the context of important life transitions.

There is potential benefit in capitalising on the opportunities these life stages provide. These opportunities include future planning for new aspirations and support for existing goals. This might include disability services building a stronger focus on life transitions into their individual planning processes. Or it might involve increasing the awareness amoung people with disability and informal carers of the value in focusing on these life phases and planning for them.

Starting and changing schools

What children and young people with disability aspire to in the context of schooling and education is not an area that has been well studied or researched. The Committee heard, however, that if managed effectively, transitions at this time in a child or young person's life can have positive consequences for establishing goals through adult life and, ultimately, on experiences of social inclusion.

Starting school is a time of excitement for many children. It brings opportunities to make new friends, to learn, and to be exposed to new and different experiences. It also involves changes to routines and patterns and, for some, can be a time of anxiety. Throughout a child or young person's schooling years there are ongoing transitions. This might include the move to secondary school or a shift from a government school into a specialist school.

The Committee heard that for children and young people with disability, if not handled well, these transitions can lead to considerable disruption and social exclusion. Melbourne City Mission emphasised the importance of:

> … additional time and support to thoroughly plan for a student's transitions, be that into primary school, secondary school, between schools or exiting school.[62]

Chapter 6 discusses transitions into school and moving across schools in greater depth.

Aspirations and leaving school

Inquiry participants emphasised that the aspirations of young people with disability soon to leave the education system require specific attention. Research evidence has highlighted the value of focusing on the goals of young people, often in the context of their future employment plans. While there have been few studies on the aspirations of young people with disability, it is broadly accepted that:

> Young people's aspirations are a critical ingredient for achievement in education and in occupational outcomes later in life …[63]

This research cites findings of other studies demonstrating that in the context of young people generally 'of all the developmental transitions, entry to employment is probably the most central to the formation of adult identity.'[64]

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[62] *Submission S111*, Melbourne City Mission, p.35.
[63] T. Burchardt (2004) 'Aiming high: The educational and occupational aspirations of young disabled people'. *Support for Learning*, Vol. 19, No. 4 (181–86), p.181.

Evidence to the Inquiry suggested that for young people with disability their adolescent years are equally important as other young people in the formation of their employment goals. The Youth Affairs Council of Victoria (YACVic) and Disability Advocacy Service (YDAS) stated that a focus on young people in times of transition is essential:

> Some of the most significant transitions in relation to learning, working, engaging and having a voice occur during a person's adolescent and young adult years. These include finishing school, moving into higher forms of education, entering the workforce, becoming involved in sexual relationships, taking part in new cultural and recreational activities, and becoming eligible to vote.[65]

In this context, Warrnambool City Council highlighted to the Inquiry that 'one of the biggest challenges for young people with disability is the transition from school to meaningful vocational options in the community.'[66] SkillsPlus and BRACE also referred to this critical time in a young person's life, stating that for young people with disability, social inclusion 'in the context of transition to adult life … would mean continued meaningful opportunities to learn, develop, contribute and be independent.'[67]

Inquiry participants emphasised that these opportunities to support young people with disability to consider and plan for their future employment often start well before schooling is over. The Committee heard there is a need for an early focus on the career pathways young people with disability might be interested in. SkillsPlus and BRACE suggested that tools used to support all young people in their transition to a career should be applied more effectively to the forward planning of young people with disability:

> The DEECD [Department of Education and Early Childhood Development] Victorian Careers Curriculum Framework offers a progression in career learning that is relevant to all young people. Careers and pathways planning has proved to be a very practical tool for school careers staff, professionals and families to work within the individual support framework while raising the aspirations of young people with disability.[68]

SkillsPlus and BRACE explained that a focus on planning is important at this time to assist in identifying aspirations and goals and preparing for an effective transition from school into meaningful employment, education or other pursuits:

> Although transition from compulsory education is often a stressful experience it should not be a negative experience. The current use of the term career challenges traditional cultural expectations of the professional with a brief case. Career in its contemporary meaning is a very useful tool to assist with progressive life planning. Career planning helps to highlight the individual's potential and value the individual's choices on how they decide to engage on their own terms in what they perceive is meaningful and challenging.[69]

Belonging Matters emphasised that the pathways for people with disability tend to be different than for other young people in the community. This is not generally due to lower aspirations or potential, but due to low expectations in the community and as a consequence of assumptions relating to their disability:

> When young people with disability leave school, they don't get career advice—instead, they receive a booklet with a list of disability service providers and programs. Continually people with disability are limited to perpetual skills training/'getting ready for work'

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64   T. Burchardt (2004) *Aiming high: The educational and occupational aspirations of young disabled people*, p.182.
65   *Submission S021*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, p.2.
66   *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.8.
67   *Submission S042*, SkillsPlus and BRACE, p.3.
68   *Submission S042*, SkillsPlus and BRACE, p.5.
69   *Submission S042*, SkillsPlus and BRACE, p.5.

which is often group-based and irrelevant to an individual's ambitions or needs. Advice from services is given on what services are available and is not based on the person's aspirations or typical options and inclusive pathways (including questions such as, 'what career would you like to pursue?').[70]

Chapter 6 discusses the transition from education into employment in greater depth.

Finding 3.5

Pathways for young people with disability tend to be different than for other young people in the community. This is not generally due to lower aspirations or potential, but due to low expectations in the community and as a consequence of assumptions relating to their disability.

Aspirations in later life

Aspirations change and evolve over time and for many people in later life, transitions such as retiring from work, experiencing ill-health or watching children move into adulthood, can all lead to changes in life goals. The Committee received little evidence relating to ageing and disability, with most references relating to intellectual disability, service provision and growing older. In 2012, this Committee conducted an *Inquiry into the social participation of Victorian seniors* and identified that most people do not want to think about getting older, to plan for later life, or to consider what their goals might be.[71] For people with disability, this may also be relevant, but there is not enough information to draw conclusions.

Some Inquiry participants stressed that it is necessary to consider the effects transitions can have for people with disability later in life—for example, they may also be retiring, downsizing their accommodation or watching their children move on from the family home. Some transitions are specific to people with disability, such as transitioning across service systems after the age of 65.

Regardless of the specific nature of transitions, these changes can have considerable influence on aspects of their lives that effect their aspirations and social inclusion. As in other transitional phases of their life, people with disability are often not considered in the same ways as other community members. In its submission, the COTA Victoria made the point that:

> … people with disability are sometimes not recognised as growing older in line with the rest of the population: there is less likely to be a focus on retiring from the workforce, with employment continuing as long as the older person with disability continues to receive disability support.[72]

The Darebin Disability Advisory Committee also raised the issue of growing older with disability in the context of the disability service system and reduced involvement in activities provided by such services:

> The complexity experienced by people with disability who are ageing and whom are also recipients of the disability sector can impact on how much choice and control the person

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[70] *Submission S030*, Belonging Matters, p.3.
[71] Family and Community Development Committee (2012) *Inquiry into opportunities for participation of Victorian seniors*. Melbourne, Parliament of Victoria.
[72] *Submission S060*, COTA Victoria, p.6.

has over decisions that are made, particularly with regard to retirement from day programs and/or employment. There are currently significant issues experienced at the day program and accommodation interface particularly when a person retires due to their age or if they are experiencing the ageing process early in life.[73]

COTA Victoria highlighted some of the transitions experienced by people with disability as they grow older can lead to a loss of independence:

> Victorians with disability will find many of the transitions associated with ageing have a great impact on their independence: loss of mobility and loss of car are good illustrations of this, particularly considering the wide geographical spread of the Disability sector.[74]

These factors can have a direct impact on the aspirations of people with disability and their future inclusion in the community. To support them to remain included, COTA Victoria emphasised the importance of planning across the entirety of a person's life:

> … the social inclusion of Victorians with disability should take a whole-of-life, flexible and individualised approach to services and a seamless interface in service delivery as people living with disability age.[75]

It went on to explain that the service system can effect these transitions, noting that 'separate funding for 65+ with disability makes things more difficult.'[76]

Research into the experiences of older people with intellectual disability specifically reveals that they can 'face significant barriers to enjoying active ageing as they transition into retirement.'[77] To overcome these barriers and achieve a successful transition to retirement, one suggested approach is 'active support' and 'co-worker training models.'[78] The Transition-to-Retirement (TTR) Program in Sydney is one model that adopts this approach. It has three core components:

- promoting the concept of retirement

- laying the groundwork for inclusion of would-be retirees with intellectual disability in the community

- constructing the reality (including five stages—planning, locating a group, mapping new routines, recruiting and training mentors, and monitoring and ongoing support).[79]

The Committee determined that like other life transitions, there is a need for greater planning for people with disability moving into later life and what this might mean for their future aspirations and social inclusion. When they retire, what do they intend to do? What financial plans do they have? Is their general health good and will it enable them to remain actively engaged and included? If they can no longer live independently, what plans are in place for support and do such supports need to be specialist? These are just some of the types of questions

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[73] *Submission S041*, Darebin Disability Advisory Committee, p.12.
[74] *Submission S060*, COTA Victoria, p.8.
[75] *Submission S060*, COTA Victoria, pp.5–6.
[76] *Submission S060*, COTA Victoria, p.6.
[77] N. Wilson, R. Stancliffe, C. Bigby et al. (2010) 'The potential for active mentoring to support the transition into retirement for older adults with a lifelong disability'. *Journal of Intellectual & Developmental Disability*, Vol. 35, No. 3 (211–14), p.1.
[78] N. Wilson, R. Stancliffe, C. Bigby et al. (2010) *The potential for active mentoring to support the transition into retirement for older adults with a lifelong disability*, p.211.
[79] C. Bigby, N. Wilson, R. Stancliffe et al. (2014) 'Transition to retirement: An effective program design to support older workers with intellectual disability participate individually in community groups'. *Journal of Policy and Practice in Intellectual Disabilities*, Vol. 11, No. 2 (117–27).

that are likely to arise for people with disability when they are moving into the later years of their life.

Aspirations after acquiring a disability

Another critical life transition is experienced by people adjusting to a newly acquired or diagnosed disability or condition. For people adapting to life with disability, there are many challenges in either maintaining former aspirations or developing new future goals. Some people want to return to the life they formerly had with additional support, others discover they will never be in a position to do this.

A number of participants told the Inquiry about the challenges of adjusting to a newly acquired disability. The experiences vary considerably. Some acquire a disability after an accident (such as a spinal cord or brain injury) or a specific incident (such as a stroke). Others experience a more gradual change in their capabilities as a health condition worsens. Regardless of the experience, the effects on their life can be enormous and have considerable consequences for their aspirations and ongoing inclusion in the community. For example, Blind Citizens Australia explained that:

> Losing your sight is one of the most difficult transitions and challenges a person can experience. A common experience among our members is difficulty holding on to employment during this very distressing time. Losing a job at the same time as losing your sight can trap people into poverty and social and financial exclusion that statistics and experience show is very hard to escape again.[80]

Vicdeaf (the Victorian Deaf Society) also commented on the challenges in maintaining social inclusion experienced by those adjusting to hearing loss and the challenges it presents in everyday life:

> For hard of hearing people isolation can be much greater than for members of the Deaf community within social settings. This can be especially true for those with an acquired hearing loss as they transition from being competent with their acoustic receptiveness to relying on visual and acoustic cues.
>
> Although written and spoken English may not present a problem to hard of hearing individuals, engaging within their community can be challenging and social exclusion experienced. Day-to-day activities such as shopping, using a telephone, catching up with friends and family, undertaking work duties or engaging with work colleagues can be highly difficult.[81]

Aspirations and goals can change after acquiring a disability or being diagnosed with a degenerative condition. For some people their goal is continuing or returning to their job. As identified by Blind Citizens Australia, however, maintaining employment after acquiring a disability can be challenging, or the challenges may relate to trying to sustain a self-employed business. Independence Australia informed the Inquiry of one man's experience who acquired a physical disability and wanted to continue managing his farm. Box 3.2 outlines this experience.

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[80]   *Submission S082*, Blind Citizens Australia. Appendix 2, p.9.
[81]   *Submission S088*, Vicdeaf, p.5.

Box 3.2: Independence Australia—support and newly acquired disability

We work with a man who has acquired a disability and who ran his own farm. He now has high service needs. He has 24-hour care in his farm, in his home. We have tried to build around him, through our service model, support for his physical needs. But in essence this man just wants to get on to manage his farm. He would like to get back to manage that farm. We have exhausted our ability in terms of providing him with a workforce for his physical needs. What we have not been able to do is to flip that around. The service model that we have at the moment looks at, 'well, here is the level of service that providers offer. We can offer you this suite of things'. In essence this man really needs farmhands who can also kind of do the extra things he now physically needs. But we have not been able to do that yet. There is a whole lot of other modelling and work we need to do in order to make that happen for him…

We can put in some of the technology and equipment he needs, but the reality is that most people need a companion, a just-in-time companion, to be there should they need something, but most of the time they may not need something.

Source: *Transcript of Evidence*, Independence Australia, Melbourne, 17 March 2014, pp.3–4.

In its submission, National Disability Services (NDS) Victoria emphasised that these types of challenges in holding onto work or a business after acquiring a disability require a focus from governments, stating that they 'must find better ways to support workers who acquire a disability to allow people to stay employed.'[82] The benefits of enabling people to maintain their employment in these circumstances extend beyond the individual to the community more broadly.

Other people who acquire a disability are faced with a changed life and will never be in a position to return to their former work or lead the life they previously lived. They often need to identify new goals for their future. Monash Health suggested that education has potential to assist people in these circumstances to develop new goals and aspirations:

> There well may have been a history of fulfilling employment and a career pathway that now has been interrupted—education gives the opportunity for new outcomes and opportunity and an increased quality of life.[83]

Disability Sport and Recreation also suggested that sport can help people through the adjustment to an acquired disability and potentially provide new goals and meaning in life. It provided information about its Rehabilitation to Recreation Program:

> Rehabilitation to Recreation Program is an outreach service in its fourth year, introducing sport and recreation to people with a recently acquired disability in Victorian rehabilitation centres, including The Royal Children's Hospital, Monash Children's Hospital, and many other health services. We educate allied health professionals and their patients on the benefits of sport and recreation as part of the transition from rehabilitation to the community.[84]

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82 *Submission S045*, National Disability Services Victoria, p.10.
83 *Submission S068*, Monash Health, p.5.
84 *Submission S055*, Disability Sport & Recreation. Appendix 1, p.6.

In its evidence to the Inquiry, Disability Sport and Recreation explained how one person experienced the transition through the rehabilitation process, the slow period of adjustment and the role that sport can play:

> One of our members often spoke about all the stuff, all the paperwork and all the information sheets, about all types of things, that you get when you leave hospital following a catastrophic injury which results in permanent disability. Amongst all of those pieces of paper is a brochure about a sport program, but in the early stages of rehabilitation it is just not something that you can comprehend doing. But the same health professionals kept asking him about sport and if it was something that he would like to try. Eventually, when the time was right, he did. He is now an avid wheelchair rugby player.[85]

Health and community services and practitioners have a vital role during these periods of transition, particularly during the rehabilitation phase. Some participants referred to positive things that have happened in this space. For example, The Able Movement told the Inquiry:

> There are already great individual examples of capability-focused services in Victoria. One example is the Transport Accident Commission's (TAC) Independence Model, which established a holistic strategy to align the TAC and their clients, plus attendant care, occupational therapy and other community providers, around the goal of transitioning clients to stable post-injury independence. In a 2011 survey, prior to the implementation of the Independence Model, 65 per cent of TAC staff and clients believed that it would result in significantly improved client outcomes.[86]

Since the mid–1990s, the Victorian Government has funded a program for people who acquire a severe brain injury when it is expected that the recovery process will be slow. One of its purposes is to support independence, identify goals and maximise social inclusion. Box 3.3 outlines the *Acquired brain injury: Slow to recover* Program.

Box 3.3: Acquired Brain Injury Slow to Recover Program

The Acquired Brain Injury: Slow to Recover (ABI:STR) Program is a state wide program funded by the Victorian Government. It provides rehabilitation and support to people with severe to profound acquired brain injuries, aged 5–64, who are not eligible for compensation or other rehabilitation services.

Through a brokerage model the ABI:STR Program provides rehabilitation and aids & equipment. The ABI:STR Program has a goal-based and outcome-focused approach to extended rehabilitation. Acquired brain injury rehabilitation aims to assist clients to reach an optimal level of independent functioning consistent with their injuries and maintain this to maximise inclusion and participation in the community.

Source: *Submission S068*, Monash Health, p.6.

Finding 3.6

Key life transitions can have an enormous influence on the aspirations and goals of people with disability and are valuable opportunities to make plans achieving goals and, if necessary, to be supported in pursuing them.

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[85] *Transcript of Evidence*, Disability Sport & Recreation, Melbourne, 20 March 2014, p.3.
[86] *Submission S089*, The Able Movement, p.12.

3.2.3. Family and friends—influencing aspirations

Relationships with family, friends, colleagues and others can all potentially influence the aspirations of people in general, including those with disability. These influences can be positive or negative. Social networks not only inspire and support the development of aspirations, they can also lead people with disability to lower their aspirations and expectations.

Chapter 4 considers the role of social networks on the inclusion of people in the community in greater depth and Chapter 8 details the low expectations of people with disability that exist in the community.

Families are often at the core of the lives of people with disability and will inadvertently influence children and young people with disability in the development and pursuit of their aspirations. This influence frequently continues into adulthood. In their adolescent years, young people are 'essentially developing and implementing a "self-concept"' and the extent to which their family supports them in this process is important in how they formulate aspirations.[87] As in all families, for people with disability some will be given opportunities and others will be held back in life.

Parents often face many challenges and negative experiences in their efforts to provide opportunities for their son or daughter with disability to pursue their goals and aspirations. The Association for Children with a Disability told the Inquiry that 'inadequate support for families of people with disability erodes their ability to stay positive and model reasonable expectations of what life should be.'[88] The Association expressed the view that:

> Children are heavily influenced by those around them and reduced expectations are very quickly accepted as the norm.[89]

VALID suggested that 'if parents don't imagine it's possible for their son or daughter to be included—in the community, in their neighbourhood, in their local school or even within their own family—it's almost guaranteed not to happen.'[90]

Parents and families are as diverse as people with disability themselves. This includes the levels of support they receive, their capacity and the resources they have to provide the opportunities they seek for their son or daughter with disability.[91] Chapter 4 discusses the experiences of families in greater detail and the nature of supports that they often need.

Many parents are extremely committed to encouraging their child to pursue and aim to achieve the goals they aspire to. Carers Victoria explained that under the right circumstances 'carers can be crucial and effective facilitators of social inclusion for the person with disability.'[92]

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[87] T. Burchardt (2004) *Aiming high: The educational and occupational aspirations of young disabled people*, pp.182–83; DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community. Summary report*, p.13.

[88] *Submission S122*, Association for Children with a Disability, p.6.

[89] *Submission S122*, Association for Children with a Disability, p.6.

[90] *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.11.

[91] DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community*, p.18.

[92] *Submission S087*, Carers Victoria, p.1.

Yet for some parents of a son or daughter with disability, they can struggle at times to look to the future. This was identified in the 2000 study on aspirations:

> Parents of children with disability, in particular, can find the future too uncertain to contemplate. A child who can be relatively healthy one day, can be profoundly ill the next; sometimes additional disorders are diagnosed. Often parents are unsure about issues such as schooling, eligibility for assistance, work and future accommodation, all of which are counter to future planning. So, thinking about future aspirations invites thoughts about all of these doubts in their lives.[93]

In the words of one parent in the study—'it's too scary. You don't want to go there basically.'[94]

The study also revealed that for some parents a sense of practicality can lead them to consider the future of their child with disability. Often this will occur when parents become conscious they will not outlive their son or daughter and want to ensure they are secure in their living arrangements, support and financial security. For example, one older man with intellectual disability who participated in the research commented that:

> I lost my mum two years ago … She said, 'you realise that I am going to go before you … it's about time I put you in your own home'. In the meantime she taught me to cook and look after myself and how to approach people towards getting the SEC put on, Telstra and the gas … without my mum I wouldn't be as far advanced as I am.[95]

Friends can be equally important in influencing the goals and aspirations of people with disability. While very few commented on the role of friends and peers in this context, some participants did refer to the value in having friends in the lives of people with disability who might share similar aspirations. For example, Mr Bret Fishley expressed his personal view of the links between interest, aspirations and friendships:

> To be 'included' requires that you are known and valued for your contribution within your chosen community/s. As a result of your participation you will have friends and a valued role/s that match with your individual interests and aspirations. These communities are by their very nature defined by interest, not ability.[96]

For some people with disability, their peers with disability are particularly supportive and provide a valuable network for sharing and developing goals and aspirations. The importance of friendships and peer networks is often undervalued in our society but these networks can provide many benefits that might support aspirations and lead to greater social inclusion. Chapter 4 discusses the value these relationships provide in the context of social inclusion.

3.2.4.   Societal influences on aspirations

Inquiry participants emphasised the role of broader society in encouraging and supporting people with disability, like any other community member, to identify and pursue their aspirations. The Able Movement expressed its view that:

> While social inclusion is underpinned by the empowerment and participation of people with disability, it also involves a positive duty on the part of the society more broadly.

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[93]   DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community. Summary report*, p.20.

[94]   DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community. Summary report*, p.20.

[95]   DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community*, p.18.

[96]   *Submission S081*, Mr Bret Fishley, p.3.

> Unless promoting social inclusion is a key component of Victorian disability strategies there is a risk that people with disability will be 'participation ready' in a society which is not 'inclusion ready,' which will ultimately set them up for failure.[97]

Disability Employment Australia echoed the concerns of many Inquiry participants, stating that:

> It ought not be forgotten that for many people with disability and their families, their experiences have not been positive and their aspirations may well have been constrained by the lack of those positive opportunities.[98]

There are multiple factors in community life that can influence the individual aspirations of people with disability. These relate to community attitudes, accessibility, flow of information, costs and opportunities. These aspects of inclusion are discussed in depth in later chapters. But in the context of their influence on the aspirations of people with disability, it is important to consider some of these aspects here.

The 2000 study on aspirations emphasised the interconnections across communities and what people with disability might aspire to, stating that a:

> … major factor impinging on aspirations is society at large. Living in a society which is often seen to be inaccessible, exclusive and unaccepting of people with disability can have the effect of lowering aspirations and expectations.[99]

Warrnambool City Council identified this issue in its consultations with people with disability in its local council area:

> … many people with disability describe the debilitating impact of negative community attitudes on their sense of self worth and their feelings of connection and membership in communities.[100]

In its submission, the Victorian Council of Social Service (VCOSS) expressed a similar view when it explained the experience of many people with disability in their pursuit of their goals. It stated that 'too often, living in a society that routinely ignores, belittles and discriminates against people with disability has an effect on their outlook and aspirations.'[101] VCOSS went further to suggest that:

> People with disability often manage by reducing their expectations, lowering their aspirations to achieve in life, and give up complaining or speaking out against unfairness because they feel they are not heard and have little ability to create change.[102]

Lacking the opportunities to pursue goals and fulfil aspirations can disempower people with disability and result in lowered expectations and goals in life. Lack of encouragement from others to pursue their hopes and dreams can be equally disempowering. Marriott Support Services expressed the view that:

> We owe it to individuals with disability—and to their families and their friends—to ensure these aspirations are shared by all within a socially inclusive society.[103]

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[97]   *Submission S089*, The Able Movement, p.6.
[98]   *Transcript of Evidence*, Disability Employment Australia, Melbourne, 20 March 2014, p.4.
[99]   DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community. Summary report*, p.20.
[100]   *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.9.
[101]   *Submission S126*, Victorian Council of Social Service (VCOSS), p.20.
[102]   *Submission S126*, Victorian Council of Social Service (VCOSS), p.20.
[103]   *Submission S020*, Marriott Support Services, p.8.

Aspirations and accessible environments

Society has been designed to meet the needs of the 'able'. While increased understanding of disability has led to profound changes in how society approaches the rights of people with disability—such as access to the environment and services—there is a consensus that much remains to be done to encourage people with disability to pursue their aspirations and to be socially included.

In the 2000 study on aspirations, the day to day experiences of people with disability were emphasised:

> The world is ordered for the able and accessibility is an aspect of disability that possibly does not appear to impinge on the consciousness of most, the supposition perhaps being that such things are catered for in the normal course of events. The reality—according to study participants—is that virtually every aspect of their daily lives is limited by access constraints.[104]

A young woman with physical disability who participated in that study explained the implications of these barriers on her outlook:

> If you can't do something or go somewhere, you automatically start thinking 'well, should I be doing this?' It affects your self-esteem because it says society doesn't give a stuff about you.[105]

In its submission, the Summer Foundation emphasised similar points. One individual who contributed to the submission stated that 'you don't feel valued when you are unable to access' and another explained that 'when you find out you think this would be great to attend but then you have to think about how you would get there.'[106]

While there have been policy and legislative changes in the past 14 years that aim to improve accessibility, the Committee heard that the accessibility of environments continues to influence the choices, goals and decisions of people with disability. One individual who submitted to the Inquiry, Ms Raelene West, emphasised the importance of accessibility in enabling greater choice, and stated that 'having a fully accessible built environment provides full social inclusion, choice and empowerment for people with disability.'[107]

The Committee identified that having freedom of choice is critical in determining what people with disability might aspire to and in their pursuit of their hopes and goals. Chapter 7 discusses the accessibility of environments and how it contributes to choice in greater depth.

3.3. The journey—pursuing dreams and realising aspirations

The Committee identified that the journey of pursuing aspirations is often as important as the outcomes themselves. The journey provides an opportunity to learn and make connections with others, the freedom to make mistakes, the chance to reassess goals, and the faith that there is value in having aspirations.

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[104] DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community*, p.19.
[105] DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community. Summary report*, p.14.
[106] *Submission S121*, Summer Foundation Ltd, p.6.
[107] *Submission S010*, Ms Raelene West, p.3.

Having aspirations may contribute to meaning in life, but not having the opportunity to pursue those aspirations can result in them seeming meaningless. While succeeding in reaching goals often contributes to ongoing aspirations in life, failing to achieve goals pursued does not necessarily equate to the loss of aspiration.

Associate Professor Paul Ramcharan emphasised the value of the actual pursuit of aspirations in all our lives:

> What makes life meaningful is that we are pursuing our aims, dreams, wishes and aspirations, and we are struggling to do that by fulfilling the skills that are appropriate at that point in time for what we are doing. We do it with the skills development and we do it with the support we need, but we might not get there. People do not necessarily ever get there, but it is the journey that really counts. That is what makes life meaningful.[108]

Yet opportunities to pursue goals are not always available to all people with disability.

The Secretary of DHS, Ms Callister, acknowledged that the opportunities for achieving aspirations can be made more difficult for people with disability given that they:

> … are more likely to live in poverty. They are more likely to have fewer educational qualifications, to be unemployed and to experience discrimination and sometimes violence and abuse in their lives.[109]

Due to their circumstances, some people with disability may have dreams or aspirations but not have the opportunity to pursue these dreams. This can have consequences for their self–belief, their future aspirations and ultimately their opportunities to be included in the community. For example, in their submission employment providers SkillsPlus and BRACE explained that:

> While a great deal of work has been done to raise the aspirations of young people with disability and their families in areas such as inclusive careers planning, parent workshops and disability awareness training the concern is that a large number of students are not achieving their employment goals once they transition from programs aimed at preparation for employment. Students are often continuing to seek educational programs where available to remain engaged as they have no work opportunities.
>
> Around 45 per cent of people with disability in Australia live either near or below the poverty line (PWC 2011) and there has been no significant improvement in employment of people with disability in Australia in 30 years.[110]

Chapter 6 discusses the need to create opportunities for meaningful participation in greater depth.

3.3.1. Limitations on activities

While people with disability aspire to have meaningful work, relationships and recreational opportunities, the Committee heard that the activities they participate in often do not reflect their aspirations or the journey towards those goals. For some, the nature of support provided in disability services limits the activities they engage in. For others seeking to participate in mainstream culture, it might be due to inaccessible environments or a lack of social networks, assistive technology or communication aids.

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[108]   *Transcript of Evidence,* Associate Professor Paul Ramcharan, p.4.
[109]   *Transcript of Evidence,* Department of Human Services, p.2.
[110]   *Submission S042*, SkillsPlus and BRACE, p.5.

Some people with disability receive support from a disability service provider, and are generally reliant on their support worker or the service to support them to engage in activities. In evidence to the Inquiry, the CEO of Inclusion Melbourne, Mr Daniel Leighton, expressed his concern about the current model of disability services and its effects on the activities that people engage in:

> … the reality is that many of the funds we continue to provide to disability services to support people with disability to live, work and engage in their community continue, we believe, to be misdirected to support services that produce the exact opposite outcomes— that is, services that simply serve to promote activities for the purpose of promoting activity without recognising activity for the purpose of promoting relationships.[111]

The 2000 study on aspirations identified the importance of relationships for people with intellectual disability to create opportunities to pursue activities that interest them:

> … those with a sibling, friend or family member who takes an interest in their lives appear to enjoy greater opportunity in terms of socialisation and activities in the community at large.[112]

People with disability often aspire to participate in the general community with the same ease of access that other members of the community have. Belonging Matters explained that:

> When first coming into contact with Belonging Matters' Personalised Consultation Services, 61 people [out of 76 adults] were wanting to be more included in community life and activities e.g. work, study, recreation however 42 people were attending segregated settings e.g. ATSS day services, education or disability programs.[113]

In the context of young people, their aspirations and the activities they actually engage in, YACVic and YDAS told the Inquiry that:

> Most young people take for granted that they can access music, entertainment and spaces to be with their friends, but young people with disability face continued barriers of inaccessible premises and lack of reliable information or understanding at venues and events. This contributes to a very real problem of social segregation and isolation.[114]

The Manager of Policy and Projects at YACVic, Dr Jessie Mitchell, explained that young people with disability often just want 'to access mainstream services and activities and to just take part in their communities as young people in youth-friendly settings.'[115]

Yet the extent of barriers in the community can result in people with disability being limited to activities that do not always reflect their preferred options. The Victorian Aids and Equipment Action Alliance provided the results of a survey it conducted in partnership with Deakin University that identified levels of satisfaction with current activities people with disability engage in:

> Overall, participants were dissatisfied with their participation levels in more than a third (39 per cent) of their preferred life areas and activities, with some activities (5 per cent) evidencing complete restriction of participation.[116]

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[111] *Transcript of Evidence,* Inclusion Melbourne, p.3.
[112] DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community*, p.23.
[113] *Submission S030*, Belonging Matters, p.2.
[114] *Submission S021*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, p.21.
[115] *Transcript of Evidence*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, Melbourne, 20 March 2014, p.3.
[116] *Submission S011*, Victorian Aids and Equipment Action Alliance, pp.2–3.

Deaf Victoria similarly explained that people will often select the type of activities they engage in by the availability of communication aids:

> Socially people who are Deaf or hard of hearing will typically participate in activities that are not dependent on communication and avoid those that are… One example of a missed opportunity for Victoria is cinemas: at this point in time they are not accessible, so Deaf and hard of hearing people will not go.[117]

In her submission, Ms Shaunagh Stevens explained that she felt the nature of activities made available to her were limited, stating that:

> The so called social inclusion activities available to me through services in my area are group activities in a facility, such as making cards with people who are approximately 75+ years of age. I am in my early 50s and would much rather mix with people around my age and participate in activities such as going to the movies, out for coffee or to a show.[118]

Other participants referred to the limited experience of people in disability services. The Deputy Director of the Centre for Development Disability Health Victoria (CDDHV), Dr Rachael McDonald, explained that in disability services the focus is on 'enabling people to have access to activities that they want to do and that they are interested in doing.'[119] She went on to state:

> But if what you are doing is that there are five of you who hop on the bus every Thursday morning to go and see a movie, you are not engaging with other people — you are engaging with the people you are with on the bus, and the movie.[120]

VALID made a similar point, noting that people with intellectual disability 'become "community tourists", being driven around in groups and visiting shopping centres in order to get their artificial dose of "community inclusion".'[121]

Other participants emphasised that there are fewer opportunities to engage in activities that people with disability might choose to participate in. Cardinia Shire Council explained that:

> For adults not wanting to be part of day services or socialize with other people with disability, opportunities for social engagement can be severely limited as attitudinal barriers to inclusion remain significant in the wider community. There is also a lack of recreational and leisure options for people with disability on weekends and out of days service operating hours.[122]

MetroAccess South Division made a similar point and also told the Inquiry that there are often 'limited choice in regards to social and recreational activities which can be due to lack of funds, transport, accessibility of venues, support workers, lack of inclusive activities; schedules of personal care staff.'[123]

The Committee heard that the experiences of people with severe or profound disability are particularly limited. In its submission, the Summer Foundation explained that 'some people go out several times a week, every week, others go out once a month … the people who can't speak and can't move or communicate very easily, they're the ones who are more marginalised.'[124] Along the same

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117 *Submission S007*, Deaf Victoria Inc, p.2.
118 *Submission S090*, Ms Shaunagh Stevens, p.4.
119 *Transcript of Evidence*, Centre for Developmental Disability Health Victoria, Melbourne, 6 March 2014, p.7.
120 *Transcript of Evidence,* Centre for Developmental Disability Health Victoria, p.7.
121 *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.9.
122 *Submission S085*, Cardinia Shire Council, p.3.
123 *Submission S131*, MetroAccess South Division: Bayside Peninsula & Southern Melbourne, p.7.
124 *Submission S121*, Summer Foundation Ltd, p.4.

vein, a former worker in the disability sector, Mr Bret Fishley expressed his personal view that:

> Life is very different for people with disability though who as a rule generally find themselves socially isolated and segregated into groups that correspond to their disability rather than their interest.[125]

The 2000 study on aspirations found that many people with disability engage in home activities, such as listening to music, reading or watching television. It noted that while they may find enjoyment in such activities, they often aspire to do more activities in the community, socially and in paid employment.[126]

Box 3.4 outlines the experience of many people with disability on a daily basis when they try to engage in their community and pursue their aspirations.

Box 3.4: A day in the life of a person with disability

We have invested substantial financial and human resources building a world and society that meets the needs of the 'average' person. For the majority of people, their journey through each day is smooth, and as a result they face each day with confidence. For many people with disability, most days are anything but smooth. To offer just some examples:

- People with physical disability often struggle to find personal care support, to access public transport, to move around our physical environment.

- People with visual impairment are often prevented from participating fully in meetings and conferences because the written word has not been provided in alternative format, and they often find our physical environment to be difficult to navigate.

- People who are profoundly deaf are faced with the challenge of finding and paying for Auslan interpreters, without whose support they are likely to be excluded from community and workplace dialogues.

- People with intellectual disability are still living in institutional housing in significant numbers and working in segregated, low paid employment.

- And the often episodic nature of psychiatric disability often makes it difficult for people in this group to contribute in our highly structured world.

Many people with disability feel disempowered and, as a result, they consider the challenges they are likely to face are simply too great and lose the necessary confidence to decide to go out into the world every day.

Source: Adapted from *Submission S089*, The Able Movement, p.8.

Finding 3.7

The Committee found that people with disability in disability supported accommodation can experience limitations in their daily activities due to the attitudes and approaches of disability service providers. The provision of supports in disability accommodation will transition to the National Disability Insurance Scheme in 2019. The Victorian Government has a responsibility to ensure that people with disability in their care are afforded social inclusion opportunities during the transition to the National Disability Insurance Scheme.

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[125] *Submission S081*, Mr Bret Fishley, p.2.
[126] DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community*.

3.3.2. Dignity of risk

Many individuals and organisations told the Inquiry that part of aspiring to goals is having the opportunity to take the risks that this may involve. This is a central part of the journey and the pursuit of goals. Families and formal supports can sometimes put duty of care and protecting people with disability ahead of opportunities to pursue or achieve goals. The Committee heard that this aversion to risk is a particular concern in the context of the formal support system.

> **Dignity of risk**—*the right of people to choose to take some risk in engaging in life experiences.*

Recent research conducted in Victoria into high risk service environments and the management of risk found that:

> While community care has made many advances in response to the policy objectives of social inclusion and individualised service provision, risk management has continued to be driven by regulatory measures framed by procedures, check lists and the continuing further restriction of professional discretion and judgment.[127]

Evidence to the Inquiry reflected these research findings, with many participants making reference to a focus on risk management and duty of care at the expense of people with disability having opportunities to pursue their hopes and goals or engage in activities of their choice. Inclusion Melbourne expressed its view that many services have:

> … an excessive focus on duty of care that is not balanced with dignity of risk. We are not saying that duty of care should be lessened; we think that dignity of risk should be equal to that — both 100 per cent, if you like.[128]

In his evidence, Associate Professor Ramcharan also suggested that the risk model needs to be challenged in order for people with disability to pursue the goals they are seeking in life.[129] He stated that 'we need to create a dignity of risk. We need to create hope, we need to create resilience and we need to free people to be unencumbered by the formalities of the service system.'[130]

VALID told the Inquiry that many services need a change in their philosophical approach, noting that these services should not be about 'providing support for support's sake.'[131] VALID went on to emphasise 'that is where it goes wrong, when the support system actually thinks that it is the focus, that it is the end point, rather than that they are a stage along a person's journey.'[132]

The Able Movement made a similar point, stating that there needs to be a cultural shift with a move towards:

> A culture in which those who have previously felt that they need to protect people with disability—and that the best way to do that is to control aspects of their lives and to make decisions on their behalf—understand that they need to let go.[133]

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[127]   A.M. Sawyer & D. Green (2013) 'Social inclusion and individualised service provision in high risk community care: Balancing regulation, judgment and discretion'. *Social Policy & Society*, Vol. 12, No. 2 (299–308), p.306.
[128]   *Transcript of Evidence,* Inclusion Melbourne, p.4.
[129]   *Transcript of Evidence,* Associate Professor Paul Ramcharan, p.4.
[130]   *Transcript of Evidence,* Associate Professor Paul Ramcharan, p.5.
[131]   *Transcript of Evidence,* VALID (Victorian Advocacy League for Individuals with Disability Inc), p.5.
[132]   *Transcript of Evidence,* VALID (Victorian Advocacy League for Individuals with Disability Inc), p.5.
[133]   *Submission S089,* The Able Movement, p.8.

In its view, the way to work towards such a culture is through a 'holistic empowerment model, [in which] professionals will instead take on roles of teachers and mentors, rather than doers and managers.'[134]

Melba Support Services provided the Inquiry with an example of how its organisation is striving to be more flexible in helping people with disability to identify their aspirations and explore them:

> Cecilia was sitting at home saying, 'Sarina, I really would like to learn how to drive'. Rather than saying, 'Ce, your eyesight's not great and you're not going to be able to drive' we looked at how we could have this happen. In Kilsyth there is an off-road part where you can drive with a driving instructor who has dual-control. She got in and around she went. She got out and said, 'I can't do that! That was too hard'. Then about a month later she said, 'do you know what? I want to give that another try'. We said, 'okay then, give it another try'. And she did. She got out and said, 'you know what? as much as I think I can drive, I can't. I don't have good eyesight, and I'm too scared, and I would be dangerous to me and everyone else'.

The support worker, Sarina, asked Cecilia if the process was valuable in her decision not to learn to drive. Cecilia's response was that 'it's important to find out.'[135] The CEO of Melba Support Services, Mr Glenn Foard, explained that this process and approach 'is part of the dignity of risk.'[136]

Dignity of risk and decision making are interconnected. In circumstances where people with disability need support to consider their decisions or communicate their choices, several Inquiry participants emphasised the importance of supported decision making over substitute decision making. The Committee acknowledges that in 2012 the DHS released a guide on supported decision making. Box 3.5 explains the importance of decision making and having control over choices.

Box 3.5: Decision making and choice

We all make decisions based on the best information that is available to us. This includes advice and support from friends, partners, family members and other significant people in our lives as well as past experiences.

People with disability are no different in this regard. However some people may require some additional assistance in order to be able to make and express choices. Such assistance might include access to communication aids or translators, information in different formats, longer timeframes or different environments in which to make decisions.

Some people may require more specific support to make decisions, including reminders of previous decisions and more explanation of the implications of their decisions.

People with disability may also be excluded from decision making processes that affect them because others make incorrect assumptions they don't have capacity to understand issues or consequences, or others believe they know what is best for them.

Where assistance is required but not provided people with disability are not fully involved in decision making.

Source: Department of Human Services (2012) *Supported decision making. A guide to supporting people with a disability to make their own decisions.* Melbourne, DHS, p.2.

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[134]   *Submission S089*, The Able Movement, p.11.
[135]   *Transcript of Evidence*, Melba Support Services Inc, Melbourne, 26 May 2014, p.9.
[136]   *Transcript of Evidence,* Melba Support Services Inc, p.9.

The DHS Guide on supported decision making contains seven principles:

- everyone has the right to make decisions about the things that affect them

- capacity to make decisions must be assumed

- every effort should be made to support people to make their decisions

- capacity is decision specific

- people have the right to learn from experience

- people have the right to change their minds

- people have the right to make decisions other people might not agree with.[137]

Parents and dignity of risk

It is not only services that struggle with risk. For very different reasons, parents of people with disability can find it difficult to get the right balance between protecting their child (even as an adult) while also providing them with the greatest opportunities in life. In some respects this is a challenge faced by most parents. But for parents of a family member with disability the considerations are often more complex.

VALID explained what it hears from parents of a person with disability:

> … as much as they might wish for their sons and daughters to be included in the community, their experiences of discrimination, bullying, exploitation and abuse often causes them to err on the side of exclusion, in order to 'keep them safe'.[138]

It explained that 'given the choice between inclusion and security – and that is exactly how it is often perceived – most parents will understandably opt for the latter.'[139]

Dr Jane Tracy, the Director of CDDHV, provided her perspective regarding the challenges parents face:

> I am the parent of a young man with intellectual and multiple disabilities so I understand the perspective of parents very well. When our children without disabilities grow up, they help us to grow up as parents too by pushing us away a bit as they grow through their teenage years—'back off, Mum or Dad. I am on my way here'. People with intellectual disabilities are not able to do that to the same extent and so parents, as well as people with disability, need a bit of help with that.[140]

YACVic and YDAS informed the Inquiry that the consequence of this challenge for parents is that:

> A lot of advocacy concerning children with disability also tends to be parent-led. Here, the approaches and environments can feel disempowering and inappropriate for young people, who wish to be included as active decision-makers in their own right.[141]

The Committee heard that the protective tendencies of parents can result in people with disability not having the opportunity to pursue their goals and

137 Department of Human Services (2012) *Supporting decision making. A guide to supporting people with a disability to make their own decisions*. Melbourne, DHS, p.28.
138 *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.11.
139 *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.11.
140 *Transcript of Evidence,* Centre for Developmental Disability Health Victoria, p.4.
141 *Submission S021*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, p.6.

aspirations. Jane contributed her experience to the Women with Disabilities Victoria (WDV) submission:

> Even now as a mature woman, my parents still exert control over my life… I feel it is time for me to move out and break away from their stranglehold. If I could find employment then I could gain the income I need to rent and live an independent life.[142]

Anj, an Ambassador for the Summer Foundation, explained her sense of empowerment when she secured employment and felt greater freedom from her parents, stating that in her job pursuits she felt 'helped by the fact my parents are backing out of the picture.'[143]

Dr Tracy explained that there needs to be greater awareness of the challenges that parents often experience during this process of transition from childhood to adulthood:

> Both health professionals and disability support staff need to be aware of the difficulty that parents have in making that transition from being a protective parent whose job it is to nurture and protect our children to having a shift in our relationship to see our children with disability — our sons and daughters with disability — as adults.[144]

Finding 3.8

In pursuing aspirations, the journey is central to the experience (regardless of whether the goal is achieved) and, like others in the community, people with disability want dignity of risk and to drive their own decision making. For many people with disability, the journey is more challenging than for other community members and the activities they engage and participate in do not always reflect their broader aspirations.

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142 *Submission S051*, Women with Disabilities Victoria, p.17.
143 *Submission S121*, Summer Foundation Ltd, p.11.
144 *Transcript of Evidence,* Centre for Developmental Disability Health Victoria, p.4.

Chapter 4
Social connections and natural networks

4-2

AT A GLANCE

Background

Social connections contribute to a sense of belonging in the community and can provide advantages such as improved health, social and economic outcomes which are known as 'social capital'. They vary and can include close bonding relationships such as family and friends, networks of more distant relationships and links to those in positions of authority in the community.

Key findings

- Social capital produced through relationships and networks is central to increasing social inclusion for people with disability. **(Finding 4.1)**

- Like all members of the community, people with disability can experience difficulties in either establishing or maintaining relationships for a multitude of reasons, yet people with disability often experience less connectedness than others in the community. The majority of research about sustaining relationships relates to people with intellectual disability and demonstrates that they often have few social connections and small networks. **(Finding 4.2)**

- There is a common perception that people with disability do not have sexuality and that they do not, or should not, have children. **(Finding 4.3)**

- People with disability are more exposed to bullying, hostility and abuse than others in the community. **(Finding 4.4)**

- People with disability need to exercise choice and control over the level and nature of their involvement in relationships and social connections across the community. **(Finding 4.5)**

- There is a strong rationale for governments and non-government organisations to increase opportunities and create favourable conditions for people with disability to establish and maintain social connections and build social capital. **(Finding 4.6)**

- While it is essential that relationships and social connections are 'natural', there are approaches that can be pursued to increase opportunities and create favourable conditions for relationships and networks to develop naturally and build social capital. **(Finding 4.7)**

Recommendation

That when developing its next State Disability Plan in 2016 and in consultation with people with disability, the Victorian Government incorporate a strategy for effectively and appropriately strengthening connections and social capital with three objectives:

- create opportunities for establishing and maintaining connections and networks—such as new networks and building the capacity of people with disability who need support

- establish favourable conditions for sustainable relationships and networks—such as social 'brokerage' (mentors, coaches) and good public infrastructure

- support existing opportunities and networks—such as existing programs that aim to provide opportunities for increased social interaction.

For most people in the community, relationships and social networks are integral to their sense of belonging, feelings of inclusion and general emotional wellbeing. Social connections can lead to other benefits, such as access to resources, services and opportunities to participate. They have the potential to contribute to positive economic, social and health outcomes—also known as social capital.

There are different types of relationships and connections that can contribute to these benefits. They might be:

- close bonds, such as intimate partners, family and friends

- distant connections across the community, such as work colleagues, neighbours, or professional service providers

- ties to people in positions of power and authority, such as a local council member or a police officer

- formed through networks, groups or online forums.

Relationships and social connections are reciprocal, dynamic and changing. They often evolve over time as people transition through different stages of their lives and forge new links or experience the weakening of pre-existing ties.

Like all members of the community, people with disability can experience difficulties in either establishing or maintaining relationships and social connections for a multitude of reasons. For people with disability, however, there can be additional challenges in nurturing their connections, which can relate to accessibility of the environment, assistive technology requirements or the need for support to build social skills.

In view of the potential benefits that flow from social connections, the Committee determined there is a strong case for creating and supporting conditions that increase opportunities for people with disability to develop sustainable relationships and networks in their communities.

4.1.   Connections and social inclusion

Social connections are central to experiences of inclusion. The sense of belonging that can result from forming relationships with other people reduces feelings of loneliness, isolation and disconnectedness. Social inclusion involves linkages with existing networks and the broader community. Without such links, people with disability are more likely to be socially excluded.

Many Inquiry participants pointed to links between social inclusion and connection with others. The Darebin Disability Advisory Committee explained the importance of relationships in this context:

> Social inclusion goes beyond mere participation. It is concerned with the connections and relationships that people form that makes for a more meaningful, rich and complex experience.[1]

The Committee determined that it is not enough to simply be present or to engage in activities. To achieve social inclusion people with disability need to

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[1]   *Submission S041*, Darebin Disability Advisory Committee, p.3.

feel connected, valued and respected when they access the community, participate in activities and events, or contribute their skills, talents and knowledge. It does not necessarily follow that through participation people with disability will feel socially included by fellow students, colleagues, team members or others in the community.[2] For example, someone may participate in the workforce when they secure employment, yet feel excluded or disconnected in their workplace. Ms Heather Forsythe explained her experience:

> I was a shy person. I was not included in a lot of things that I wanted to do with my old work, but when I started working for VALID, VALID included me in everything we do at VALID. I am not just a person with intellectual disability at VALID; I am part of the VALID team.[3]

Research validates these views. In an extensive review of evidence exploring social networks and supports, one research study identified that participating in activities does not automatically lead to feelings of belonging:

> Physical presence within the community does not guarantee greater social inclusion. Moreover, facilitating people to simply participate in community-based activities does not necessarily lead to meaningful social contact with others.[4]

Box 4.1 provides some examples of the many statements Inquiry participants made about the links between social connectedness and social inclusion.

Box 4.1: Inquiry evidence—relationships and social inclusion

- Social Inclusion is about connectedness and a sense of belonging—opportunity to build informal networks—positive relationships (acquaintance, peer, friend). (*Submission S018,* Ms Valerie Johnstone, p.1)

- Social inclusion is characterised by meaningful contribution, connections and relationships with the community. (*Submission S109,* Life without Barriers, p.2)

- True social inclusion is experienced through the relationships and connections with others. (*Submission S049,* Office of Disability Services Commissioner, p.11)

- It is more than just participating in activities; it's about relationships, having natural support systems. (*Submission S132,* Mornington Peninsula Shire, p.3)

- Social inclusion enhances relationships with a range of people, including those with and without disabilities, and means that people are well known, part of their neighbourhood and valued. This can be assisted by a focus on sharing common interests (e.g. sport, music, art) rather than focusing on disability types or disadvantage as a point of connection. Joining community is then based on interest and not a label. (*Submission S030,* Belonging Matters, p.1)

- Social and community influences such as social support networks, high quality relationships, feelings of attachment and having a perceived sense of control over ones life, are very important factors in ensuring inclusive societies, which offer both protective and preventative benefits. (*Submission S056*, Inclusion Melbourne, p.10)

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[2] Policy Research Initiative (2005) *Social capital as a public policy tool. Project report.* Government of Canada, p.25.
[3] *Transcript of Evidence*, VALID (Victorian Advocacy League for Individuals with Disability Inc), Melbourne, 3 March 2014, p.3.
[4] C. Duggan & C. Linehan (2013) 'The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature'. *British Journal of Learning Disabilities*, Vol. 41, No. 3 (199–207), p.204.

Box 4.1: Inquiry evidence—relationships and social inclusion

- For people with intellectual disabilities, like everyone else, being 'included' is fundamentally about relationships—with families, friends and community. (*Submission S059*, VALID, p.10)

- At a personal level when people are fully included in the community the experience can be deeply engaging and enable people to feel a strong sense of connection and belonging with others who share their interests. (Warrnambool City Council, *Submission S067*, p.5)

- Relationships, partnerships and local responses relevant to the local context are seen as the most effective way to increase social inclusion in the Mansfield area. (Mansfield Shire Council, *Submission S057*, p.6)

- Social inclusion is about connection… It is the opportunity to connect with family, friends and the local community and in doing that feel belonging. It is the difference between participation and what I would call genuine participation. (Karingal, *Transcript of evidence*, p.3)

Inquiry participants emphasised that emotional wellbeing is one of the key personal benefits resulting from social connectedness. Inclusion Melbourne explained that 'we know that when people are connected to social networks they are generally happier, healthier and better able to adjust to life's ups and downs.'[5] This view is supported by research evidence. For example, in a study on friendship and mental illness, Dr Ann Montclaire stated that 'it is well established that friendship has a positive effect on health and wellbeing across the general population.'[6] Similarly a research study in Canada referred to the psychological benefits of relationships alongside other advantages of social networks:

> People and groups with extensive social connections linking them to people with diverse resources tend to be more hired, housed, healthy, and happy.[7]

Most people in the community want to feel valued by others. People with disability are no different in their desire to feel valued and respected in the community. In her submission, Dr Christine Baxter explained that 'contributing and being valued in social relationships' is an important component of social inclusion and that through supportive relationships there is the opportunity to 'gain information and skills to have a more satisfying life'.[8] For example, Aaron explained the benefits he has experienced through working in a supportive environment:

> With the extent of my brain injury, I experience challenges every day. I've been lucky to have had really supportive colleagues and supervisors. I've found my current role to be a huge challenge (because it is more of a solo role), so if I miss something, there isn't as much back-up.

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[5] *Transcript of Evidence*, Inclusion Melbourne, Melbourne, 20 March 2014, p.2.
[6] A. Montclaire (2011) *Friendship really matters: Exploring effects of Compeer friendships for people experiencing mental illness*. Box Hill, Victoria, St Vincent de Paul Society, p.2.
[7] Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, p.1.
[8] *Submission S093*, Dr Christine Baxter, p.2.

> But management have been great in identifying that it'll take me a little longer to work it out and have been supportive, and also providing training in areas that will help me get on top of things.[9]

Carers Victoria made a similar point, stating that for people to live a 'good life' they need a:

> … sense of connection and relationships with others. This is necessary for a sense of belonging, both in relation to other people (friends, family, workmates and so on) and society more broadly.[10]

Extended Families Australia also told the Inquiry that it considers that for people with disability 'to be authentically included is to be genuinely valued and connected with others and have a role and contribution to make.'[11] Central to this is ensuring that people with disability drive their relationships, regardless of any support they may require.

4.2.   Social capital and natural networks

At the very least, meaningful relationships with others contributes to emotional wellbeing and a more satisfying life. Connections can also have flow on benefits such as opportunities to form new relationships and to participate in new activities. These benefits are described as 'social capital'. Social capital is not a new concept, but provides a useful perspective for considering the social inclusion of people with disability.

In its report recommending the introduction of the National Disability Insurance Scheme (NDIS)—*Disability care and support*—the Productivity Commission highlighted the need to 'stimulate social capital' by strengthening voluntary links between the community and people with disability.[13]

> **Social capital**—*Social capital relates to the social norms, networks and trust that facilitate cooperation within or between groups. It can generate benefits to the whole community by reducing transaction costs, promoting cooperative behaviour, diffusing knowledge and innovations, and through enhancements to personal wellbeing and associated spillovers.*[12]

Several participants suggested to the Inquiry that social capital can help to understand the value of social connections and how they contribute to social inclusion. For example, Inclusion Melbourne expressed its view that 'relationships are a necessary precondition to long-term success both for the individual and also for the communities around that person.'[14] More specifically, Carers Victoria explained the benefits that flow from social networks:

> … social interaction not only contributes to emotional well-being but is an important source of social capital, the resources, opportunities and influence that flow from social engagement.[15]

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[9]   *Submission S111*, Melbourne City Mission, p.11.
[10]   *Submission S087*, Carers Victoria, p.5.
[11]   *Submission S063*, Extended Families Australia, p.3. See also *Submission S093*, Dr Christine Baxter, p.2.
[12]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*. Canberra, Commonwealth of Australia, p.207.
[13]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.13.
[14]   *Transcript of Evidence,* Inclusion Melbourne, p.2.
[15]   *Submission S087*, Carers Victoria, p.7.

Associate Professor Paul Ramcharan from RMIT University also emphasised that social capital is about 'building social networks of support that will outlast and outlive the present people in those persons' lives.'[16]

Karingal also emphasised the importance of social capital in the context of the rollout of the NDIS—which it described as an 'individual transaction'. Given the nature of the NDIS, it stated that 'we need social inclusion and social capital for capacity building still to be there … we need to make sure that people's individual packages can be taken to the community and there will be support in the community.'[17] Karingal went on to emphasise that:

> If we do not have those efforts to build social capital, and there is not that happening across the community, NDIS will never achieve what it is intended to. If we really want independence and a reduction in reliance on paid supports over time, that means we have to build those supports in community.[18]

In 2005, the Policy Research Initiative in Canada undertook a study into social capital and its relevance as a policy tool. It identified that 'social networks (formal and informal) can bring many advantages' and that 'the value of social capital depends on the value of the flow of benefits that can be drawn from an activation of these networks.'[20]

> **Natural networks**—*refers to real world links between groups or individuals, such as networks of friends, family networks or networks of former colleagues.*[19]

The nature of the benefits that social capital can produce is wide and varied, such as:

- material goods and services—source of informal support such as child care, language training or housing

- information—networks informally share information that might otherwise not be easily available

- reduced transaction costs—groups or organisations may spend less time finding new business or other contacts if social ties can act as intermediaries

- emotional support—sharing of experiences can lead to informal support that would not otherwise be readily available

- reinforcement of positive behaviours—friends and family can influence healthy eating, exercise, or other good habits

- service brokerage—access to health, employment or training services for those who might be unable or unwilling to access services on their own.[21]

The Policy Research Initiative concluded that 'adopting a social capital perspective emphasises the importance of paying attention to the value, usefulness, and dynamics of social ties.'[22] Figure 4.1 provides an overview of the

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[16] *Transcript of Evidence*, Associate Professor Paul Ramcharan, Centre for Applied Social Research, RMIT University, Melbourne, 3 March 2014, p.9.
[17] *Transcript of Evidence*, Karingal, Melbourne, 26 May 2014, p.7.
[18] *Transcript of Evidence,* Karingal, pp.7–8.
[19] Organisation for Economic Co-operation and Development (OECD) (2007) *OECD Insights: Human capital. How what you know shapes your life.* Paris, OECD, p.103.
[20] Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, p.9.
[21] Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, pp.9–10.
[22] Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, p.2.

framework the Initiative developed to analyse social capital, highlighting the multiple dynamics and potential outcomes.

A research study that focused specifically on social capital and disability concluded that 'social capital approaches' can enhance strategies to increase social inclusion, particularly in view of their goal to 'seek to build the capacity of people with disability themselves to form relationships and support networks.'[23]

Figure 4.1: Framework for understanding social capital
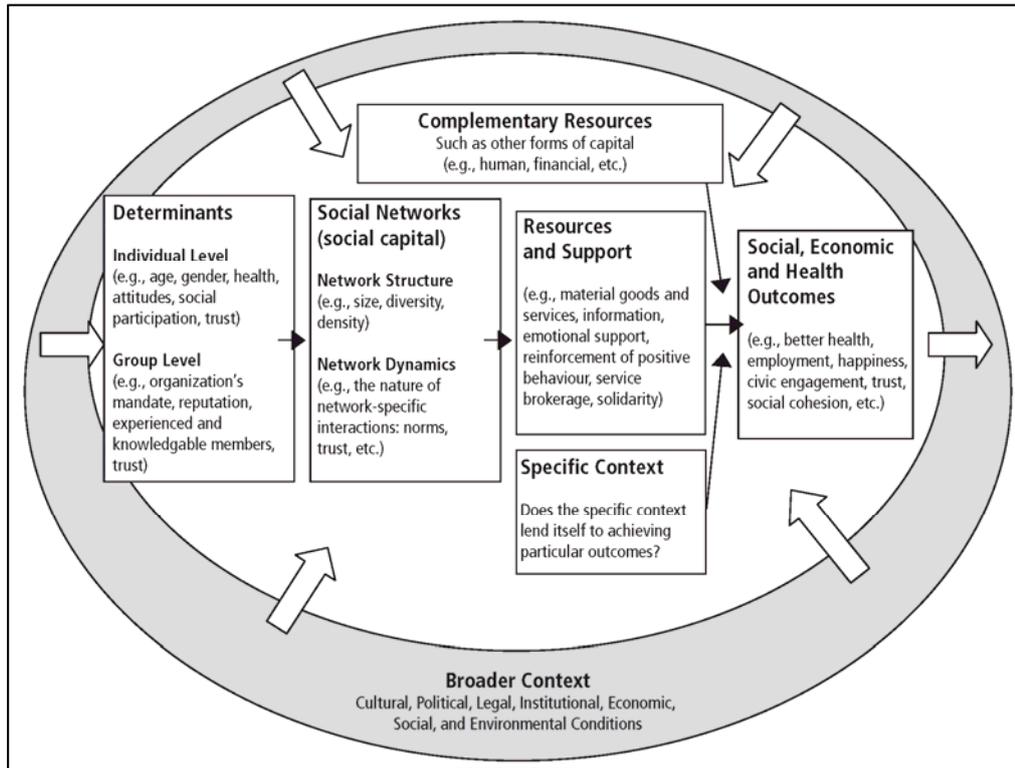
Source: Policy Research Initiative (2005). *Social capital as a public policy tool*. Project report, Government of Canada, p.6.

4.2.1. Different types of social capital

Relationships and social connections can take many forms and lead to different types of benefits. They might be close bonds, such as intimate partners, family and friends. They might be connections more broadly across the community. Some people may create ties with people in positions of power and authority, such as a local council member or a police officer. Other connections include networks, groups and online forums.

The World Bank has adopted the concept of social capital in its work and explains how relationships and social networks vary:

> There are different forms of social capital. It can be a tie among family members, with neighbors, ties from shared experience, cultural norms, common purposes and pursuits. Social capital can have a group base, a network base or an institutional base. An extended

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[23] C. Duggan & C. Linehan (2013) *The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature*, p.205.

> family network, a clan, a tribe, a farmers' group, community-based groups in a traditional sense; and a book club, a youth club, NGOs, internet forums, social networking sites, in the modern sense. Membership in a political party or even citizenship of a state can qualify as a social capital.[24]

Different types of social relationships may be useful for different purposes, and also provide varying forms of benefits. Academic literature and reports that discuss the concept of social capital have identified these different forms of social capital as 'bonds', 'bridges' and 'linkages'. That is:

- Bonds—links to people based on a sense of common identity ('people like us'), such as family, close friends and people who share our culture or ethnicity.

- Bridges—links that stretch beyond a shared sense of identity, for example to distant friends, colleagues and associates.

- Linkages—links to people or groups further up or lower down the social ladder.[25]

Social capital is not confined to individuals, groups can also acquire the assets associated with valuable social networks. For example, Warrnambool City Council made reference to the:

> … premise that strong partnerships and collaboration between people with disability, local government, community organisations and disability support services are critical to expanding the terms of community membership available to people with disability and opening up opportunities for them to participate in all aspects of community life.[26]

Finding 4.1

Social capital produced through relationships and networks is central to increasing social inclusion for people with disability.

4.3.   Experiences of connectedness

The Committee heard that the level of connectedness that people with disability experience is often far from what they aspire to achieve in their life. As with all people in the community, people with disability can feel disconnected and excluded, leading to feelings of loneliness and isolation. These experiences can change through the course of a person's life, with friendships and social networks growing at times and waning at others.

Inquiry participants considered that many people with disability do not have the extent of relationships and networks to possess social capital. The City of Boroondara made the point to the Inquiry that in its community consultations people with disability express that maintaining social connections is frequently difficult:

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[24]   S. Panth (2010) *Bonding vs. bridging.* People, Spaces, Deliberation, The World Bank. Accessed on 11 July 2014 from http://blogs.worldbank.org/publicsphere/bonding-and-bridging.

[25]   Organisation for Economic Co-operation and Development (OECD) (2007) *OECD Insights: Human capital. How what you know shapes your life*, p.103. See also Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, pp.11–12; P. Bates & F. Davis (2004) 'Social capital, social inclusion and services for people with learning disabilities'. *Disability & Society*, Vol. 19, No. 3 (195–207), p.199.

[26]   *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.1.

> … people communicated the challenges faced in staying informed and connected with other families, carers and the wider community. Without these social support links, people with disability are more likely to be socially excluded from current community and disability initiatives.[27]

SkillsPlus and BRACE emphasised that the consequence is that 'social capital for people with disability is very limited.'[28]

The Committee heard that people within the disability service system in particular have fewer connections and experience greater levels of loneliness. Inclusion Melbourne explained to the Inquiry that:

> … many people who receive funded supports are profoundly lonely. Most of the disadvantage that they experience perhaps comes not as a result of their disability but as a result of their isolation.[29]

The Australian Community Support Organisation (ACSO) also suggested that people with intellectual disability in particular have few social connections:

> People with an ID, whether they have a history of institutionalisation or not, typically have small and highly restricted social networks characterised by interactions with co-residents or co-participants in day programs, immediate family members, and service workers who are paid to support them.[30]

The majority of research relating to social networks and disability focuses on people with intellectual disability and the evidence confirms the view of Inquiry participants. On the whole 'the evidence base indicates that people with intellectual disability tend to have small social networks typically comprising paid caregivers, family members and other people with intellectual disability.'[31]

For example, a longitudinal study undertaken in 2006 explored the relationships of people with disability who had lived in institutions over a 12 year period following their move into the community. It identified a:

> … lack of, and need for, friendship, especially during evenings and weekends, seems most notable in the lives of many people with intellectual disabilities living independently or with family in the community; friendship seems to be the least successful aspect of resettlement.[32]

It is not just people with intellectual disability whose relationships and connections are narrow or limited. Research evidence reveals that in comparison with the general community, on the whole, the social networks of people with other forms of disability are smaller:

> The social networks of those who have disabilities other than intellectual are generally deemed poorer than the general population, with social activities being more likely to occur in public rather than private places.[33]

The researchers explain that people with disability other than intellectual disability experience different types of barriers from those experienced by people with intellectual disability:

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27   *Submission S048*, City of Boroondara, p.10.
28   *Submission S042*, SkillsPlus and BRACE, p.3.
29   *Transcript of Evidence,* Inclusion Melbourne, p.2.
30   *Submission S050*, Australian Community Support Organisation (ACSO), p.4.
31   C. Duggan & C. Linehan (2013) *The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature*, p.201.
32   R. Forrester-Jones, J. Carpenter, P. Coolen-Schrijner et al. (2006) 'The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals'. *Journal of Applied Research in Intellectual Disabilities*, Vol. 19, No. 4 (285–95), p.286.
33   C. Duggan & C. Linehan (2013) *The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature*, p.203.

> While the composition of these networks is more likely to be dominated by friendships when compared with the social networks of individuals with intellectual disability, challenges in forming friendships exist with rurality, transport and fewer social occasions being identified as barriers.[34]

In 2012, Scope (Vic) conducted its *1 in 4 poll on social inclusion* and identified similar experiences to those expressed by Inquiry participants and the research evidence outlined above. Box 4.2 outlines its key findings about relationships, social networks and participation levels.

Box 4.2: *1 in 4 poll on social inclusion*—relationships and participation

Looking at specific elements of social inclusion at a national level, the survey found that people with disability said their needs were fully met in the following contexts:

- 9 per cent—social contact

- 6 per cent—community participation

- 10 per cent—feel valued and belong

- 10 per cent—access to services.

People with disability said their needs were not fully met in the following contexts:

- 89 per cent—having a social life

- 89 per cent—going out to cafes, bars and pubs

- 87 per cent—getting support in times of crisis

- 88 per cent—accessing mental health services

- 86 per cent—accessing disability support services.

Source: Adapted from *Submission S129*, Scope (Vic), p.14.

The Committee noted that the Scope *1 in 4 poll on social inclusion* makes no comparison with how other members in the general community feel their needs are being met in the context of relationships and participation.

The Australian Bureau of Statistics (ABS) also measures the involvement of people with disability in a range of social, community and civic activities within and away from their home. As outlined in Chapter 1 this includes interaction with family and friends, attendance at cultural and sporting events, and participation in special interest groups. While it does not compare this with the general population, it does demonstrate how there have been changes over time:

> We have seen an increase in participation in social activities over the last 10 years with people with disability more likely to be visiting family and friends.[35]

The Regional Director of the ABS, Ms Judy Henson, explained that 'the 2012 survey also showed that in terms of social or community participation at home, people with disability were most likely to have contact with family and friends, regardless of whether this was through visits, which was up around 90 per cent, or talking to them on the phone, which was at 91 per cent.'[36] She went on to state that:

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[34] C. Duggan & C. Linehan (2013) *The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature*, p.203.

[35] *Transcript of Evidence*, Australian Bureau of Statistics, Melbourne, 17 March 2014, p.4.

[36] *Transcript of Evidence,* Australian Bureau of Statistics, p.4.

Visiting family and friends was also the most common type of social activity away from home for people with disability, and many — 66 per cent — had also gone to a restaurant or club in the last six months.[37]

Finding 4.2

Like all members of the community, people with disability can experience difficulties in either establishing or maintaining relationships for a multitude of reasons, yet people with disability often experience less connectedness than others in the community. The majority of research about sustaining relationships relates to people with intellectual disability and demonstrates that they often have few social connections and small networks.

4.3.1.   Family and friends

Family and close friends often provide a sense of belonging and connection for people with disability. They can also often provide emotional and other forms of support. In many circumstances, family and friends can be key facilitators of social capital for all people in the community.

The value of bonding networks such as family and friends are well known and a number of Inquiry participants emphasised their importance to people with disability. For example, Uniting Church Synod of Victoria and Tasmania (the Uniting Church) made reference to their enabling qualities on social inclusion:

> Family and friends are important gateways to social participation and belonging. Friendship networks in particular are worthy of further investigation as an enabler of social inclusion.[38]

In her submission to the Inquiry, Mrs Delia Fisher agreed with the value that bonding relationships provide, stating that 'it is people and families with disability who drive social inclusion.'[39]

Some participants emphasised that emotional and practical support is a key benefit of positive relationships with family and friends. For example, the Victorian Advocacy League for Individuals with Disability (VALID) stated that 'families are the most effective and powerful source of support for the inclusion of people with intellectual disability.'[40] Northern Support Services explained that benefits of relationships with good friends might include 'having a friend to drop in and visit, someone to have a coffee with, someone to look after their pet if they went away or someone to leave a spare key with.'[41]

In its submission, the Disability Services Commissioner suggested that family and friends can also provide important protections for people with disability:

> … social inclusion, and in particular the existence of close relationships with family and friends, is an important safeguard for people who may otherwise be vulnerable as a result of the support needs arising from their disability.[42]

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[37]   *Transcript of Evidence,* Australian Bureau of Statistics, p.4.
[38]   *Submission S009*, Uniting Church Synod of Victoria and Tasmania. Appendix 1, p.34.
[39]   *Submission S008*, Mrs Delia Fisher, p.1.
[40]   *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.4.
[41]   *Submission S123*, Northern Support Service's My Place-KeyRing Program, p.5.
[42]   *Submission S049*, Victorian Disability Services Commissioner, p.8.

But while often positive, these relationships can also experience strains. Breakdowns in family relationships and the loss of friends can lead to feelings of isolation, loss and further exclusion for people with disability.

The Committee heard that for many people with disability developing friendships has been challenging since childhood. In its submission, Ablelink explained that 'for many people with disability, mainstream school was a lonely experience with very few friendships formed.'[43] It also explained that:

> Deafblind people living in Victoria live in profound isolation and can only relate one-on-one. Social interaction is minimal or non-existent for many. They rely heavily on family and carers for their interactions and they usually require interpreters and mobility guides for their activities in the community.[44]

For other people their social networks narrowed when they acquired their disability. These changes can occur as a consequence of attitudes towards disability held by friends or new challenges, such as accessibility and difficulties moving through the community. Inability Possability explained how connections can narrow for people with an acquired brain injury (ABI):

> Due to the confronting nature of ABI, most friendship groups reduce or disappear after injury. An inappropriate living environment is a further hindrance for young people with an ABI to maintain and develop their social connections. Social interaction is vital for any person, and especially so for the rehabilitation of a young person after their brain injury.[45]

Shaunagh, a woman who acquired a disability, explained to Women with Disabilities Victoria that:

> My social life used to be visiting friends and family. Now (with disability) I'm isolated and alone. Homes aren't universally designed. If I want to see people they have to come to me. Public buildings are a bit more accessible. But homes are where a lot of socialising happens.[46]

Acquired disability can lead to the loss of previously held relationship skills and contribute to relationship breakdowns over time if appropriate support is not provided. Box 4.3 outlines the experience of Brendan who experienced two strokes resulting in an ABI which affected his capacity to maintain relationships and had damaging consequences for his family.

Box 4.3: Family breakdown—Brendan's experience

Social inclusion—it wasn't around ten years ago. Now we've got the NDIS, but back then, unless you [acquired your brain injury] in a car accident, they didn't care about you.

You have a lot of behavioural issues after a stroke. Did I have access to any support? No. I got divorced. I've got two kids I no longer speak to. I have the ability to see things [more clearly] now, but it's taken me a long time. For me, social inclusion is having access to experts that can give you advice on what happens to you after you have a brain injury.

When I was at rehab, there was no follow-up on how I was going socially. I wouldn't have minded walking with a permanent limp if I still had my family. Social work support is needed after a brain injury [to prevent relationship breakdown and social isolation].

Source: *Submission S111*, Melbourne City Mission, p.7.

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[43] *Submission S033*, Ablelink, p.2.
[44] *Submission S033*, Ablelink, pp.1–2.
[45] *Submission S098*, Inability Possability, p.4.
[46] *Submission S051*, Women with Disabilities Victoria, p.7.

Informal carers

In their role as informal carers, many parents or family members provide a vast range of supports to their son, daughter, parent, sibling or other family member with disability. In addition to often providing a gateway to social interactions and participation in society, informal carers frequently support people with disability in their personal care, daily living activities, obtaining information, financial support and/or physically moving around the community. Most informal carers willingly assume this role.

While family carers are often vital to the lives of people with disability, the Committee heard that without adequate support and opportunities to take a break from their caring roles, carers can inadvertently have a negative effect on the social connections of people with disability. For example, VALID explained to the Inquiry that:

> The most important support team for people with, particularly intellectual, disability is their family, but often families themselves are so burdened with the stresses and strains of caring and trying to navigate the service system and all of that that it becomes very difficult for them to be ambitious for their sons and daughters …[47]

The organisation went on to explain that 'without … support families are often left to become disillusioned and overwhelmed'.[48]

Evidence to the Inquiry indicated that due to the demands of caring, informal carers can:

- find it difficult to work and can become financially disadvantaged[49]

- become socially isolated from friends and networks[50]

- experience poor health and wellbeing.[51]

The Committee heard that the diverse experiences of informal carers can add a further layer of complexity to their disadvantage in caring roles. For example, Carers Victoria informed the Inquiry that there are unique circumstances for young people under the age of 25 years in caring roles. In a 2013 research paper titled *Unfinished business*, it identified that young carers also experience difficulties sustaining employment and impacts on their social lives and recreational opportunities due to limited time and low incomes. In addition to these issues they also often experience difficulties participating in education.[52]

In 2010, the Ethnic Communities' Council of Victoria (ECCV) also drew attention to its findings that:

> Young people from refugee or migrant backgrounds are more likely to have caring responsibilities. However, services often struggle to identify these young people as carers and provide appropriate support.[53]

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[47] *Transcript of Evidence,* VALID (Victorian Advocacy League for Individuals with Disability Inc), p.3.

[48] *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.12.

[49] *Submission S087*, Carers Victoria, p.8; *Submission S037*, Whittlesea Disability Network, p.4.

[50] *Submission S101*, Occupational Therapy Australia, p.14; *Submission S125*, Mr Matthew Potocnik, p.2; *Submission S122*, Association for Children with a Disability, p.3.

[51] *Submission S087*, Carers Victoria, p.6; *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.9.

[52] Carers Victoria (2013) *Unfinished business: Public policy and children in families with a person with a disability or mental illness. A discussion paper.* Footscray, Carers Victoria, p.13.

[53] Ethnic Communities' Council of Victoria Inc, Centre for Multicultural Youth, & Carers Victoria (2010) *Who cares? Refugee and migrant young people with caring responsibilities. Background paper.* ECCV. Accessed on 27 August

In addition, carers in culturally and linguistically diverse communities (CALD) can experience additional challenges due to cultural expectations about caring roles and not being aware that they can access benefits, services, supports or respite.[54] ECCV told the Inquiry carers in CALD communities 'are four times less likely to gain access to accommodation support services, two and a half times less likely to be the recipient of community support and access services, three times less likely to access respite services.'[55] It explained that:

> Most people from culturally diverse backgrounds originate from countries where disability care and support systems are not as developed and complex as those in Australia. Therefore, the responsibility of caring for a person with disability invariably passes to immediate or extended family members. This approach in dealing with disability is very common within families who come from collectivist cultures that value social interdependence and an individual's role within the larger family, and therefore see caring for a disabled family member as normal behaviour.[56]

The stigma of disability in some ethnic communities can contribute to reluctance to access services. The Executive Director of Action on Disability within Ethnic Communities (ADEC), Mr Keith Hitchen, made reference to the 'stigma' and the 'shame' that 'isolate the people who we deal with'.[57] ECCV went further to explain that:

> Cultural factors play a key role in migrant communities' perceptions of disability, including their understanding of disability and engaging with support services. For example, many cultures may attribute causes of disabilities to factors such as the influence of 'past lives', the past actions of a parent or the 'evil eye'.[58]

The Committee also heard that the isolation of caring can be intensified in rural communities due to distance.[59] Other submissions emphasised the experiences and challenges for older carers who are concerned about what will happen to their son or daughter when they are no longer alive. REAL Inc (Rights, Employment, Accommodation, Leisure) captured the views of many, stating that:

> Ageing carers are tired and unable to continue support for additional activities for their dependents. They become overwhelmed by issues relating to housing and care and concern about the time when they can no longer fulfil this role.[60]

Carers Mr Joe and Mrs Rosa Miot told the Inquiry that 'we want to be loving and happy parents NOT tired, weary, stressed old carers.'[61]

Stigma and discrimination can also lead to greater exclusion for informal carers. Occupational Therapy Australia (OTA) told the Inquiry that circumstances of 'exclusion are not the sole experiences of a person with disability. Rather, they are often experienced by the individual with disability as well as the person's unpaid/informal carer.'[62]

2014 from http://eccv.org.au/library/file/policy/Who_Cares_-_Refugee_Migrant_Young_People_with_Caring_Responsibilities_-_Background_Paper.pdf.

[54] *Submission S019*, Ethnic Communities' Council of Victoria Inc, p.2.

[55] *Submission S019*, Ethnic Communities' Council of Victoria Inc, p.1.

[56] *Submission S019*, Ethnic Communities' Council of Victoria Inc, pp.2–3.

[57] *Transcript of Evidence*, Action on Disability within Ethnic Communities Inc, Melbourne, 6 March 2014, p.2.

[58] *Submission S019*, Ethnic Communities' Council of Victoria Inc, p.5.

[59] For example, see *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.5; *Submission S091*, Ms Wai L. Cheung, p.1.

[60] *Submission S065*, REAL Inc (Rights, Employment, Accommodation, Leisure), p.4.

[61] *Submission S035*, Mr Joe & Mrs Rosa Miot, p.3.

[62] *Submission S101*, Occupational Therapy Australia, p.14.

OTA emphasised that 'disability does not just affect one person—it affects a family.'[63] In turn, stressed, overburdened families can contribute to negative implications for people with disability, their social connectedness and inclusion in communities. Section 3.2.3 of Chapter 3 explained that families who are overwhelmed struggle to maintain their positive outlook, which sometimes results in lowered expectations for their son or daughter with disability.

These types of strains can lead to circumstances and experiences that are difficult for both the carer and the person with disability. The Cerebral Palsy Support Network explained that 'stressed and overwhelmed parents can contribute and lead to feelings of helplessness' for people with disability.[64] Others told the Inquiry that people with disability want to feel independent and not to be a burden on others.[65] Project worker for the Victorian Aids and Equipment Action Alliance, Mr Carl Thompson, explained how he tries to get the balance right:

> I live at home with my family and they can support me to a certain extent, but they are getting older as well. Anything that I can do to reduce the strain on them makes me feel better about myself and makes them feel happier to keep me at home and not raise my rent too high![66]

The Committee also heard that stigma and discrimination can have negative consequences for both informal carers and people with disability, which in turn can affect social inclusion. For example, Carers Victoria mentioned that 'families and carers can also be affected by the stigma of disability and caring.'[67] Research supports this, with one systemic analysis of 37 studies identifying that 'both individuals and family carers experience stigma and it may have a negative impact on psychological wellbeing.'[68]

In a story provided to the Inquiry, a parent of two children with disability, Annie, explained that engaging in social activities at school can be 'too much hard work' and feel like 'yet another social situation that's potentially disastrous'.[69] She explained:

> The real dilemma most parents of kids with special needs have is, how much do you divulge? You don't necessarily want people to be pre-judging you. Some people are fantastic. Some people don't know what our issues are and don't care. Some people are frightened. They automatically think autistic children are dangerous.
>
> You get to a point where you don't feel like 'being public'. Every morning when I'd take Thomas to school [in Prep], he would be screaming. And then I'd have Sarah, just a toddler, and I'd have no idea where she was while I was dealing with Thomas. There's quite a lot of judgement [from other people].[70]

One individual with disability referred to the impact of this type of judgement and stigma on his opportunity to be connected to community—'I couldn't go to my brother's funeral. Mum thought I'd make too much noise.'[71]

[63] *Submission S101*, Occupational Therapy Australia, p.14.
[64] *Submission S043*, Cerebral Palsy Support Network, p.3.
[65] *Submission S083*, Wellington (Local Government Area) Community, p.3.
[66] *Transcript of Evidence*, Victorian Aids and Equipment Action Alliance, Melbourne, 20 March 2014, p.3.
[67] *Transcript of Evidence*, Carers Victoria, Melbourne, 3 March 2014, p.3.
[68] A. Ali, A. Hassiotis, A. Strydom et al. (2012) 'Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review'. *Research in Developmental Disabilities*, Vol. 33, No. 6 (2122–40), p.2122.
[69] *Submission S111*, Melbourne City Mission, p.6.
[70] *Submission S111*, Melbourne City Mission, p.6.
[71] *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.10.

More serious consequences include the exposure of people with disability to abuse and neglect. In 2009, the Australian Institute of Family Studies identified that the functioning of some families can be negatively affected by caring for a family member with disability.[72] MacKillop Family Services told the Inquiry that:

> In MacKillop's view an absence of support for families further exacerbates the risk of harm to children with disability. In her review of recent research about child abuse, child protection and children and young people with disability, Robinson highlights the evidence indicating the disproportionate number of children and young people with disability who have been subject to abuse and neglect. Although Robinson urges caution in relation to relying on rates and prevalence data on abuse of children with disability, she concluded that 'children and young people with disability experience abuse and neglect at rates considerably higher than their peers who do not have disability.'[73]

For some families, the pressures of caring can become too challenging, resulting in them withdrawing from the day to day care of their son or daughter. The Victorian Council of Social Service (VCOSS) told the Inquiry that 'carers without sufficient support continue to relinquish children into the care of the Victorian Government.'[74] Similarly the Association for Children with a Disability stated that it:

> … has witnessed a steady increase in the number of children with disability being relinquished into the care of the State, because the ability to access support when and where it is most needed has all but vanished.[75]

The Committee heard that the decision by informal carers to relinquish the care of their son or daughter is profoundly distressing for all involved. In 2012, the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) explained that it:

> … found that 50 or more Victorian families surrender the day-to-day care of their child with disability to the state each year because they cannot access the support they need to continue caring full time.
>
> We found the impacts of relinquishment to be profound—children and families experience trauma, grief, fear and confusion.[76]

In 2011, the Productivity Commission considered the withdrawal of supports by informal carers and estimated the cost to the Australian economy:

> … where the rate of relinquishment is 0.3 (or 0.5) per cent of the potential population, the annual cost of carer withdrawal is around $160 million (or $267 million) if supported accommodation is used, $230 million (or $383 million) if respite is used, and $317 million (or $528 million) if long stay hospital is used. Hence, the rate of carer withdrawal will also determine the costs associated with carer withdrawal.[77]

The Productivity Commission went on to state that 'carer withdrawal is often associated with inadequate provision of supports in people's homes.'[78] The next section considers the importance of respite and carers having an opportunity to take a break. Section 4.5.1 discusses the nature of supports that informal carers require and what can be done to improve their circumstances.

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[72] B. Edwards, D. Higgins, M. Gray et al. (2008) *The nature and impact of caring for family members with a disability in Australia. Research Report No.16,* Melbourne, Australian Institute of Family Studies, p.47.
[73] *Submission S105*, MacKillop Family Services, p.4.
[74] *Submission S126*, Victorian Council of Social Service (VCOSS), p.21.
[75] *Submission S122*, Association for Children with a Disability, p.7.
[76] *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.15.
[77] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.144.
[78] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.144.

Respite

The Committee heard that there is a need for informal carers to have access to respite to enable them to provide care to their son, daughter or family member with disability. Taking a break from their caring role is essential to both their own health and wellbeing and has benefits for the person with disability they care for.

Many Inquiry participants emphasised the importance of respite. For example, VEOHRC expressed the view that the community needs to demonstrate how it values informal carers by providing 'opportunities for respite and other forms of support to help carers in their caring role of family members who have disability.'[79] The City of Boroondara explained to the Inquiry that 'respite allows families caring for a person with disability the opportunity to take a break from their caring role and is therefore integral to the health and wellbeing of people with disability and their families.'[80] Box 4.4 outlines the challenges some families experience in accessing respite.

Box 4.4: Availability of respite care for informal carers

- Our lives revolve almost completely around our daughter. We are ageing parents. Access to respite is available but limited. (*Submission S035*, Mr Joe and Mrs Rosa Miot, p.2)

- In terms of Boroondara's ageing population, the need for ageing carers and people with disability aged over 18 to have access to appropriate respite continues to be an area of urgent need. (*Submission S048*, City of Boroondara, p.9)

- Families of children with disability in Cardinia Shire, both in the rural townships and the growth corridor report a lack of flexible and responsive respite care to meet their needs; some programs only cater for a certain level of disability or support needs and only offer limited hours of availability or very few hours per week. Some respite and recreation programs cater for children with mild to moderate disability whilst those with high support needs miss out. (*Submission S085*, Cardinia Shire Council, p.2)

- Lack of choice when it comes to facility based respite options within Victoria. For example, there are only four DHS [Department of Human Services] managed facility-based respite centres in the whole of the North Division of DHS, with a total of 24 beds between them. (*Submission S038*, Disability Justice Advocacy, p.7)

- … due to lack of sufficient funding and resources such as respite care, people with disability depend on their families to access and participate in the community. (*Submission S118*, Yarra City Council, p.13)

The Committee recognises that with the introduction of the NDIS, some informal carers will be eligible for respite through the scheme. The NDIS will fund respite care in the following circumstances:

> The Respite Support for Carers of Young People with Severe and Profound Disability Program provides immediate and short-term assistance to carers:

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79 *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.15.
80 *Submission S048*, City of Boroondara, p.9.

- of a young person with severe or profound disability under 30 years of age and/or

- who experience significant stress in caring for a person with disability and where both carers are under 65 years of age.

This program:

- provides immediate and short-term respite to carers of young people with severe or profound disability and

- provides access to information, respite care and other support or assistance to the individual needs and circumstances of both carers and care recipients.[81]

The Committee recognises that there will be informal carers who are not eligible for funding under the NDIS, and that they will continue to have access to their current levels of support. VCOSS explained to the Inquiry that respite is one component of a number of supports that are essential for carers:

> Access to parenting and employment support, quality child care, respite care and simply providing the required services for people with disability are all part of allowing carers to lead fulfilling lives while undertaking their caring role.'[82]

Strategies for supporting informal carers are also discussed in Section 4.5.1.

4.3.2.   Intimate relationships

Intimate relationships with a lifetime partner are one of the most significant relationships in a person's life. They are upheld by society and the focus of ceremony, ritual and tradition—such as engagements, weddings and marriage anniversaries. They are what many people aspire to have in their life, including people with disability, and they are the frequent subject of conversation with family and friends. They contribute to social inclusion in the simplest but most important ways.

When a person meets someone they consider their lifetime partner, this person will often be their closest confidant, their emotional support, a social partner to attend events with and to travel and holiday with. They are often a live-in companion and the co-parent of their children. Lifetime partners can provide access to connections in the community, social capital and increased social inclusion. AMAZE explained that for people with autism spectrum disorder, social inclusion 'means being able to find a partner, it means being able to have a family, but in reality this has not happened for a lot of our people.'[83]

Due to community attitudes about disability, achieving their desire to be in a loving, intimate relationship with a life partner can be difficult for some people with disability. In its evidence Monash Health highlighted these difficulties:

> Sexuality is often an area where people with disability face restrictions and challenges yet is a fundamental component of social inclusion.[84]

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[81]   National Disability Insurance Scheme *Respite support for carers of young people with severe and profound disability program and the NDIS.* NDIS fact sheet, p.1. Accessed on 27 August 2014 from http://www.ndis.gov.au/sites/default/files/documents/respite_support_for_carers.pdf.

[82]   *Submission S126*, Victorian Council of Social Service (VCOSS).

[83]   *Transcript of Evidence*, AMAZE, Melbourne, 17 March 2014, p.3.

[84]   *Submission S068*, Monash Health, p.12.

VCOSS explained to the Inquiry that 'people with disability face a common misperception that they do not have sexuality, including the possibility of being lesbian, gay, bisexual or transgendered.'[85]

In 2013, Women with Disabilities Australia released an Issues Paper that highlighted some of the difficulties women with disability can experience in forming and negotiating relationships:

> Women with disabilities express desires for intimate relationships but report limited opportunities and difficulty negotiating relationships. For women with intellectual disabilities in particular, attitudes toward sexual expression remain restrictive and laws addressing sexual exploitation may be interpreted by others as prohibition of relationships.[86]

The Committee also heard that some people with disability need additional support to establish and maintain relationships. For example, in the context of people with autism spectrum disorder, AMAZE provided an example of one man who wanted to be in a relationship:

> … we know that for some young people, the measures and the messages that they are getting are built around what they are seeing on TV and what they are seeing in the movies, and that is a very romanticised notion of relationships. It leads to some of our people actually being charged with stalking.

> I met a young man the other day, 30 years old, a practising chartered accountant. He has been interviewed three times now for stalking. On all occasions he keeps saying, 'But in the movies it says if you love someone, you want to spend 24 hours a day with them', and so when he falls in love he follows them home, he sits outside their house, he follows them back to work the next day and ends up being charged with stalking — not because he is stalking but because in his head the method and the message he got was that you live with them and want to spend 24 hours a day.[87]

The Committee heard that in general people with disability, particularly women, can find it difficult to access appropriate information about relationships and sexuality. The misconceptions and assumptions about people with disability and their desires to be in intimate, sexually active relationships can have consequences for the views of health professionals. Women with Disabilities Victoria (WDV) expressed its view that:

> … women are 'protected' from information about healthy relationships and healthy sexual practices in the belief that this will keep them safe. In reality evidence suggests that women who are informed and empowered to understand their bodies, sexual health and healthy respectful relationships are safer from exploitation and unsafe sex.[88]

Others had similar views. Women's Health West stated that 'exclusion from sexual and reproductive health education is often justified as a means of preventing sexual abuse by limiting sexual expression, which is an assumption that is not informed by current evidence.'[89]

Participants told the Inquiry that people with disability who form long-term, intimate relationships usually want to live independently in the community as a couple. For many people with high support needs, shared supported accommodation is often their only housing option. This means that they will be

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[85] *Submission S126*, Victorian Council of Social Service (VCOSS), p.18.
[86] C. Frohmader & S. Ortoleva (2013) 'Issues paper. The sexual and reproductive rights of women and girls with disabilities' (Paper presented to ICPD Beyond 2014 International conference on human rights, The Hague, 7–10 July 2013), p.7.
[87] *Transcript of Evidence,* AMAZE, p.3.
[88] *Submission S051*, Women with Disabilities Victoria, p.16.
[89] *Submission S071*, Women's Health West, p.4.

sharing with three to five other people with high support needs who they have not chosen to live with.

The Committee heard that there are challenges in finding accommodation that is suitable to meet the needs of people with disability who want to live in their own home with their partner and receive the support they require. Independence Australia highlighted these difficulties, stating that:

> I have a case at the moment where a person with high-level disability in shared supported accommodation wants to ask a lady who also has high-level disability and lives in a different shared supported accommodation in a different organisation to marry him. Even with the families involved and the different agencies we have not been able to find a model where they could live together. There is not really consideration being given to that situation and how it would work … maybe with some flexibility in funding arrangements going forward we might be able to get better at supporting people in that situation to be able to live together and to marry.[90]

The Committee heard that others experience similar challenges. For example, Grayden stated that if he were socially included he would have housing and privacy and 'I'd be living with my wife and my newly formed family.'[91] Jason similarly explained that:

> I'd like to live in a place where I've got a spare room and I can say to the kids come by and come and crash any time they like. There is nowhere for them to stay where I live.[92]

Regardless of their living circumstances, some people with disability will have additional, specific support requirements to sustain their sexual relationship. The Committee heard that sourcing and securing this specialist support can be difficult. Inclusion Melbourne, explained that:

> Whether residing in supported accommodation or a family home, many people with disability do not have support to maintain sexual relationships or engage in sexual activities, including physical support for positioning or the use of contraception.[93]

Section 4.5.1 discusses strategies for supporting people with disability to establish and maintain intimate relationships and lifetime partners. Chapter 5 discusses housing further.

While intimate relationships often produce positive social capital, some relationships have negative consequences for social inclusion. Violence and abuse inflicted on people with disability by people they know and trust is highly damaging and can contribute to social isolation and loss of social connectedness. Section 5.5 of Chapter 5 discusses the experience of family violence that women with disability, in particular, are more highly exposed to.

4.3.3. Parenting with disability

For many adults becoming a parent is something they hope for and dream of, and many successfully have children and assume a parenting role. In addition to experiencing the unique relationship that parents and children share, being a parent provides opportunities for inclusion and building social connections. These connections can occur through parenting groups, family gatherings, school

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[90]   *Transcript of Evidence*, Independence Australia, Melbourne, 17 March 2014, p.8.
[91]   *Submission S121*, Summer Foundation Ltd, p.9.
[92]   *Submission S121*, Summer Foundation Ltd, p.9.
[93]   *Submission S056*, Inclusion Melbourne, p.5.

activities, sport events, and many other interactions that occur naturally through parenting responsibilities.

For people with disability the desire to be a parent is often no different from others in the community. Yet VCOSS told the Inquiry that people with disability 'may face a misconception that they do not, or should not, desire children.'[94] In a recent report on parenting and disability, Women with Disabilities Australia pointed to community assumptions about people with disability as recipients of care not the providers of care:

> Women with disabilities the world over are discouraged or denied the opportunity to bear and raise children. They have been, and continue to be perceived as asexual, dependent, recipients of care rather than care-givers, and generally incapable of looking after children.[95]

For those who do have parenting experiences, many find it rewarding and the source of new and lasting social networks. One man with disability explained his experience:

> This is me … A stay at home dad with disability. I went to my local neighbourhood house to enrol my child in three year old kindergarten, through my involvement with the kindergarten I become a member of their committee, later joining the neighbourhood house steering committee. I did some small courses. I still have friends from that time, 24 years ago.[96]

Box 4.5 outlines the experience of Anita, a woman with a spinal cord injury, who had always wanted to be a mother and through determination adjusted to the demands of parenthood.

Box 4.5: Anita's story—wanting to be a mother

I've been in a wheelchair since I had a car accident when I was 16. I'd always wanted to be a mother and a year after I got married, I had my first son.

When the children were young I got by through designing and modifying things to suit my needs. When they were babies I had them on a sheepskin with two wooden handles so I could pick them up. When they started crawling they'd wear a little harness or I'd dress them in overalls. I had a change table and bassinette modified to suit my chair, and used a bath that supported the babies well.

The hardest part, when the children were young, was the isolation. We were living in a semi-rural area and I was very much confined to the house while my husband worked. Getting outside was difficult, so I couldn't play with the children in the garden as much as I'd have liked—I had to rely on my mum a bit for that. Even though I drive, getting to the shops and leaving the house is quite an ordeal when you've got to put the kids in the car and put your chair in too. So I tended to stay at home and because of that I had a really solid routine. I think that helped a lot. But it was tiring. Lifting nappy buckets and all those things are very tiring when you're in a wheelchair.

But it wasn't just physical isolation. I felt a lot of frustration and could get depressed when I just couldn't do the things I wanted to do because I was so isolated and tired. I was lucky because I had a supportive husband, and when we went out he had to change the children because I didn't have the special table. But this was frustrating too.

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94 *Submission S126*, Victorian Council of Social Service (VCOSS), p.18.
95 C. Frohmader & S. Ortoleva (2013) *Issues paper. The sexual and reproductive rights of women and girls with disabilities*, p.5.
96 *Submission S132*, Mornington Peninsula Shire, p.7.

Box 4.5: Anita's story—wanting to be a mother

My approach has always been that I'm a mother before I'm a person with disability. I tried really hard to be part of the children's lives. I went on the kindergarten committee to make the kindergarten wheelchair accessible, and I did fruit duty and reading. I've done spinal injury awareness talks at the children's schools and have been as much a part of my children's recreational activities as I could—the calisthenics committee, and racing around the three phases of dressage, show jumping and cross-country in my three-wheel motorbike. Now one son is an Olympic athlete and my daughter is getting there in equestrian events.

Source: Raising Children Network *Parenting with physical disability*. Accessed on 9 July 2014 from http://raisingchildren.net.au/articles/parents_with_physical_disability.html.

While rewarding, parenting presents challenges for all people in the community who take on a parenting role. Different people in different circumstances will find aspects of parenting more challenging than others. Similarly for people with disability—some will adjust comfortably to the role of parenting while others may find it more challenging due to their circumstances (which may or may not relate to their disability).

Attitudes in the community, however, can make the experience of parenting even more challenging for people with disability. For example, evidence has revealed that parents with disability (more often mothers and those with cognitive disability) are more likely than other parents in the general community to have a child removed from their care when there is no evidence of neglect or abuse. Research has found that parents with disability are far more:

> … likely than other parents to have a child removed from their care, with the child removed by authorities on the basis of the parent's disability, rather than any evidence of child neglect.[97]

In 2009, the Australian Institute of Family Studies (AIFS) confirmed this, reporting that parents with intellectual disability are over-represented in the child protection system. It went on to explain that 'factors contributing to the over-representation of parents with intellectual disability in child protection include discrimination, prejudice and a lack of support services.'[98]

The Committee also acknowledges that parents with intellectual disability do require additional parenting support. Depending on the nature of their disability, without such support they can pose risks to their children. The Cummins Inquiry highlighted the need to work effectively with parents with intellectual disability to prevent risks to children and the Victorian Government has implemented some actions in response. This is discussed in Section 4.5.1.

In its submission, MacKillop Family Services expressed its view 'that the implementation of some child protection policies and practices has the unintended consequence of punishing women with disability, rather than supporting them to parent effectively, which we would assert is in the best

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[97] C. Frohmader & S. Ortoleva (2013) *Issues paper. The sexual and reproductive rights of women and girls with disabilities*, p.6. See also *Submission S086*, Brimbank City Council, p.6.

[98] A. Lamont & L. Bromfield (2009) *Parental intellectual disability and child protection: Key issues*. Melbourne, National Child Protection Clearinghouse, Australian Institute of Family Studies, p.1.

interest of the child.'[99] It also stated there can be negative consequences from prematurely removing children from their parents with disability:

> … through our Heritage and Information Service, MacKillop is aware of the devastating consequences of removal of children from their parents. In our view, removal of children from parents with disability has the potential to lead to similar negative impacts as those experienced by members of the Stolen Generations and victims of forced adoption.[100]

In the current context of minimal information and society's reluctance to acknowledge the sexuality of people with disability, women will continue to have children often without support or appropriate information. The Committee heard that for women with intellectual disability in particular, forced sterilisation and forced adoption have been approaches to prevent them from assuming parenting roles. These approaches are in breach of the human rights of people with disability and are not solutions.

Section 4.5.1 discusses strategies to support people with disability in making decisions around parenting matters. Chapter 8 discusses strategies for changing attitudes about disability and how society treats people with disability.

Finding 4.3

There is a common perception that people with disability do not have sexuality and that they do not, or should not, have children.

4.3.4.   Bullying, hostility and abuse

Community attitudes towards disability are evolving and there have been improvements over time. Yet people with disability continue to experience bullying and abuse. The Committee heard that people with disability are more exposed to excluding behaviour, discrimination, bullying and violence than others in the community. These experiences can have negative consequences for building sustainable relationships and social connections. They can lead people to lose trust in others resulting in a narrowing of their networks, and higher levels of social exclusion.

In 2009, in its consultation report titled *Shut out*, the National People with Disabilities and Carer Council explained the links between the treatment of others and experiences of exclusion:

> People with disability and their families, friends and carers reported daily instances of being segregated, excluded, marginalised and ignored. At best they reported being treated as different. At worst they reported experiencing exclusion and abuse, and being the subject of fear, ignorance and prejudice.[101]

In 2013, Scope's *1 in 4 poll on attitudes* identified that levels of hostility towards people with disability in Victoria are concerning. Scope defined these types of community attitudes or behaviours as 'the tendency to express feelings of antipathy and hatred towards people with disability.'[102] Chapter 8 outlines these findings in greater detail.

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[99]   *Submission S105*, MacKillop Family Services, p.5.
[100]   *Submission S105*, MacKillop Family Services, p.5.
[101]   National People with Disabilities and Carer Council (2009) *Shut out: The experience of people with disabilities and their families in Australia*. Canberra, Commonwealth of Australia, p.3.
[102]   *Submission S129*, Scope (Vic) Ltd, pp.16–17.

One research study explained that 'the shameful reality of bullying, oppression and discrimination that is a daily experience for many people with learning disability' is often overlooked in approaches that focus only on increasing their participation in activities.[103]

Studies exploring the value of social capital have identified that while it produces positive 'assets' it can sometimes produce 'anti-social capital' that can result in the further oppression of disadvantaged or socially excluded groups in society.[104] The Public Research Institute in Canada considered this 'anti-social capital' or the negative consequences that can result from some social connections, explaining that:

- Social networks can privilege their members at the expense of outsiders— old-boy networks or networks of 'not in my backyard' neighbours are typical examples.

- Individuals or organisations may draw on their social capital for criminal purposes—such as the Mafia or terrorist networks.

- Social ties can also drain one's resources—strong norms of mutual assistance can lead people to take advantage of overly generous people at the expense of their well-being.

- Communities with strong social capital may demand conformity and restrict individual freedom.

- Similarly, social networks may enforce downward-levelling norms—as in some tightly knit families with low aspirations for their children's education.[105]

The Organisation for Economic Co-operation and Development (OECD) also identified that:

> … bonds can hinder people, too. Almost by definition, tightly knit communities, such as some immigrant groups, have strong social bonds, with individuals relying heavily for support on relatives or people who share their ethnicity. Simultaneously, their lack of social bridges can turn them into eternal outsiders from wider society, sometimes hindering their economic progress. Of course, social exclusion works both ways: tightly knit groups may exclude themselves, but they may also be excluded by the wider community.[106]

The consequences of negative experiences in the community can lead to loss of trust, which in turn can make people reluctant to reach out and make connections. Inclusion Melbourne told the Inquiry that:

> … abuse can potentially lead to a mistrust of people. It is very difficult for people to then look to include those individuals into their communities, their homes, their streets or their sporting clubs.[107]

For example, in the Melbourne City Mission submission to the Inquiry, Michael explained his experience in the workplace:

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[103] P. Bates & F. Davis (2004) *Social capital, social inclusion and services for people with learning disabilities*, p.200.
[104] P. Bates & F. Davis (2004) *Social capital, social inclusion and services for people with learning disabilities*, p.201.
[105] Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, p.11.
[106] Organisation for Economic Co-operation and Development (OECD) (2007) *OECD Insights: Human capital. How what you know shapes your life*, p.104.
[107] *Transcript of Evidence,* Inclusion Melbourne, p.2.

I'm lucky where I am. But if it's busy, people are not as tolerant, they push me aside. [Sometimes] they lose it. They're short with me. They don't mean it, but sometimes I feel like a child.

[In the kitchen], they call the food, but they [the wait staff] don't always come [immediately]. [On one occasion], I had noticed the table number and moved closer to the door [to help the wait staff get the food moving quickly from the kitchen to the table]. They shouted at me. When something like that happens to you, [you don't try to show initiative like that again]. It's like a dog – if you've been hit, you avoid that [situation in the future]. I don't trust that person anymore. It's a protective mechanism you develop after you have a brain injury.[108]

Research has identified that there are different forms of trust—thick, thin and no trust:

Thin trust is present when strangers view each other as potential friends and absent when they regard each other as potential enemies …

We all have to run the gauntlet of meeting strangers from time to time and negotiate our way through thin trust in order to locate the new friends and colleagues with whom we might enjoy thick trust, but there are extra challenges for visible minorities, and this includes some people with learning disabilities.[109]

At times, people with disability have good reason not to trust others. It is well-established that they are at higher risk of abuse and violence than other members of the community.[110] The Committee heard that children and young people with disability are exposed to higher levels of bullying and violence, particularly in schools, and learn from a young age that relationships with others can be difficult to navigate.[111] Mornington Peninsula Shire explained that in its community consultations it heard that 'in the mainstream education system [k]ids continue to be bullied, isolated and segregated from peers.'[112]

Research undertaken by the VEOHRC revealed that children with disability are exposed to higher levels of bullying in schools, stating that 'based on our research, bullying appears to be a significant and widespread problem for students with disability' and that 'bullying for a student with disability is much higher than the general student population.'[113]

The Committee heard that people with disability can experience bullying and abuse in segregated settings. While the majority of bullying occurs in mainstream, independent and Catholic schools, there is also exposure to bullying in specialist schools.[114] VALID explained that:

Parents also tell us that … [they] err on the side of exclusion, in order to 'keep them safe'. The fact that segregated settings have proved to be equally conducive to abuse, and often more so than the community, simply adds to their burden of anxiety and fear.[115]

In addition to specialist schools, the Committee heard that some people with disability have been exposed to abuse in specialist disability services, such as shared supported accommodation. The Committee questioned the Department of

[108]   *Submission S111*, Melbourne City Mission, p.10.
[109]   P. Bates & F. Davis (2004) *Social capital, social inclusion and services for people with learning disabilities*, p.200.
[110]   *Transcript of Evidence*, Department of Human Services, Melbourne, 3 March 2014, p.2.
[111]   *Submission S021*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, pp.10, 12.
[112]   *Submission S132*, Mornington Peninsula Shire, p.7.
[113]   *Submission S115*, Victorian Equal Opportunity and Human Rights Commission. Appendix 3, p.72.
[114]   *Submission S115*, Victorian Equal Opportunity and Human Rights Commission. Appendix 3, p.72; *Submission S021*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, pp.10–11.
[115]   *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.11.

Human Services (DHS) regarding its strategies to prevent and respond to abuse in government and non-government disability services.[116] DHS explained that:

> The Disability Act (2006) provides a framework for practice and service delivery to be monitored and audited by a range of statutory authorities who have the legal right in circumstances defined by their governing legislation to:
>
> - scrutinise individual staff actions
> - investigate service delivery and adverse events
> - recommend policy and practice change.[117]

DHS also informed the Inquiry that it has a critical client incident reporting process that ensures a process of immediately responding to any incidents of abuse in government and non-government disability services. It explained that it has recently commenced a 'review to streamline and strengthen the critical client incident management approach in consultation with the community service sector.'[118]

Finding 4.4

People with disability are more exposed to bullying, hostility and abuse than others in the community.

4.3.5.   Diverse connections across the community

Relationships with diverse networks across the community are also highly relevant to the social capital of people with disability. They assist people to feel included, they build stronger communities and they enable people with disability to be well-connected and to identify opportunities for greater inclusion.

For example, Vision Australia explained that the 'importance of a social capital perspective [is] in enabling interaction between a diversity of groups including those normally outside of existing contacts.'[119] SkillsPlus and BRACE also referred to the value in the diversity of social interactions:

> … opportunities such as employment, participating in general community education programs, sport activities and clubs provide valuable opportunities to engage with people outside the disability space and provide different perspectives of personal identity beyond the disability.[120]

The value for people with disability in nurturing various types of 'bridging' relationships or social interactions with people outside of their usual networks is well demonstrated in the context of employment. In the United Kingdom (UK), a government survey found that more people secure jobs through personal contacts than advertisements.[121] Diverse connections across the community can build social capital—creating employment opportunities and increasing social networks through new contacts in the workplace.

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[116] *Submission S100*, Communication Rights Australia & Disability Discrimination Legal Service Inc; *Submission S125*, Mr Matthew Potocnik.

[117] *Supplementary evidence*, Response to request for information, Department of Human Services, 27 June 2014, p.2.

[118] *Supplementary evidence*, Response to request for information, Department of Human Services, 27 June 2014, pp.2–3.

[119] *Submission S112*, Vision Australia, p.15.

[120] *Submission S042*, SkillsPlus and BRACE, p.3.

[121] Organisation for Economic Co-operation and Development (OECD) (2007) *OECD Insights: Human capital. How what you know shapes your life*, p.103.

The Australian Community Support Organisation (ACSO) explained that without relevant connections, securing employment can be more difficult for people with disability:

> … lack of social capital, in terms of pro-social networks, further compounds unemployment through consequential loss of introductions to available work opportunities.[122]

Carers Victoria told the Inquiry that 'social capital developed through participation can facilitate getting a job and vice versa.'[123] These views have been asserted by academics in different fields:

> Advocates of social inclusion have rightly highlighted the importance of waged employment as a route to income, status and relationships, while social capitalists point the spotlight on informal roles and relationships.[124]

The Committee heard that there are opportunities for social connections in most workplaces, including both supported and mainstream employment. For example, Marriott Support Services explained that for people involved in its service:

> … their fellow employees are an important central part of their 'community'. In our experience the ADE [Australian Disability Enterprise] is where they have developed friendship groups which often extend outside of working hours into social activities and groups.[125]

Participation in employment is discussed in more detail in Chapter 6.

4.4.   The value of building sustainable relationships

Sustainable relationships contribute to increased social capital, which in turn leads to greater inclusion in society. People with disability successfully establish and maintain social connections in the community. Yet as discussed in this chapter, when considering people with disability as a population group, it is well established that they are more socially excluded than other members of society.

People who benefit the most from social capital are those who tend to have a high degree of variation in their networks. According to research evidence, often these tend to be people who are socially included and have higher levels of education, are actively involved in voluntary organisations and/or in paid employment (particularly in higher status occupations). Others with greater network diversity include people with a spouse or partner, who have children, or who are in their mid-years in life.[126]

In view of the advantages that relationships and networks can generate there is value in facilitating the development of such connections in the community. Relationships are two-way experiences—they are dynamic and can vary in the extent to which they are mutual or reciprocated.

In creating opportunities for people with disability to have sustainable relationships in their lives, the Committee identified that specific responsibilities rest with non-government organisations and governments at all levels.

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[122]   *Submission S050*, Australian Community Support Organisation (ACSO), p.4.
[123]   *Submission S087*, Carers Victoria, p.4.
[124]   P. Bates & F. Davis (2004) *Social capital, social inclusion and services for people with learning disabilities*, p.198.
[125]   *Submission S020*, Marriott Support Services, p.6.
[126]   Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, p.11.

People with disability need to be at the centre of all efforts to increase their social connections and meaningful relationships. Mrs Delia Fisher expressed her view that there is a mutual responsibility across the community and people with disability (potentially collectively) in building connections:

> Communities need to promote the empowerment of people with disability … People with disability themselves need to create and keep strong, constructive networks locally, nationally and internationally.[127]

People with disability need to determine the relationships and social networks they want in their lives. They rightly demand this, and advocacy groups such as VALID emphasised that 'for people to truly enjoy the benefits of relationships and opportunities within the community, they need to be continually exercising choice and control over the level and nature of their involvement.'[128]

The Committee heard that in Victoria disability support services are increasingly focusing on improving opportunities to increase the social connections of people with disability. State and local governments are also increasingly active in this space. Local government has a unique role and the capacity to understand and identify ways to build social capital in local communities. The Centre for Rural Regional Law and Justice explained that:

> There is often incredibly good community infrastructure and social capital that can be built upon …
>
> … you have to look at the person within their community and what is available to them and then build on the social capital that is already there.[129]

Section 4.5 discusses how this can effectively be achieved and current approaches that aim to build social capital.

Finding 4.5

People with disability need to exercise choice and control over the level and nature of their involvement in relationships and social connections across the community.

4.4.1. Role of governments and non-government organisations

Communities benefit from a society in which its citizens are well-connected and have strong social capital. The Victorian Government and local government have a role in creating opportunities for building and nurturing social networks and, where necessary, supporting people with disability to engage in them. Non-government organisations have considerable potential to make an effective difference in building the social capital of people with disability through innovative initiatives.

At first glance, increasing opportunities for relationships and social networks seems an intangible goal. The Policy Research Initiative in Canada directly asked the question—'Does government have any business influencing people's choices about investing in their social capital?'[130] In responding to this question:

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[127] *Submission S008*, Mrs Delia Fisher, p.2.
[128] *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.10.
[129] *Transcript of Evidence*, Centre for Rural Regional Law and Justice, Deakin University, Melbourne, 6 March 2014, pp.3, 7.
[130] Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, p.13.

One might suggest that the social relationships we choose to pursue lie at the very heart of our most basic freedoms, and there is no room for the state in making those choices.[131]

However, the Initiative went on to explain that it is a reality that governments inadvertently influence social connections in numerous ways:

Governments inevitably affect patterns of social capital development. Taking into consideration the role of social capital (and the interactions between social relationships and policies) in a more systematic way in program design, implementation, and evaluation can potentially make a significant difference in the achievement of policy objectives.[132]

Box 4.6 outlines the ways that the decisions and actions of governments affect patterns of social capital development.

Box 4.6: Governments and social capital

Governments already and inevitably influence the development of social capital in a myriad of ways. This is done at two levels.

- Some policies have a broad but indirect effect on how social relations are formed. Decisions about public transport and housing, parental leave and education, day care and recreation facilities, to name but a few, significantly shape the social connections people make.

- Some policies already implicitly integrate or promote social-capital building activities. Many programs and initiatives at the federal, provincial, or local level incorporate elements of social capital in their efforts to build individual or community capacity (e.g., mentoring, building organized support networks, brokering community partnerships). This is done, for example, through activities that increase, influence, or mobilize:
    - networks of social support
    - intra-community bonds or networks
    - inter-community networks
    - linkages to various institutions.

If social capital is an important resource for individuals and groups, and if governments already inevitably affect the creation and development of social capital, would there be a public benefit from a more explicit and deliberate focus on social capital within government policies and programs?

The overall conclusion from experts consulted was 'yes', but with a healthy dose of caution.

Source: Policy Research Initiative (2005). *Social capital as a public policy tool*. Project report, Government of Canada, p.13.

The Policy Research Initiative in Canada has suggested that in partnership with non-government organisations there is relevance for governments to adopt a social capital perspective in three broad areas of social policy:

- helping populations at risk of social exclusion

- supporting key life-course transitions

- promoting community development efforts.[133]

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131   Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, p.13.
132   Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, p.2.
133   Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, p.15.

A review of research specifically relating to disability and natural supports found that 'there is substantial consensus that assistance is needed in the formation and facilitation of natural supports', concluding that 'consequently, strategies are required to nurture social networks so as to enable the potential spectrum of informal network functions to be fulfilled.'[134]

The Committee determined that to increase the social inclusion of people with disability future State Disability Plans in Victoria would benefit from a more explicit focus on increasing social capital and opportunities for establishing and maintaining social networks. This needs to be a strategic and coordinated approach to create opportunities and favourable conditions for natural networks which acknowledges the limits of intervention and system formalities.

Given social connections form naturally in communities, the Committee considered that local government is well positioned to facilitate opportunities for connection across people with disability and other members of the community. Local councils told the Inquiry that they are well placed to assume a role in building social capital. For example, Mansfield Shire Council explained that:

> Local Government is key to building relationships, partnerships and local responses. Local Government has the knowledge about each individual community and the partnerships and relationships already in place.[135]

Monash City Council also emphasised that local councils are uniquely placed to create favourable conditions for developing sustainable relationships:

> A strength of Councils is to facilitate relationships at the local level and building partnerships with local community groups, agencies, service providers and individuals that supports the provision of meaningful services and programs and advocacy at other levels of government.
>
> It is believed that the community development and facilitation roles of Councils are one of their great strengths that should be supported and strengthened.[136]

It is evident that local councils also consider that partnerships with non-government organisations and others are essential for the success of any efforts to facilitate social networks. Associate Professor Paul Ramcharan explained that non-government organisations are embracing approaches that aim to build social connections:

> … a number of the initiatives that are taking place at the moment, they are about how you develop peer support, for example, or how people can actively learn and build naturally existing networks. It is how you build social capital: what is the bridging, what is the bonding, what are the sorts of ways in which people are being supported in naturally occurring settings?[137]

He stressed the need for caution in the nature of the support non-government organisations provide, emphasising how connections must be 'natural' in order to build social capital. He indicated that while services can have a role, it is essential that they do not interfere with the creation of natural networks through excess formality:

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[134] C. Duggan & C. Linehan (2013) *The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature*, p.204.

[135] *Submission S057*, Mansfield Shire Council, p.6.

[136] *Submission S120*, Monash City Council, p.4.

[137] *Transcript of Evidence,* Associate Professor Paul Ramcharan, p.5.

> We need to create hope, we need to create resilience and we need to free people to be unencumbered by the formalities of the service system. We need supportive natural networks and to leave those networks to be natural.[138]

Disability support services that participated in the Inquiry informed the Committee that they are increasingly focusing on building the networks of people with disability. For example, Melba Support Services explained that it has a commitment to 'individuals being recognised and accepted as valued and contributing members of their community' and to 'working in partnership with local communities' to achieve this.[139] It went on to explain that:

> In our planning process … we actually map who is currently in a person's life and who is closest to them in terms of family, friends, community and services. We take a bit of a look at who is already there and how we build on that. Through our planning process we actually support people if they want to deepen those connections.[140]

Associate Professor Ramcharan stated that we need to get smarter about how we understand the role of non-government organisations and measure their effectiveness in building connections:

> The ideas about how services support must be about how they support people in communities, not how the service acts. We cannot evaluate the outcomes on the basis of whether the service is successful; we have to evaluate them in terms of what it means for the person in their communities, their natural supportive networks.[141]

Inclusion Melbourne expressed its view that governments can be reluctant to or disinterested in focusing on developing policy in the area of social capital:

> … when we get down to the nitty-gritty of forming relationships we find it difficult to get governments to legislate and regulate in that space. We recognise that it is difficult.[142]

Even when governments create policies that contribute to social capital, these are not policy areas that traditionally attract government investment. In an evaluation of a program to increase opportunities for developing friendships for people with mental illness, Dr Ann Montclaire stated that:

> Friendship is an important part of community participation, and is clearly necessary for human flourishing. However, because of its apparent simplicity … it may also be easily overwhelmed in a competitive funding environment.[143]

The Committee determined that to reduce the social isolation of people with disability through social capital initiatives, small investment can go a long way.

Finding 4.6

There is a strong rationale for governments and non-government organisations to increase opportunities and create favourable conditions for people with disability to establish and maintain social connections and build social capital.

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[138]   *Transcript of Evidence,* Associate Professor Paul Ramcharan, p.5.
[139]   *Submission S080*, Melba Support Services Inc, p.7.
[140]   *Transcript of Evidence*, Melba Support Services Inc, Melbourne, 26 May 2014, pp.7–8.
[141]   *Transcript of Evidence,* Associate Professor Paul Ramcharan, p.3.
[142]   *Transcript of Evidence,* Inclusion Melbourne, p.3.
[143]   A. Montclaire (2011) *Friendship really matters: Exploring effects of Compeer friendships for people experiencing mental illness*, p.16.

4.5.   Increasing opportunities for sustainable relationships and networks

This chapter has emphasised the need to facilitate sustainable relationships across the community that enable people with disability greater opportunity to connect with others and develop social capital. Some people with disability are content with the social connections in their lives. Others would welcome greater opportunities for social interaction.

The Committee identified that there are innovative efforts underway in many communities that are contributing to increased opportunities for people with disability to engage and participate. It determined that existing efforts need to be further developed through a strategic approach for building social capital for people with disability across Victoria through creating opportunities and establishing favourable conditions for networks. Such an approach needs to:

- be driven by people with disability

- emphasise the importance of naturally occurring networks

- take advantage of the value that volunteers can contribute

- create opportunities and establish favourable conditions for social connections to develop and be sustained.

Participants told the Inquiry that there is considerable value in increasing social inclusion through a focus on the social connections of people with disability and the conditions to enable them to succeed. Warrnambool City Council explained that:

> Programs that build opportunities for participation, connection and friendship and engagement with others who share your interests are critical in improving an overall sense of wellness for people with disability.[144]

MetroAccess Southern Division emphasised that 'more informal or semi-formal opportunities need to be created.'[145] It went on to explain that there needs to be:

> More activities that are inclusive and accessible—not just programs run by disability service providers; would rely on these options being well serviced and supported; trained staff at sporting centres, community centres etc. that can provide attendant support as required. Roles and opportunities that provide social connection—volunteering, buddy programs, employment, social gatherings especially for younger people—not just during business hours.[146]

The Committee identified that there is a need for a specific approach to strategically develop opportunities for increased connections and social capital. The Policy Research Initiative in Canada undertook its study to determine how social capital can be used strategically as a policy tool. Using that evidence base, the Committee considers three components that can contribute to building social capital:

1. Creating opportunities for establishing and maintaining connections and networks—such as new networks and building the capacity of people with disability who need support.

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[144] *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.8.
[145] *Submission S131*, MetroAccess South Division: Bayside Peninsula & Southern Melbourne, p.8.
[146] *Submission S131*, MetroAccess South Division: Bayside Peninsula & Southern Melbourne, p.8.

2. Supporting existing opportunities and networks—such as existing programs that aim to provide opportunities for social interaction.

3. Establishing favourable conditions for sustainable relationships and networks—such as social 'brokerage' (mentors, coaches) and good public infrastructure.[147]

Chapter 2 outlined current initiatives that are contributing to increased community capacity to include people with disability through the Building Inclusive Communities Program (formally known as the Community Building Program). These Access initiatives also need to be considered in the context of a social capital strategy. The Building Inclusive Communities Program 'is not simply about physical access to buildings, but about access to being a valued member of all aspects of community.'[148] In this context the Program can make a unique contribution to building social connections and relationships at the grassroots level.

The Committee considered that disability support services and other non-government organisations have a role in building greater capacity in areas that support people with disability to be socially connected. Chapter 2 discussed workforce capacity in non-government organisations.

To achieve an increase in social capital, the Committee considered it is important to 'raise the awareness of policy makers and decision makers about the potential impacts of new interventions or changes in policy directions on the social capital already present in communities.'[149]

The remainder of this section considers relevant programs and initiatives that currently exist in Victoria and how they relate to the above three components. It also considers program areas that could potentially be further developed. Other chapters, and specifically Chapter 2, also consider the innovative initiatives that are related to other aspects of social inclusion, but recognise these may also influence social connectedness.

4.5.1. Creating opportunities—sustainable relationships and networks

There is a multitude of ways to create greater opportunities for people with disability to establish sustainable relationships and networks. This section considers approaches that:

- support people with disability (particularly cognitive disabilities) who need assistance to increase their capacity to form sustainable relationships and networks

- explore new opportunities to increase social interactions and build connections

- support families in informal caring roles to enable them to continue to provide support.

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[147] Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, p.17.
[148] Department of Human Services *What is the community building program? Tip sheet 1.* Linking self-direction and community building series, DHS, p.1. Accessed on 15 April 2014 from http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/linking-self-direction-and-community-building-tip-sheets.
[149] Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, p.22.

Integral to this strategy is building the skills and capacity of others in the community to interact more appropriately with people with disability. Chapter 2 considers the nature of support communities might need and the capacity of non-government organisations to contribute to increased social inclusion. Chapter 8 explores strategies for changing attitudes across the community.

Building capacity—supporting people with disability

For some people with disability forming friendship and engaging in social interactions occurs easily. Like all members of the community, people with disability have diverse personalities—some are extroverted, others more introverted. But for some people with disability, the nature of their disability might mean they have less confidence or knowledge in identifying opportunities to make new connections, or they may not have the level of social skills to sustain relationships that they make.

VALID told the Inquiry that there are unique circumstances for people with intellectual disability in developing social connections:

> For most of us, inclusive relationships and connections are made naturally through our interactions within the community, but people with intellectual disability often need support to clear and pave the way, to nurture relationships, to seek out and pursue opportunities, to build connections and to maintain them.[150]

It suggested that the level of support required can be quite intensive for people with intellectual disability. In regard to their specific needs VALID explained that:

> Without 'inter-dependent' support and assistance, many people with intellectual disability find it difficult to be included within the community. They often require support to be included within their own families, to make and maintain friendships and relationships, and even to be included in decisions regarding their own lives.[151]

Northern Support Services also considered that 'people with intellectual disability … often need the support to establish these connections.'[152] Rhiannon is a woman with intellectual disability who appeared before the Inquiry with Melba Support Services. She explained that 'I like to go swimming and shopping. As well, Melba supports me with the interaction with all my friends.' Rhiannon went on to state that 'I hope that everyone at Melba can interact as well as I do.'[153]

Research studies have demonstrated that there is value in providing support for people with disability who need assistance to establish and maintain relationships. In an extensive review of literature on natural supports and independent living, one study proposes that policy-makers consider four types of programs that can contribute to sustainable relationships for people with disability:

- Circles of support—formalised support that draws on family and friends to provide support in achieving goals.

- Peer-based approaches—those with a shared disability providing support to each other.

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[150] *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.16.
[151] *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.9.
[152] *Submission S123*, Northern Support Service's My Place-KeyRing Program, p.5.
[153] *Transcript of Evidence,* Melba Support Services Inc, p.2.

- Training programs—to build skills for those who may need them.

- Befriending strategies—disability organisations support people to develop friendships with volunteers.[154]

Several Inquiry participants highlighted the benefits of peer-based approaches and self-advocacy programs. For example, VALID explained to the Inquiry that 'through the kind of peer mentoring and positive role modelling that is available through independent self-advocacy groups and peer support networks, people with intellectual disability can "launch" themselves with confidence into community activities and relationships.'[155]

Others supported the value of self-advocacy programs. Warrnambool City Council told the Inquiry about Advocacy South West, which is designed to develop skills in assertiveness, rights and responsibilities. It also explained that:

> In general, advocacy organisations receive only very limited government funding. If people with disability are going to be more central in planning and developing inclusive communities, then more appropriate resourcing of self-advocacy initiatives needs to be developed within regional Victoria.[156]

In its vision for the NDIS the Productivity Commission highlighted the important role of advocacy in the disability system:

> Advocacy plays an important role in the disability system. Systemic advocacy pushes for broad policy and social change, while individual advocacy promotes the interests of particular individuals by acting on their behalf to resolve specific issues.[157]

It went on to explain that to avoid conflicts of interest, the functions of advocacy should 'lie outside the NDIS' and that current funding arrangements should continue, including funds provided by states and territories.[158]

The *State disability plan 2013–16* made a commitment to 'strengthen the approach of advocacy and self-advocacy.'[159] As part of this strategy in April 2014, the Victorian Government provided a small increase in funding to the Self Advocacy Resource Unit. The Committee supports this and considers there is room to further expand the self-advocacy program and how it approaches its work.

The Committee heard that in rural and regional areas there is a growing need for access to advocacy support. The Centre for Rural Regional Justice explained to the inquiry that:

> There are certainly regionally based disability advocacy services throughout Victoria. Over the last little while they have tended to become a little more thinly spread than they used to be.[160]

When the Committee queried whether this related to demand or their location, Research Fellow, Mr Ian Parsons, from the Centre explained that:

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[154]   C. Duggan & C. Linehan (2013) *The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature*, p.204.

[155]   *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.10.

[156]   *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.7.

[157]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.26.

[158]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.26.

[159]   Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014*. Melbourne, DHS, p.15.

[160]   *Transcript of Evidence,* Centre for Rural Regional Law and Justice, Deakin University, p.5.

> It is little bit of both. They tend to be located in the major regional towns. There used to be a lot more of them, smaller services located more locally. Mainly in the 90s, they had to amalgamate a fair bit and cover bigger regions, so they would have slightly bigger offices covering much larger regions.[161]

Mr Parsons also explained that often there is only one staff member covering the whole region as an advocate, 'so their ability to meet the need is fairly limited.'[162]

The Committee also heard that non-government organisations and local councils are exploring innovative approaches to working with people with disability who need support to build relationship skills. Northern Support Services informed the Inquiry about its approach within the Keyring housing model (discussed in more detail in Chapter 5. Box 4.7 provides an example of how the organisation actively seeks to support people with disability in an informal community setting.

Box 4.7: Supporting people with disability to form friendships

We had two people introduced to KeyRing who both lived in the same block of units. They worked at the same supported employment workplace and caught the same train to and from work. They said hello to each other if they ran into each other at the front door but apart from that they had no contact with each other outside of their structured work time. Through the support of KeyRing we began to build a connection between these two people, supporting them to have conversations and organising some opportunities for social get togethers. Over time they developed a good friendship and gave each other a spare key to their units so if they locked themselves out they had someone readily available to help out. Without this intervention they may never have connected with one another is this informal setting.

Source: *Submission S123*, Northern Support Services, p.5.

The Football Integration Development Association (FIDA) told the Inquiry how relationship skills can be built in an informal, but structured setting such as sport. The Football Administration Manager, Mr Logan Whitaker, explained that:

> … sport is such a powerful tool for teaching life lessons — teaching right from wrong, teaching respect for umpires, respect for team mates, how to socialise…

> Their social skills are incredibly increased. It is quite funny when you are talking to a coach or someone, and they will come running up to you. You are engaged in a conversation, and you hear, 'Logan, Logan, Logan, Logan!'. I say, 'Hang on 5 minutes. I'm talking here, and I'll talk to you in a second'. It can be teaching them little things like that — basic social conventions that we all understand quite well but that do not quite click with those guys.[163]

Maribyrnong City Council told the Inquiry about a specifically targeted approach that it has taken with its 'RAMPS' Program—Relationships and More Personal Stuff. It explained that the Council formed a partnership with Hobsons Bay City Council 'to offer a program that aims to provide adults, who have intellectual disabilities, with the skills to develop meaningful and lasting relationships through a series of training sessions.' These skills related to their

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[161] *Transcript of Evidence,* Centre for Rural Regional Law and Justice, Deakin University, p.5.
[162] *Transcript of Evidence,* Centre for Rural Regional Law and Justice, Deakin University, p.5.
[163] *Transcript of Evidence*, Football Integration Development Association (FIDA), Melbourne, 26 May 2014, pp.3–4.

personal lives and also more broadly in the community, including the work place. The objectives of the program are to provide people:

- the skills to be able to initiate, establish and maintain different types of relationships
- knowledge to be able to make informed choices in relationships
- the skills to be able to act and behave appropriately in social situations.

Maribyrnong City Council advised that the 'participants were very enthusiastic to find out more about socialising and how to meet people to form meaningful relationships that are both fulfilling and safe.'[164]

The Committee also identified a need to support people with disability in developing and sustaining intimate relationships. The nature of support varies considerably according to the specific needs of people with disability. It can range from information about relationships and sexuality to specialist physical assistance for people to engage in sexual activity. In its submission, Brimbank City Council stated that:

> Students with disability require the same information around sexuality education as their peers without disability.[165]

Manningham City Council also suggested that people with disability can benefit from opportunities to meet potential partners and has developed a forum to assist:

> Relationships and Sexuality Forum for parents, carers and people with disability— Anecdotal feedback indicated that people with disability have limited opportunities to engage and have their needs met. This forum provided attendees with options and alternatives to assist in facilitating a relationship or one off experience.[166]

The Committee also heard that there is a need for more mainstream opportunities for people with disability to access information and education about relationships and sexuality.

Some organisations acknowledged that efforts are being made in the education sector to address the relevance of school programs to people with disability. The Department of Education and Early Childhood Development (DEECD) states the importance of this in its standards for sexuality education, *Catching on early*:

> Students with disability need the same information as everyone else. Students with learning disabilities should still receive information that is relevant to their age, for example, information about puberty; however, the teaching methods may need to vary to accommodate the disability.
>
> Students with disability may also in some cases need additional information relevant to their disability.[167]

However, the extent to which this commitment is effectively implemented appears unclear. Women's Health West told the Inquiry that 'while this is an important position statement, the resources and support available to facilitate alternative lesson plans that are responsive to the needs of students with disability are still extremely limited.'[168]

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164   *Supplementary evidence*, Response to request for information, Maribyrnong City Council, 30 July 2014.
165   *Submission S086*, Brimbank City Council, p.7.
166   *Submission S064*, Manningham City Council, pp.3–4.
167   Department of Education and Early Childhood Development (2011) *Catching on early: Sexuality education for Victorian primary schools*. Melbourne, DEECD, p.22.
168   *Submission S071*, Women's Health West, p.5.

When people do form relationships, the Committee heard that like others in the community, they generally want to live independently as a couple. Section 4.3.2 identified that there are many challenges to achieving this goal. The Committee acknowledges that DHS Guidelines state that 'people who live in residential supports may choose to have their partner stay at their home and sleep in the same bed' while also ensuring that 'the wishes of other residents [are] considered'.[169]

Yet the Committee identified that greater support is required for those couples who do not want to live in disability shared supported accommodation. Melba Support Services provided a story of an experience of a couple who successfully found independent housing with appropriate support. Box 4.8 outlines the experience of Margy and Stavros who successfully moved to their own home as a couple.

Box 4.8: Living together—Margy and Stavros

Margy and Stavros Kalomiris share a passion for Greek culture, were childhood sweethearts and enjoy each other's great sense of humour. Together, Margy and Stavros overcame doubt and disapproval from several quarters to develop a relationship, live together and finally marry. Margy and Stavros both have cerebral palsy.

When Stavros proposed to Margy on his birthday, in front of his parents and his future in-laws, both sets of parents were shocked. Margy, however, said yes. And with their gentle ways, Margy and Stavros gradually brought their parents around to realising that they really were in love and really did intend to live together, just like any other couple in love.

At that point, Stavros was living in a group home, and looking for alternatives. 'No one could talk. It was boring,' says Stavros. 'It was depressing … I was lonely. I couldn't do anything I wanted to do. I was fed up.' Margy was struggling too. The agency she was with at the time didn't want her to have a relationship with someone, so Margy had to shop around to find an agency that would support her goals and dreams. 'I like to use our life as an example to show that people with disability can achieve their goals in life, with the right support' says Margy.

But to achieve their dream, Margy and Stavros needed a home they could live in together. With the assistance of support staff and advocates, Margy and Stavros were offered a unit to rent by the then Disability Housing Trust. They are very proud of their home and enjoy an inclusive life together in their local community that without appropriate housing would not be possible.

Source: *Submission S080*, Melba Support Services, pp.5–6.

In the context of people with disability in parenting, Section 4.3.3 also outlined that people with disability are often affected by community attitudes that they should be the recipients of care, not the providers of care. The Committee determined that there is a need for greater support for women with disability who are pregnant and for parents with disability.

Women's Health West emphasised the need for specialist support for women with intellectual disability as early as possible in pregnancy:

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[169]　Disability Services, Department of Human Services (2006) *Personal relationships, sexuality and sexual health policy and guidelines*. Melbourne, DHS, p.23.

Delayed recognition of pregnancy, delayed contact with services, external pressures on decision-making and additional complex support needs of women with intellectual disability, indicate the need for specialised support services.[170]

A number of Inquiry participants raised the need for specialist, tailored parenting support for people with disability, particularly those with intellectual disability. For example, MacKillop Family Services expressed the view that there is a 'need to provide tailored support to parents with disability and their children to improve the wellbeing, connectedness and social inclusion.'[171]

The support needs of all parents vary considerably, and people with disability are no different. In 2009, the Australian Institute for Family Studies (AIFS) also stressed the need for supports to be available for people with disability entering into parenthood, concluding that:

Further research is needed that focuses on how the child protection system can better accommodate the needs of parents with intellectual disability so that their children are provided with the best care and protection. Particular attention should be directed at making assessments, establishing case plans and agreed parent actions, and identifying appropriate support services and interventions for parents with intellectual disability involved in the child protection system.[172]

In 2012 the *Protecting Victoria's vulnerable children inquiry* (the Cummins Inquiry) gave consideration to the issue of parenting with disability and it drew the following conclusion:

The Inquiry draws attention to the significance of disability as a risk factor among vulnerable families in Victoria affecting the prevalence of child abuse and neglect. This is a matter that should be further considered.[173]

The Department of Human Services (DHS) informed the Committee that in partnership with the Parenting Research Centre (PRC), DHS Child Protection has developed a training package specifically for child protection practitioners in relation to working with parents with learning difficulties. In 2013, it trained 28 'champions' in the sector to share learnings with other child protection staff.

The Committee heard that there is a range of additional support requirements that can assist those people with disability who need specific types of support to establish and maintain connections. Table 4.1 outlines the range of initiatives important to consider in building the capacity of people with disability in intimate relationships, family and across the community.

Table 4.1: Specialist support for people with disability—sustainable relationships and connections

Type of support	Description
Support to build connections	• skills development in personal interaction—social interaction and communication skills • increase knowledge about settings in which to make and pursue connections • self-advocacy programs—peer mentoring, positive role modelling, building self-esteem and advocacy.

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[170] *Submission S071*, Women's Health West, p.7.
[171] *Submission S105*, MacKillop Family Services, p.6.
[172] A. Lamont & L. Bromfield (2009) *Parental intellectual disability and child protection: Key issues*, p.17.
[173] P. Cummins, D. Scott, OAM, & B. Scales, AO (2012) *Report of the protecting Victoria's vulnerable children inquiry*. Melbourne, Department of Premier and Cabinet, p. lxvi.

Type of support	Description
Support to develop safe and healthy intimate relationships	- access to mainstream information and education on relationships and sexuality - opportunities and support to meet people and to be sexually active - increased housing and support options for couples to live together - specialist support for couples who need assistance for sexual activity.
Specialist support for pregnancy and parenting	- specialist support during pregnancy for women with disability relevant to their needs - specialist parenting support for women with cognitive disability who are not in the child protection system.
Workforce capacity	build workforce capacity to provide non-traditional supports for people with disability in intimate relationships and parenting.

Source: Compiled by Family and Community Development Committee.

Exploring new opportunities for increasing social interaction

The Committee determined that there is scope to consider new ways to create opportunities for people with disability to build social connections and networks. For example, it considered there is value in exploring options for children with disability. In particular, these may relate to skills development and programs in schools or the skills development of adults who interact with children, such as professionals in the education system. Importantly any interventions need to avoid creating artificial or 'unnatural' connections.

The need for support begins at an early age and children take the skills they develop in interacting socially through their lives. Noah's Ark made reference to this point and stated that:

> Children with disability particularly benefit from the opportunity to develop skills in supportive environments and in the company of typically developing children. If this happens, they are more likely to use these skills in all aspects of their lives and to develop friendships and connections within their community.[174]

In its submission the Youth Affairs Council of Victoria (YACVic) and Youth Disability Advocacy Service (YDAS) also suggested children can benefit from support to develop social connections. It emphasised that there is a particular need for children in their middle years (8 to 12 years) to have access to 'programs that help foster social networks—children with disability are often isolated socially, especially in regional or rural areas.'[175]

The Committee heard that such support for children to develop social connections can have real benefits. Noah's Ark told the Inquiry:

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[174] *Submission S102*, Noah's Ark, p.3.
[175] *Submission S021*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, p.19.

> … evidence shows that despite the challenges, children with disability can and do form meaningful friendships with typically developing children and these connections 'not only provide enjoyment, but help promote their growth and development'.[176]

School environments are an obvious setting for the development of friends and social networks. The *National quality standard for early education and care and school age care* has set specific standards for all children in the development of relationships, with one seeking to ensure that 'each child is supported to build and maintain sensitive and responsive relationships with other children and adults.'[177]

In this context, Noah's Ark has developed a resource for early childhood educators titled *Participating and belonging: inclusion in practice*. The resource has a specific section on relationships, providing guidance on how to encourage children with disability to engage with other children and vice versa. It explained to the Inquiry that:

> We use that in our work with early childhood education and care. It has tip sheets in it for teachers and that sort of thing, so it is very practical and down to earth. These are some of the things that help. We would very much argue that it is not changing the child that is needed, so you do not 'therapise' the child; you change the environment, you change the adults and you change the attitudes.[178]

Section 4.3.4 outlined the experience of bullying that children with disability continue to experience in schools that is a consequence of attitudes to disability. STAR Victoria told the Inquiry that there needs to be a stronger focus on building social interactions in school settings:

> We have an expectation as a community and as a society that young people will get not only the academic stimulus they need to set them up both currently and for their future life but also the social skills — making friends, keeping friends, peer support, having a sense of belonging and finding a place in the world.[179]

It suggested that Victoria needs to be more innovative in how it goes about creating environments that help children with disability to form friendships and social networks:

> It is doing things like starting friendship circles, because the one thing we found is that friendship is a major issue for our students — how we can help friendships in classrooms using friendship buddies, learning buddies, teamwork, creating an environment where we all look out for each other.[180]

Supporting families

The Committee heard that informal family carers are often the gateway to the social networks and connections of many people with disability, and frequently can enhance (or weaken) their experience of social inclusion. Section 4.3.1 established that, on the whole, informal carers willingly support and provide care to their family member with disability. Yet many feel burdened by the strains and stresses of caring.

In view of the important role that informal carers often have in the lives of people with disability, the Committee determined that it is important that they

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176   *Submission S102*, Noah's Ark, p.3.
177   Australian Children's Education & Care Quality Authority (11 April 2013) *Quality area 5—Relationships with children.* ACECQA. Accessed on 30 July 2014 from http://www.acecqa.gov.au/Relationships-with-children.
178   *Transcript of Evidence*, Noah's Ark, Melbourne, 31 March 2014, p.4.
179   *Transcript of Evidence*, STAR Victoria Inc, Melbourne, 5 May 2014, p.3.
180   *Transcript of Evidence,* STAR Victoria Inc, p.4.

are supported too. The Policy Research Initiative in Canada made the following point regarding building social capital:

> A first approach is to support directly the care recipients, as through home care, which alleviates the burdens placed on their care network of close friends and family members. A second approach lies in supporting the networks of caregivers directly through such programs as respite care or the compassionate care leave.[181]

In his evidence, Associate Professor Ramcharan from RMIT University emphasised the importance of supporting the supporters:

> I think it is about the way in which you fund advocacy but it is also, to be frank, about the way in which you support the naturally existing networks and families who are under huge amounts of stress and pressure—so families and also friends, too, who provide that supportive fabric for people with disability in the community.[182]

Chapter 2 outlines the legislative and policy frameworks for carer recognition at national and state levels. Carers Victoria explained, however, that 'while 10 years ago they wanted recognition, carers no longer want recognition; they want to be valued and supported.'[183] The Committee identified that in the UK, legislation has been passed that extends beyond recognition and provides carers with legal rights and entitlements:

- right to have needs considered

- right to have an assessment of needs

- right to have co-operation from authorities.

The NDIS will potentially move in this direction in a practical way. In its report, the Productivity Commission stated that 'the support provided by families would be considered in assessments, and where appropriate, carers also assessed and given additional supports.'[184] As outlined in Chapter 2 the Australian Government has established legislation to recognise carers and developed a *National carer strategy*.

Carers Victoria explained to the Inquiry that 'informed, connected and skilled caring families' can support the social inclusion of their family members with disability in a range of ways that include:

- knowledge of and access to economic resources and systems such as education, training and employment

- knowledge of and access to mainstream agencies and services such as health, housing, income maintenance, law and advocacy services, transport, leisure and recreation services

- social capital, the facilitative influence and advantages flowing from the totality of the relationships of the caring family

- strong networks of emotional support from wider family and close friends and neighbours

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[181]   Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, p.18.
[182]   *Transcript of Evidence,* Associate Professor Paul Ramcharan, p.7.
[183]   *Transcript of Evidence,* Carers Victoria, p.7.
[184]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.11.

- access to competent and responsive disability services for the benefit of the person with the disability, and access to specialist carer services to enhance their own capacity in the caring role.[185]

VALID also emphasised the need for support for informal family carers in view of the valuable role they have in supporting people with disability:

> Families play a critical role in supporting people to be included, but families themselves need support to avoid feeling isolated and overwhelmed. Because many families have negative experiences of systemic resistance and social stigma, they often need support to remain positively focused and ambitious for their sons and daughters.[186]

Noah's Ark provided its perspective that 'this care is different to the care needed to support the inclusion of adults with disability and needs to embrace the whole family, not just the individual child.'[187]

The Committee heard that there is a broad range of supports that informal carers often need when caring for a person with disability. These include access to disability and other allied services, education, skills and tools, the opportunity to take a break, and greater financial stability. Table 4.2 lists some of the evidence received by the Inquiry relating to support requirements and examples of programs providing such support.

Table 4.2: Support requirements for informal carers

Support type	Description	Examples of programs and forums
Adjusting to disability	- support for grief and loss - peer support for carers	*Planning for the future forum* (Manningham City Council) [188] *Norparrin parent to parent peer support* (Whittlesea Disability Network) [189] *Power on for carers (Women's Health West)*
Practical support	- providing health care to family member - navigating support systems - supported decision making - legal support—powers of attorney and estate planning - special disability trusts	*Strengthening families* (Independence Australia) *Planning for the future forum* (Manningham City Council) [190] *Families as planning partners* (VALID)
Personal support	- building resilience - developing supports and building strong relationships	*Norparrin parent to parent peer support* (Whittlesea Disability Network) [191]

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[185] *Submission S087*, Carers Victoria, p.2.
[186] *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.11.
[187] *Submission S102*, Noah's Ark, p.3.
[188] *Submission S064*, Manningham City Council, p.4.
[189] *Submission S037*, Whittlesea Disability Network, pp.3–4.
[190] *Submission S064*, Manningham City Council, p.4.
[191] *Submission S037*, Whittlesea Disability Network, pp.3–4.

Support type	Description	Examples of programs and forums
	• skills to manage challenging behaviours	• *Planning for the future forum* (Manningham City Council) [192] • *Affirming families* (Melbourne City Mission)

Taking a break	• respite— short-term or time-limited break while someone else supports the person with disability	• Multiple initiatives that include:
		  ♦ after school care
		  ♦ in-home support
		  ♦ camps, holidays, weekends away
		  ♦ facility based respite
		  ♦ community activities
		  ♦ school holiday programs.

Source: Compiled by Family and Community Development Committee.

The Committee heard that there is a need for increased peer support for carers. The Geelong Parent Network stated that 'carers need more interaction with their peers.'[193] Whittlesea Disability Network also expressed a need for more parent to parent support, referring to the Norparrin Early Childhood Intervention Service which it explained 'recognises and builds on the power of peer support for parents of young children with disability who face years of dealing with a complex and often alienating education and service system.'[194] It went on to state that:

> The parent to parent support program links families of children with disability with other families. It facilitates the social inclusion of children and their families by demonstrating respect for their individual needs and circumstances whilst building resilience. Families often form lifelong and strong supportive relationships. The current DEECD framework does not fully support this model of service.[195]

In its submission, Melbourne City Mission also explained the value of these peer support approaches, stating that:

> With families coming together in groups to share their feelings of grief, despair and often exclusion, they begin to feel 'normal' when they hear others tell the same story. They begin their resilience training by hearing other parents have similar experiences to tell.

> They strengthen their resolve to tackle new situations [in the broader community and in mainstream services] where they may face adversity, through sharing others' success and tactics.[196]

As outlined in Section 4.3.1, many Inquiry participants spoke of the importance of respite to provide families with the opportunity for a break. The Association for Children with a Disability stressed that respite needs 'to provide a high

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[192] *Submission S064*, Manningham City Council, p.4.
[193] *Submission S034*, Geelong Parent Network, p.2.
[194] *Submission S037*, Whittlesea Disability Network, pp.3–4.
[195] *Submission S037*, Whittlesea Disability Network, pp.3–4.
[196] *Submission S111*, Melbourne City Mission, p.22.

quality experience for both the person with disability and their family carer.'[197] The Department of Human Services (DHS) told the Inquiry that:

> As the name suggests, respite aims to provide parents and carers of people with disability with a break, but we have moved markedly from this simply meaning that a person goes into a facility for an evening. There are many great examples of how innovative respite approaches promote social inclusion.[198]

The Whittlesea Disability Network provided information about one innovative initiative known as the Whittlesea Respite Consortium. Box 4.9 outlines how this consortium is operating.

Box 4.9: Respite—exploring alternatives

Carers identify responsive and flexible respite as essential to their capacity to 'keep on keeping on' caring for their family members with disability.

WDN [Whittlesea Disability Network] and Council staff established the Whittlesea Respite Consortium to enhance collaboration between existing respite providers in the municipality. Through collaboration and learning from each other we have been able to attract new funds (from Federal and State governments) to the municipality for respite services, building on funding already provided by Council e.g. WhiSKHA (Whittlesea Special Kids' Holiday Activities) holiday programs for both primary school children and teenagers. We meet quarterly to review current activities and discuss how we can work together to address continuing service gaps and emerging needs. In a municipality where there are very few services and a hugely expanding population, this collaboration has enabled us to envisage and develop creative service responses to meet the needs and aspirations of people in our community

Source: *Submission S037*, Whittlesea Disability Network, p.3.

The Committee also heard that some respite initiatives are being developed with a core focus on creating opportunities for people with disability to build social connections while their carer takes a break. Maribyrnong City Council outlined its 'SCRAM' Program—*Social club recreation at Maribyrnong*. It explained that:

> A trial program involved group outings for people with disability under the age of 65. The outings were met with an enthusiastic response and involved a variety of activities. Participants suggest the activities they would like to do and the outing is chosen by majority of votes. The program was developed to encourage social connectedness and opportunity to have a choice of group respite as well as one on one respite outside of the program. This program was in response to client requests to extend their social activity.[199]

In addition to respite, practical support was another form of assistance that families indicated they need. Independence Australia told the Inquiry about the type of practical support it provides to families adjusting to a family member with newly acquired disability:

> When we sent our support workers to work with a client, a number of carers and families were saying to us, 'Hey, that's really great. We got a bit of training on how to do bowel care and how to do a PEG feed, but once we left the hospital and came home we had forgotten. We're not confident. We would like to do that training.' We started to think

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[197]   *Submission S122*, Association for Children with a Disability, p.8.
[198]   *Transcript of Evidence,* Department of Human Services, p.4.
[199]   *Supplementary evidence*, Response to request for information, Maribyrnong City Council, 30 July 2014.

about how to address this and how to actually train up family members to feel a bit more confident with the nature of the work and support they need to provide to their loved ones, and that is where the Strengthening Families Program grew from.[200]

4.5.2.   Supporting existing opportunities and networks

Many opportunities already exist in the community that contribute to people with disability expanding their social connections. Some are specifically designed to create opportunities for social interactions—such as meal programs and social events. Others are focused on an interest area or have a specific objective, yet by default create opportunities for social interaction and building connections—such as sport teams and community gardens. Some are informal networks, others are more formal.

The City of Boroondara explained that greater initiatives are needed at the local level to build social capital:

> In order to facilitate meaningful and on-going connections, both local government and the community sector must work to deliver initiatives that link up existing disability networks with service user, advocacy and support groups within their municipality.[201]

Specific initiatives to increase social interaction opportunities

Many non-government organisations and local councils have identified a need for greater opportunities for people with disability to engage in social interactions. In response to this need, some have established initiatives to specifically provide these opportunities for engaging with others in social settings.

SkillsPlus and BRACE provided information about the programs that they have established, stating that:

> Ballarat Northern knights, Options Social Club and interclub engage people with a sense of community. There are a range of opportunities for convivial interactions that promote self-determination and raise aspirations for the individual and the family such as career development planning, transition education budgeting and employment programs.[202]

One key point made by participants is that these types of social functions need to expand beyond people with disability socialising only with other people with disability. Table 4.3 outlines examples of these types of initiatives and programs provided in evidence to the Inquiry that are specifically designed to increase opportunities for social interactions.

Table 4.3: Examples of initiatives to increase social interaction

Program	Description
Social Events / Family Fun Days	• Children and families accessing Extended Families programs and also those waiting for access to other services are invited to family fun days and other social events held each term, such as the annual Family Fun Day at the zoo.[203]

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[200] *Transcript of Evidence,* Independence Australia, p.3.
[201] *Submission S048*, City of Boroondara, p.10.
[202] *Submission S042*, SkillsPlus and BRACE, p.7.
[203] *Submission S063*, Extended Families Australia, p.2.

Program	Description
ABI Clubhouse	• The ABI Clubhouse (in metro Melbourne) is a place for adults with brain injury to meet, develop friendships, work and learn. It encourages self-confidence, self-determination and regaining self-confidence.[204]
Sunrise	• A program that offers friendship, social connectedness, information and skills development for women in the west who identify as having disability.[205]
Options Social Club	• Engages young adults in the community encouraging friendship groups and social interaction. Users choose events and activities which include movies, art tours, zoo visits, bowling, swimming, meals out, in house nights at interclub with games and themes.[206]
Centre Based Meals	• A program that provides a community based location for residents of Stonnington to enjoy a nutritious meal in a social environment.[207]
Debutante Ball for All	• An event that brought together community groups, residents and agencies to work together on a common goal. • Provided a celebration of local young people from diverse backgrounds, who came together and made connections and friendships that they may not have otherwise.[208]

Source: Compiled by Family and Community Development Committee.

Other initiatives—social interactions by default

The Committee heard that there are many activities and forms of participation that contribute to opportunities for social interactions that are not designed specifically for the purpose of making connections. Sport is a good example of how social interactions can occur by default through an activity with a specific goal, such as playing with a team to win a sports game. Disability Sport and Recreation explained this:

> Socialising is a fundamental human need and is a determinant of health, which is our focus. As humans we need acceptance and understanding from other humans where we work, live and play. Sport and recreation provides this platform for human interactions, connections and acceptance.[209]

FIDA also spoke of the value that sport contributes to increasing social connectedness. FIDA is an association designed to give people with disability an

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[204] *Submission S069*, Victorian Coalition of ABI Service Providers Inc (VCASP), p.18.

[205] *Submission S071*, Women's Health West, p.1.

[206] *Submission S042*, SkillsPlus and BRACE, p.7.

[207] *Submission S017*, City of Stonnington, p.3.

[208] Department of Human Services *The Debutante ball for all: A case study.* Community building program guidelines - Disability services, DHS, p.2. Accessed on 1 August 2014 from http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/policies,-guidelines-and-legislation/community-building-program-guidelines-disability-services.

[209] *Transcript of Evidence*, Disability Sport & Recreation, Melbourne, 20 March 2014, p.2.

opportunity to participate in football. It has over 500 players participating in a regular football competition. Mr Whitaker from FIDA explained that:

> We have got a lot of clubs where there are groups of players who will go out on a weekend together, whereas before they would spend the Saturday night sitting at home on the couch. They might go out and see a band play or go and have a few drinks somewhere, which is fantastic; that is exactly what we want. It gives them a reason to socialise. Without having sport and that place to go to, to be honest, they do not have a huge circle of friends. There is no reason to socialise without that club environment.[210]

The Policy Research Initiative in Canada highlighted the value that community building and development approaches can bring to the expansion of social connections:

> Applying a social capital perspective to community development policy problematiques and program design can help emphasize the positive resources that communities already have. This is highly relevant in a context where governments are increasingly interested in developing partnerships at the local level as a basis for policy development.[211]

A range of other opportunities exist for unplanned, fortuitous social interactions. These might include groups that form for specific purposes such as advocacy or community activities. For example, some councils have disability advisory groups that advise their council on issues relating to access and inclusion, but also lead to connections and interactions with a broader network.

Other opportunities include online networks and communities. Ablelink told the Inquiry of the benefits of online forums for the deafblind community, stating that they 'are now learning, slowly, how to conduct themselves socially, by participating in social networks online.'[212] Monash City Council told the Inquiry that this is an avenue that needs further exploration and that:

> … the internet and social media such as Facebook and Twitter could be an effective way for some people with disability to find a positive connection with society.[213]

Table 4.4 provides examples of programs that potentially provide opportunities for greater social interaction while engaging in common interests. This is by no means an exhaustive list given the multitude of activities that people participate in.

Table 4.4: Spontaneous social interaction—examples of activities of common interest

Program	Description
Scooter and Wheelchair Access Team (SWAT)	SWAT is a Council-convened local scooter user group, which advocates for people with mobility issues including Boroondara's ageing population and people with disability. The group provides advice, information and guidance to the City's residents and visitors, as well as building sustainable social connections with the various clubs, groups and networks in the region. Through SWAT, people with disability are able to actively engage in self-advocacy and social participation. (City of Boroondara)

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[210] *Transcript of Evidence,* Football Integration Development Association (FIDA), p.3.
[211] Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, p.17.
[212] *Submission S033*, Ablelink, p.2.
[213] *Submission S120*, Monash City Council, p.7.

Program	Description
Ballarat Northern Knights	An AFL rules Football team for players with disability under FIDA organisation, Melbourne social club for players away from football here at interclub. Nth Ballarat Knights have been together for 21 years and 18 years in FIDA league. Players have purpose and focus, personal confidence, parents, carer's and volunteers feel connected with club and staff improved health, fitness and footy Skills (SkillPlus and BRACE)
Collaborative Garden Group	Mornington Peninsula Shire MetroAccess has partnered with Konnections and Connecting Skills Australia to offer a fortnightly gardening and social group at the Eco Living Display House at the Briars, Mt Martha. Now in its 4th year, this group learns about growing vegetables, healthy eating and cooking in a fun and friendly environment. (Mornington Peninsula Shire)
Community garden group	Glen Eira MetroAccess has been working with Yooralla to facilitate their engagement with the broader community. The group provided plants for a carers day event, community conference and participated in GE Council's cultural diversity festival selling their produce. (Mornington Peninsula Shire)

Source: Compiled by Family and Community Development Committee.

Peer support and advocacy groups

The Committee heard that while disability peer groups are usually segregated from others in the community, they can provide important opportunities for social interaction and support. Peer-based approaches 'involve those with a shared disability providing support to each other, sometimes exclusively of others who do not have disabilities. These supports may include drop-in centres or peer-counselling where there is a shared pooling of experience.'[214]

Some research has suggested that there is value in peer-based approaches, but it also identifies that opinion is divided on whether such approaches are beneficial. Many distinguish between advocacy groups and peer groups:

> Advocacy groups, in particular, are highly valued and are deemed to differ from other segregated groups on the basis that membership is voluntary rather than by default. Advocacy groups, in particular, may have considerable potential in relation to independent living, most notably in relation to directing policy and service development.[215]

The researchers continue on to explain that 'these self-regulatory or self-authored spaces for people with disability divide opinion, as for some they

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[214] C. Duggan & C. Linehan (2013) *The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature*, p.204.

[215] C. Duggan & C. Linehan (2013) *The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature*, p.204.

represent a return to a segregation of people with disability, while for others they provide an opportunity for new discourses and imaginings of disability.'[216]

The Committee heard that some organisations use peer groups in the context of providing support. Vision Australia referred to its peer support programs:

> … peer support and recreational services to its clients to reduce the social isolation commonly experienced by people who are blind or have low vision. Telelink is an ongoing telephone based group program that is facilitated by volunteers via teleconference. It provides regular social and peer support, as well as special interest and recreation activities for people who are socially or geographically isolated.[217]

Participants informed the Inquiry that some people with disability choose to interact with peers with a similar experience of disability due to shared experiences that can create a sense of both support, connection and cultural affinity. Some peer networks have developed their own culture over time, such as the deaf community. In its submission Vicdeaf explained that:

> Many Deaf people view themselves as belonging to a cultural and linguistic minority. They possess a shared sense of history, experience, language and collective aspirations. Most, however, are born to hearing parents and not directly into Deaf culture and community.[218]

It went on to state that 'when Deaf people communicate with each other in Auslan they do not experience isolation or exclusion. In this context they are neither disabled nor disadvantaged by their deafness.'[219]

Ablelink also explained that deafblind people 'are developing a sense of belonging with their "deafblind culture"' and that this is reducing their feelings of isolation in the community.[220] Deafblind Victorians also emphasised the value in coming together as an advocacy group.[221]

In its submission Wellington (Local Government Area) Community provided an example of how through peer support, people with disability can increase their social capital. The Community explained the importance of 'individual reflection' and how:

> … in the Five Star Project community everyone rallies around each other. People always encourage each other to get out and join in. We are working out how we can look after each other when parents/care givers cannot support us.[222]

Greg expressed his views about the importance of peer support, explaining that:

> I want to have a place I can come to where [there are people like me], and where I can be challenged. Mentally, it makes you feel better about yourself.
>
> I went to a neighbourhood house, but [in terms of what they could offer me], I saw myself at a different level.
>
> I did a course through the Life Moves 'Peers Inspiring Peers' program. I absolutely loved it. It was a demanding course and I was [learning alongside people who were] functioning at a high level with their brain activity.[223]

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[216] C. Duggan & C. Linehan (2013) *The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature*, p.204.

[217] *Submission S112*, Vision Australia, p.12.

[218] *Submission S088*, Vicdeaf, p.4.

[219] *Submission S088*, Vicdeaf, p.4.

[220] *Submission S033*, Ablelink, p.3.

[221] *Submission S113*, Deafblind Victorians, p.1.

[222] *Submission S083*, Wellington (Local Government Area) Community, p.5.

[223] *Submission S111*, Melbourne City Mission, p.8.

4.5.3.   Establish favourable conditions for building connections

Many different circumstances, programs and initiatives will contribute to favourable conditions for building connections. Some are obvious, others much less so. For example, it is well known that accessible environments and public infrastructure are important foundations for enabling people with disability to move around the community and connect with people in their networks.

Other favourable circumstances are not as well known, such as 'social brokerage'. Common forms of social brokerage include mentors and coaches, usually in a voluntary capacity. Social brokers can come in many shapes and sizes. For example, Australian and New Zealand Assistance Dogs (ANZAD) made the point that while assistance dogs are trained to provide practical supports to enable independent living, they 'are very strong social magnets. They open up many social interactions for their owners.[224] In this instance, the assistance dogs could also be considered 'social brokers'.

Public infrastructure

Public infrastructure can make a significant difference to the lives of people with disability and the extent to which they can sustain their social connections. Accessible transport enables people to move around the community and meet with friends and other social connections. Accessible buildings enable people with disability to join friends for coffee or meet over meals at restaurants. Universal housing would enable people to visit their friends and family in their homes. Issues relating to accessibility and enabling environments are discussed in greater depth in Chapter 7.

The Committee heard extensively about the importance of accessible toilets for people with disability socialising and connecting in their communities. In particular, many Inquiry participants referred to the Changing Places initiative on the social lives of people with disability. This is discussed in greater depth in Section 7.3 of Chapter 7. Local councils also advised the Inquiry about the importance of accessible events and that many councils have provided guidelines for assisting event organisers to ensure they take accessibility into consideration.

Another example of how public infrastructure affects social connections relates to housing and how it can create favourable conditions for increasing social connections. Where people with disability live and who they live with can impact on how they establish and maintain friendships. Melba Support Services explained to the Inquiry that:

> … group homes can serve to limit social inclusion. Notably, living in homes with four or five unrelated adults may make it more difficult to establish and maintain relationships that lie at the heart of social inclusion.[225]

Research evidence supports the potential for independent living, natural supports and increased social inclusion. In an extensive review of relevant literature one study stated that a 'consistent and unambiguous finding is that those living in community settings have larger and more active social networks than those living in institutional contexts and that the closer the living arrangements

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[224] *Submission S127*, Australian and New Zealand Assistance Dogs Inc (ANZAD), p.3.
[225] *Submission S080*, Melba Support Services Inc, p.5.

approximate to independent living, the larger and more active are those social networks.'[226]

Northern Support Services provided information to the Inquiry about the KeyRing housing and support model. This model is discussed in greater depth in Section 5.3.4 of Chapter 5, which explains that KeyRing supports people who live in a variety of housing arrangements. The model involves nine people living in close proximity to each other and the 'idea of KeyRing is that because people are living close to one another maybe they can walk to one another's houses or they can get in contact with each other via a public transport route—a train or a bus.'[227]

Northern Support Services told the Inquiry that those living in the KeyRing can 'develop a close peer support friendship network within their local neighbourhood, and they are supported through KeyRing to do that.'[228]

The Research Program Leader and Deputy Chair of the Academic Board at La Trobe University, Professor Christine Bigby, explained that a central component of the KeyRing model is building social connections with new friends and others across the community. She stated that this model has:

> … a very important role in planning opportunities for social encounters, in initiating individual social encounters by introducing people and by prompting interaction, and in terms of monitoring and supporting encounters, reassuring the public, stepping in, interpreting and helping people in the community to know how to interact and feel comfortable in doing that.[229]

Northern Support Services explained the benefits that it has witnessed for people participating in the housing and support model:

> We find that when people have stable housing, they have friends they can drop in on and visit. Many people have been very isolated before joining KeyRing; they have never had anyone to have a cup of coffee with or drop in and visit. Once they have those close support friendship networks in place, we really start focusing on building community connections for people.[230]

Social brokerage

Social brokers are individuals who take on a voluntary, intermediary role in the community or in networks. These roles can include mentoring, coaching or formal, voluntary friendship. The individuals or brokers act as connectors across various individuals in a network, and in this sense can provide opportunities for people with disability to build social connections and networks.

The Policy Research Initiative in Canada outlined the role of social brokerage in the context of social capital:

> One potential complementary resource to investment in public spaces and infrastructure involves supporting social brokers or entrepreneurs. These are the coaches, the neighbourhood activists, and the local leaders who can play the role of community broker by breathing life into public spaces and facilitating social connections and alliances.[231]

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[226] C. Duggan & C. Linehan (2013) *The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature*, p.203.

[227] *Transcript of Evidence*, Northern Support Services, Melbourne, 20 March 2014, p.2.

[228] *Transcript of Evidence,* Northern Support Services, p.2.

[229] *Transcript of Evidence*, Professor Christine Bigby, La Trobe University, Melbourne, 20 March 2014, p.4.

[230] *Transcript of Evidence,* Northern Support Services, p.2.

[231] Policy Research Initiative (2005) *Social capital as a public policy tool. Project report*, pp.20–21.

Disability services and other non-government organisations are increasingly introducing programs that use social brokers to provide opportunities for people with disability to develop the types of connections that are important to them. Research has explored the role of social brokers and the opportunities that they can provide for people with disability and for communities. For example, Karingal also emphasised the broader benefits that these types of efforts can have within communities and for people with disability:

> … social capital comes into so much of the work we are doing. Even though we might be doing it for a particular person with disability, when we partner with community stakeholders to create an opportunity for them we are invariably creating a place where other persons with disability can belong.[232]

Box 4.10 outlines the experience of Adam whose goal was to regularly visit a café independently.

Box 4.10: Independence and social capital—Adam

[Adam] had some behavioural issues and anger management issues associated with his disability. One of his big goals was to be able to go to a local coffee shop for coffee in the morning, and he wanted to be able to do that by himself — he wanted his independence. Working with Adam, we ensured that he was safe and that he had independence skills to be able to get there and get back. The work we did with the coffee shop proprietors and staff to build their understanding of disability and Adam individually to accommodate him each morning and to make sure that there was an appropriate response and an inclusive response, if issues occurred, was a vital part of that. Now that coffee shop is probably one of the biggest champions of people with disability in the local area. The skills that the people there learnt in relation to that initial client they carry through in their interactions with all other people coming into that shop, and I am sure that now they are champions more broadly.

Source: Karingal, Transcript of Evidence, p.4.

While some organisations are improving their approaches and adopting more innovative approaches to socially including the people with disability they work with, the Committee heard that there is a preference for volunteer social brokers rather than paid support workers taking on these roles. For example, one research study considered voluntary support for inclusion in comparison with paid support and concluded:

> … that unpaid supports provided to a person with intellectual disability, as part of the host setting, can be an effective means to enhance their inclusion. By contrast, paid disability-specific supports can introduce a range of often unnecessary barriers to achieving inclusion.[233]

STAR Victoria suggested that there is a strong role for volunteers in this space and that there is value in looking to South Australia and its Volunteering Strategy.[234] Chapter 2 also emphasised the value of volunteers in initiatives that aim to increase social inclusion.

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232 *Transcript of Evidence,* Karingal, p.4.
233 N. Wilson, C. Bigby, R. Stancliffe et al. (2013) 'Mentors' experiences of using the active mentoring model to support older adults with intellectual disability to participate in community groups'. *Journal of Intellectual & Developmental Disability*, Vol. 38, No. 4 (344–55), p.346.
234 *Submission S028*, STAR Victoria Inc, p.3.

Table 4.5 provides examples of existing forms of social brokerage in Victoria, mostly involving volunteers and the types of programs that have been established.

Table 4.5: Program models promoting social brokerage

Program	Description
Family Match Program	• Individual volunteers (or volunteer families) provide long term companionship and flexible respite support to a child/young person and their family.[235]
Live Your Community Program (LYCP)	• Individual volunteers provide friendship, practical assistance and mentoring support to a child/young person, helping them develop important life skills and to take part in sport, recreation and leisure events or activities that are of interest to the child.[236]
Compeer Program	• Provides intentional friendships that support the reduction of the isolation and exclusion of people experiencing mental illness who wish to change their situation.[237]
Community Friend Program	• A social support service for people with mild disability. The program gives people the opportunity to access the community, make new friends and enjoy socialising and getting out and about, enriching the lives of both the volunteer and the person with disability through one-to-one friendship and group activities.[238]
Volunteer Friends Program	• The Volunteer Friends Program is a respite activities and holiday program which gives individuals who have disability and live independently or permanently with a carer, the opportunity to enjoy social gatherings and outings, with the support and participation of volunteers.[239]

Source: Compiled by Family and Community Development Committee.

Many Inquiry participants provided examples of how these types of programs have had a positive influence on people with disability. For example, Extended Families Australia outlined the experience of 13 year old Luke and his transition between specialist and mainstream schools.[240] Luke had the opportunity to participate in a pilot with a mentor and experienced positive outcomes. Box 4.11 outlines Luke's experience. Section 3.2.1 of Chapter 3 discussed the value of coaching in the context of people's aspirations.

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[235]   *Submission S063*, Extended Families Australia, p.1.

[236]   *Submission S063*, Extended Families Australia, p.2.

[237]   *Submission S014*, St Vincent de Paul Society, p.3.

[238]   Melbourne City Mission *Community friend program.* Accessed on 10 July 2014 from http://www.melbournecitymission.org.au/get-involved/volunteer-with-us/programs-requiring-volunteers/program-detail/community-friend-program.

[239]   Community Accessability Inc *Volunteer friends.* Accessed on 10 July 2014 from http://gettingthere.net.au/commacc/?page_id=760.

[240]   *Submission S063*, Extended Families Australia, p.3.

Box 4.11: Changing schools—Luke's experience

[Luke] was finding it hard to adjust to his first year at a specialist high school for children with Autism Spectrum Disorders after his mainstream primary school advised his family that Luke would not do well academically and was having significant behavioural issues within a mainstream schooling setting. The challenges Luke experienced in transitioning schools was reflected in his behaviour which had become even more challenging and [was] impacting significantly upon his personal relationships both within his family and at school.

Under the Live Your Community Project, Luke was linked to a volunteer (Jeremy) who supported him to develop his basketball skills so that his membership within a local mainstream Basketball club could be strengthened. Up until this time, Luke had been spending minimal time on court and was not fully included in the team he was assigned to. For a period of 6 months, Luke and Jeremy (a university student living locally to Luke, studying Sport and Recreation Education) met weekly to practice ball skills. Jeremy went to training with Luke and supported the coach to understand Luke's disability. As a consequence of the support he received under the program, Luke's game skills and confidence grew. He became one of the team's key players and felt more authentically included as a member of the Basketball club.

The pilot ended in December 2010 and with its conclusion, formal volunteer support for Luke came to an end. By this time however, Jeremy's weekly practice sessions with Luke were no longer necessary as Luke was now fully involved and included in his team. The boys however had developed a friendship that has endured beyond the pilot with Luke and Jeremy catching up on the phone regularly and getting together every couple of months to go to the footy or for Jeremy to watch Luke playing Basketball. This enduring connection between the two boys is very important to the family who has described Jeremy's friendship and the impact it has had in Luke's life as 'gold'.

During 2010, Luke was doing better academically at his specialist school but he felt increasingly socially disconnected from his peers and this was impacting upon his mood. As a consequence, his family decided to move Luke to a mainstream high school at the beginning of 2011. While Luke was finding the school work challenging at his new school, his family report that he was connecting well with classmates on a social level. For the first time in his life, Luke's Mum says that he was receiving invitations to birthday parties and other events organised by the kids at school. His Mum attributes this growing new dimension in her son's life in part to Basketball and the help he received under the Live Your Community Pilot. By strengthening his membership at his Club and through his friendship with Jeremy, Luke's confidence in interacting with mainstream school peers has grown.

Source: *Submission S063*, Extended Families Australia, pp.3–4.

St Vincent de Paul's Compeer Program is another approach that 'matches one individual to another for the purposes of reducing isolation, developing friendship through regular, friendly meetings that gradually re-engage the companion socially with a patient, non-judgemental person.'[241] St Vincent de Paul Society told the Inquiry that:

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[241] *Submission S014*, St Vincent de Paul Society, p.4.

The boundaries set by the program support both volunteer and companion in developing their friendship without having to negotiate some of the difficulties that naturally developing friendships may deal with in a more relaxed way e.g. who pays for refreshments or activities, how long they meet, whether alcohol can be consumed, how long they should spend together.[242]

Box 4.12 outlines the Compeer Program.

Box 4.12: Compeer Program—reducing isolation through friendship

The Compeer Program began in the USA in 1976. It was brought to NSW, Australia in 1995 under the auspice of St Vincent de Paul Society. It has operated in Victoria since 2003 in eastern and southern Melbourne and in Bendigo. The Victorian Program is fully funded by St Vincent de Paul Society for under $500,000 annually.

The Compeer Program provides intentional friendships that support the reduction of the isolation and exclusion of people experiencing mental illness who wish to change their situation.

In a study conducted by Dr A. Montclaire she states that 'It is well established that friendship has a positive effect on health and wellbeing across the general population.'

Unfortunately those who have lived for significant periods of their life with the effects of a mental illness are often in a situation where they are unable to forge friendships without some external assistance. As part of the study those involved in the Compeer Program were surveyed and interviewed about the benefits they found in the way this program delivered opportunities for social inclusion.

The voluntary nature of this model is a very positive aspect for the companion. They appreciate that someone 'wants' to be with them, rather than being 'paid' to be with them as is the case for many/most of their other interactions. They also appreciate that there is no coercion on their involvement. It cannot be made a requirement of their access to any other service, program or support.

Volunteers enjoy this very personal, individual role of volunteering as something that offers them an opportunity to contribute directly to the wellbeing of another person. Many feel they learn so much from the experience and are better at relating with others in their other social circles than they were prior to their involvement. They comment on the fact that learning about the life of a person who lives with the challenges of mental illness also gives them a better understanding of mental illness and its place in society.

Source: *Submission S014*, St Vincent de Paul Society, p.3.

Finding 4.7

While it is essential that relationships and social connections are 'natural', there are approaches that can be pursued to increase opportunities and create favourable conditions for relationships and networks to develop naturally and build social capital.

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[242]   *Submission S014*, St Vincent de Paul Society, p.4.

Recommendation 4.1

That when developing its next State Disability Plan in 2016 and in consultation with people with disability, the Victorian Government incorporate a strategy for effectively and appropriately strengthening connections and social capital with three objectives:

- create opportunities for establishing and maintaining connections and networks—such as new networks and building the capacity of people with disability who need support

- establish favourable conditions for sustainable relationships and networks—such as social 'brokerage' (mentors, coaches) and good public infrastructure

- support existing opportunities and networks—such as existing programs that aim to provide opportunities for increased social interaction.

Chapter 5

Foundations for social inclusion

AT A GLANCE

Background

There are core foundations to achieving social inclusion for all members in the community. These foundations include good health, financial security, and safe, affordable and secure housing. For people with disability, however, it is well-established that they:

- experience poorer health and wellbeing than the general community due to lower awareness of health issues and attitudes of health practitioners

- are more economically disadvantaged than other members of the community often due to the costs associated with disability

- have fewer choices about their living arrangements than other community members.

The National Disability Insurance Scheme will contribute to transformational change in areas that are the foundations for social inclusion, such as service provision.

Key findings

- Evidence demonstrates that people with a severe or profound core activity limitation report having greater physical and mental health concerns and higher levels of distress compared with others in the community, including suicidal thoughts. **(Finding 5.1)**

- In the context of the National Disability Insurance Scheme, mainstream health services will need to be accessible and build capacity to support people with disability. **(Finding 5.2)**

- A range of disability specific supports are required to meet the diverse needs of people with disability and the move to individualised support is increasing their choice and control over the nature of supports they purchase. **(Finding 5.3)**

- Factors such as location, appropriate support and housing design are key considerations to ensure housing contributes to social inclusion. **(Finding 5.4)**

- People with disability need to choose the living arrangements that are suitable to their lifestyles and generally have the following options:

  - living in the community (own home, renting, or living with a partner, family or friends)

  - living in communities with specialist disability support (such as KeyRing models and supported living arrangements)

  - living in government funded disability accommodation (such as shared supported accommodation). **(Finding 5.5)**

AT A GLANCE

Recommendations

That the Victorian Government incorporate into future State Disability Plans specific strategies, actions and targets that aim to:

- improve health promotion efforts for people with disability

- ensure accessible health information

- identify and respond to the causes of mental health issues that people with disability experience. **(Recommendation 5.1)**

That the Victorian Government:

- Negotiate with the National Disability Insurance Agency to establish an online forum for the disability service sector to ensure up-to-date and clear information about the services available to people with disability and their families in Victoria, in order to ensure a smooth transition between Victorian supports and supports to be provided under the National Disability Insurance Scheme. **(Recommendation 5.2)**

- Is more specific about its intentions to encourage the building industry, councils and social housing providers to incorporate the national *Livable housing design guidelines* and introduces specific incentives to encourage the development of affordable housing that meets livable housing design guidelines. **(Recommendation 5.3)**

- Negotiate with the National Disability Insurance Agency to ensure resourcing for flexible housing models that have proven success in promoting the social inclusion of people with disability. **(Recommendation 5.4)**

Self-determination, choice and control are central to social inclusion. For people with disability there are a number of factors that can assist in achieving self-determination and autonomy, including appropriate levels of support. This chapter addresses good health, access to quality supports, choice in living arrangements, financial security, and access to justice. These factors are the core foundations for social inclusion of people with disability.

Through its *State disability plan 2013–16*, the Victorian Government has identified strategies and implementation actions to improve aspects of health, housing and support for people with disability. The Committee recognises that with the introduction of the National Disability Insurance Scheme (NDIS) and the changing responsibilities of all levels of government, a number of these strategies will need to be adjusted, particularly in the context of disability support services.

The NDIS is anticipated to bring transformational change to the lives of many Australians with disability. It is anticipated to influence factors such as money, services and supports, which are all important contributors to the social inclusion of people with disability. It will change how people with disability access services they need and is intended to address the financial constraints many people experience.

The Victorian Government will continue to hold some responsibility in the transition to the NDIS from 2016 to 2019 for aspects relating to the health, housing and financial security of people with disability. This chapter discusses health, supports, housing, financial security and access to justice. In view of the transition to the NDIS, the Committee does not focus extensively on service provision for disability supports.

5.1. Good health and social inclusion

The Committee heard that health and inclusion are 'inextricably intertwined'.[1] Poor health and wellbeing can undermine a person's capacity and desire to participate in economic, social and cultural spheres of society. Dr Jane Tracy, Director of the Centre for Developmental Disability Health Victoria (CDDHV) at Monash University highlighted the links between health and social inclusion in evidence to the Inquiry:

> Ill health is a major barrier to social inclusion. People who are feeling unwell or in discomfort or distress—all of us when we are feeling in pain, discomfort or distress—tend to turn inwards. To engage and to be socially included we need to feel as well as we can and be free of pain and distress in that regard … Social inclusion is all about engagement, and we need to be optimally engaged in order to be included.[2]

In addition, Dr Tracy explained that social inclusion also leads to improved health and wellbeing, particularly mental health. She stated that 'social inclusion is important to our health: to be included, to be valued and to build self-esteem builds resilience and builds confidence in people.'[3]

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[1] *Submission S079*, North East Primary Care Partnership, p.9; *Submission S108*, Centre for Developmental Disability Health Victoria, p.3.

[2] *Transcript of Evidence*, Centre for Developmental Disability Health Victoria, Melbourne, 6 March 2014, p.2.

[3] *Transcript of Evidence,* Centre for Developmental Disability Health Victoria, p.2.

The Committee heard that people with disability experience more issues relating to their overall health and wellbeing than others in the community. This difference in health often does not relate to a specific health condition or disability but more broadly to the status of people with disability in society.[4] The multiple disadvantages that people with disability encounter are major contributors to their levels of physical and psychological health and wellbeing.

CDDHV suggested to the Inquiry that:

> The kind of ill health that people with developmental disabilities experience is similar to other groups in the population. Indeed there are similarities with the indigenous population in Australia, with people with intellectual disabilities dying 20 years earlier than the general population, as is the case with indigenous Australians. The vulnerability and the barriers that people experience in relation to health overlaps with other vulnerable groups such as those with mental illness and homeless people.[5]

A 2012 VicHealth research report, *Disability and health inequalities in Australia*, supports these views, indicating that people with disability are more likely to have a chronic illness or early onset of many chronic conditions compared with other people in the community.[6]

The Victorian Government has also identified that people with disability experience more health issues than others in the community. Its *Companion document* to the *State disability plan 2013–16* points to 2010 data released by the Australian Bureau of Statistics (ABS). This data reveals an estimated 43 per cent of Australians with a core activity limitation rated their health as excellent/very good or good and 57 per cent as fair or poor, compared with 96 per cent and 4 per cent respectively of Australians with no recognised disability.[7]

People with disability are also more likely to experience mental health problems. Data produced by the Australian Institute of Health and Wellbeing (AIHW) in 2007–08 revealed that Australians with a severe or profound core activity limitation are almost five times as likely as the wider population to report having moderate and high or very high distress levels and having suicidal thoughts, and are nine times more likely to attempt suicide.[8] Some types of disability make people more at risk of mental illness. Dr Tracy stated to the Inquiry that:

> … there is that big overlap where people who have intellectual disability have a much greater risk of developing a mental illness. That is a compounding factor that needs to be understood so that we address the treatable condition and we provide support for the lifelong aspects of people's needs.[9]

In addition, Inquiry participants emphasised the significant adjustment people who acquire a disability need to make. One research study concluded that people who acquired a brain injury after a trauma 'often find the process of social rehabilitation extremely difficult.'[10] This is consistent with evidence heard by the Inquiry. Mr Bil Hurley who appeared with the Summer Foundation before the Committee explained his experience:

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[4]   VicHealth (2012) *Disability and health inequalities in Australia. Research summary*. Carlton South, VicHealth, p.1.

[5]   *Transcript of Evidence,* Centre for Developmental Disability Health Victoria, p.2.

[6]   VicHealth (2012) *Disability and health inequalities in Australia. Research summary*, p.3.

[7]   Australian Bureau of Statistics (2012) *General social survey: Victoria 2010. cat. no. 4159.05,* Canberra, ABS. Referred to in Department of Human Services (2012) *Victorian state disability plan 2013–2016. Companion document*. Melbourne, DHS, p.20.

[8]   Department of Human Services (2012) *Victorian state disability plan 2013–2016. Companion document*, p.22.

[9]   *Transcript of Evidence,* Centre for Developmental Disability Health Victoria, p.9.

[10] M. Izaute, C. Durozard, E. Aldigier et al. (2008) 'Perceived social support and locus of control after a traumatic brain injury (TBI)'. *Brain Injury*, Vol. 22, No. 10 (758–64), p.760.

> Until my early 20s, I was a street artist—a paid vandal. I was out with mates one night celebrating the opening of my first art exhibition. To make a long story short, I was in the wrong place at the wrong time. I was assaulted. From hospital I went into rehab in a nursing home. It is difficult to know how to describe that time. I can tell you that I tried to end my life.[11]

Mrs Mary Nolan AM, a parent of a son with disability, asked the Committee to consider the experience of acquiring a disability:

> Can you imagine being in the prime of life one day and coming to consciousness/ 'waking up' days/weeks/months later unable to speak, move or see much? Often in pain with severe spasticity. And everything is being done to you in a clinical environment which is like an alien land? Depression and fear are rife. Then discharge from hospital to aged care, home or disability facility with staff/carers with little or no knowledge of how to care/support such a person.[12]

Monash Health explained that 'adjusting to a new disability can take time and nurturing.'[13] Many health and community service organisations have recognised this and developed programs to assist people undergoing such a life altering transition.

For example, in recognition of the emotional and psychological challenges in adjusting to an acquired disability, SANE Australia has developed a specific program for people who have suffered a spinal cord injury (SCI), acknowledging that 'the emotional impact of a new SCI—feeling sad, frightened, confused, worried or angry, for example—can be overwhelming.'[14] The Committee considered there is scope to expand this model to provide mental health support for people adjusting to other forms of disability.

The evidence reflects that people with disability continue to experience poorer physical and psychological health and wellbeing than others in the community, which has negative consequences for their levels of social inclusion.

Finding 5.1

Evidence demonstrates that people with a severe or profound core activity limitation report having greater physical and mental health concerns and higher levels of distress compared with others in the community, including suicidal thoughts.

5.1.1.   Factors that influence the health of people with disability

According to the World Health Organization (WHO), there are multiple variables that influence the health of people with disability 'including individual factors, living and working conditions, general socioeconomic, cultural and environmental conditions, and access to health care services.'[15]

Certain factors can compound the health concerns of people with disability. For example, some people with disability can experience earlier onset of age-related health concerns. As COTA Victoria told the Inquiry:

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[11]   *Transcript of Evidence*, Summer Foundation Ltd, Melbourne, 17 March 2014, p.4.
[12]   *Submission S128*, Mrs Mary Nolan AM, p.4.
[13]   *Submission S068*, Monash Health, p.5.
[14]   SANE Australia (2014) *Staying mentally healthy when you have a spinal cord injury*. SANE factsheet 38 slide 1, SANE Australia. Accessed on 4 July 2014 from http://www.sane.org/information/factsheets-podcasts/848-staying-mentally-healthy-when-you-have-a-spinal-cord-injury.
[15]   World Health Organization (2011) *World report on disability*. Geneva, WHO, p.57.

> For Victorians living with disability, the challenges of ageing and age discrimination-which affect all older Australians—are likely to be compounded, with major transitions in health and social support, changes to finances and to 'place'.[16]

Similarly, Women with Disabilities Victoria (WDV) told the Inquiry that gender can play a compounding role in achieving good health. WDV commissioned a literature review that was undertaken by the Centre for Women's Health, Gender and Society at the University of Melbourne. This review found that women with disability are often unable to access the health services they need to optimise their health and wellbeing and their capacity to participate in community life.[17]

Access to affordable health services helps people to maintain good health through prevention of illness or through the treatment of health issues as they arise. For example, the Spina Bifida Foundation Victoria told the Inquiry that individuals who proactively manage their health 'are hospitalised less and are therefore able to acquire better educational outcomes, sustain employment and are more socially active.'[18]

However, as identified in the 2012 VicHealth report *Disability and health inequalities in Australia*, there are significant barriers that currently prevent people with disability from accessing optimal health care, such as 'inadequate transportation, failure to provide assistance with communication, and discriminatory attitudes among healthcare staff.'[19] In its submission, CDDHV reinforced these issues:

> People with disability are not fully included in healthcare services as significant barriers still exist to access appropriate health services. Adults living with intellectual disability also encounter barriers to disease prevention and health promotion interventions. This then compounds the risk of preventable and secondary health conditions such as diabetes, pressure ulcers, pneumonia, depression and other mental health conditions. These health conditions interfere with the person's ability to participate in family and community life.[20]

Some of the barriers to good health identified in evidence to the Inquiry include:

- attitudinal barriers in service provision

- failure to include people with disability in decision-making about their own health

- inadequate sexual and reproductive health services

- failure of health promotion initiatives to adequately reach people with disability

- failure to provide health information in a range of accessible formats

- limited knowledge and understanding about health that could hamper the ability to seek medical help.[21]

The Committee heard that people with disability are often treated differently in the health system from others in the community. It also heard that there is a continuing need for health services to be more responsive to people with

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[16]   *Submission S060*, COTA Victoria, p.5.
[17]   *Submission S051*, Women with Disabilities Victoria, p.15.
[18]   *Submission S031*, Spina Bifida Foundation Victoria, p.3.
[19]   VicHealth (2012) *Disability and health inequalities in Australia. Research summary*, p.4.
[20]   *Submission S108*, Centre for Developmental Disability Health Victoria, p.3.
[21]   *Submission S051*, Women with Disabilities Victoria, p.15; *Submission S097*, Whitehorse City Council, p.11. See also, for example, *Submission S100*, Communication Rights Australia & Disability Discrimination Legal Service Inc, p.12; *Submission S010*, Ms Raelene West, p.10.

disability. For example, WDV told the Inquiry that its members repeatedly convey experiences of inadequate and non-responsive health services, including:

> … not feeling respected; not being involved in the decisions that affect their health care and treatment; not being able to get onto the examination table; or the recurrent focus on their disability, rather than their health concerns.[22]

Similarly, the Victorian Council of Social Service (VCOSS) stated that:

> Many people with disability report problems in receiving health services, especially that they are not respected by health professionals, their requirements are not met, that they are excluded from involvement in decisions about managing their health, and they are not given sufficient information about their health status.[23]

Other Inquiry participants emphasised that health services focus unduly on a person's disability rather than on the specific health concerns that might be raised. For example, Ms Raelene West told the Inquiry that:

> … many Victorians with disability are excluded from fair and equitable treatment by the medical profession in hospital settings where decision-making on treatment is made through the basis of the disability alone.[24]

Many Inquiry participants indicated that communication can be a significant barrier to health for people with disability. For example, some people with disability may have difficulty communicating their illness, their pain, or their needs. In turn, services may fail to effectively communicate with people with disability. Whitehorse City Council, for example, suggested that problems can arise when health professionals communicate with support workers rather than directly with the person with disability.[25]

The *State disability plan 2013–16* identified some of the specific barriers and its *2013–14 Implementation plan* contains strategies and actions to improve responses to the health needs of people with disability. There are four overarching strategies:

- improve the coordination of health services

- improve the accessibility of health service provision

- improve understanding of the health needs of people with disability

- provide better support for people with autism spectrum disorder.[26]

These strategies contain 14 implementation actions. Seven of these actions aim to improve services relating to a specific disability, such as acquired brain injury (ABI), mental illness, autism spectrum disorder, and co-morbid substance use. The following sections touch on some of the other actions, also identifying potential additional areas for action.

5.1.2. Preventative health measures and rehabilitation

In view of the higher levels of chronic and other health concerns for people with disability, the Committee heard there is a need for increased preventative health

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22   *Submission S051*, Women with Disabilities Victoria, p.15.
23   *Submission S126*, Victorian Council of Social Service (VCOSS), p.17.
24   *Submission S010*, Ms Raelene West, p.10.
25   *Submission S097*, Whitehorse City Council, p.11.
26   Department of Human Services (2012) *Victorian state disability plan 2013–2016. Companion document*, pp.11–13, 29.

initiatives. Research evidence demonstrates that health promotion interventions such as physical activities are beneficial for people with disability. However, internationally the WHO has identified that:

> Misconceptions about the health of people with disability have led to assumptions that people with disability do not require access to health promotion and disease prevention.[27]

The WHO also made the point that 'health promotion activities seldom target people with disability, and many experience multiple barriers to participation.'[28]

Inquiry participants identified a lack of preventative health promotion strategies that target people with disability, their families and carers.[29] Dental Health Services Victoria, for example, told the Inquiry:

> Health services may have limited capacity to support people with disability. The health care system will need to review models of care, including the skills of health professionals and how they can be expanded to assist in the prevention and early identification of health problems, including poor oral health.[30]

Screening and early identification

WDV identified that preventative services such as mammography and Pap screening are 'not currently meeting their service obligations to reach women with disability.'[31] In 2011 the Department of Health in Victoria undertook research that found:

- Fewer women aged 50–69 with intellectual disability had a mammogram in the last two years than other women of the same age (55 per cent compared with 76 per cent).

- In Victoria, fewer women aged 20–69 years with intellectual disability were screened for cervical cancer than other women of the same age (14 per cent compared with 71 per cent).[32]

The City of Stonnington also indicated in their submission that Victorian research has shown a low uptake of preventative health screening by people with intellectual disability.[33]

The *State disability plan 2013–16* has recognised the importance of improving preventative health strategies and early intervention. The plan identifies two actions to increase the accessibility and awareness of cancer screening programs:

- Ensure cancer screening services are responsive to the needs of people with disability including providing information and training to health professionals and support workers where appropriate.

- Conduct a cancer-screening awareness project for people with intellectual disability.[34]

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[27] World Health Organization (2011) *World report on disability*, p.60.
[28] World Health Organization (2011) *World report on disability*, p.60.
[29] *Submission S097*, Whitehorse City Council, p.12. *Transcript of Evidence*, Disability Sport & Recreation, Melbourne, 20 March 2014.
[30] *Submission S114*, Dental Health Services Victoria, p.4.
[31] *Submission S051*, Women with Disabilities Victoria, p.15.
[32] Department of Health (2011) *Victorian population health survey of people with an intellectual disability 2009*. Melbourne, Department of Health. Referred to in VicHealth (2012) *Disability and health inequalities in Australia. Research summary*, p.4.
[33] *Submission S017*, City of Stonnington, p.3.

The specific approach to implementing these actions is not stated in the *Implementation plan 2013–14.*

The Committee heard that Access Officers in the Building Inclusive Communities Program (formerly the Community Building Program) have developed initiatives within local government to improve the uptake of preventative health screening. For example, in Stonnington and Bayside local government areas, workshops have been conducted to promote the take up of preventative cancer screening for women with intellectual disability.[35] The City of Stonnington worked with Bayside Medicare Local, Cancer Council Victoria and another MetroAccess program to plan and deliver these workshops.

In Geelong, collaboration between Breast Screening Victoria, PapScreen Victoria, Cancer Council and Medicare Local led to the identified barriers to screening for people with disability and implemented strategies to overcome them to ensure more inclusive cancer screening services.[36] A workshop to overcome barriers experienced by people with disability accessing screening services was organised for the Geelong area. The City of Greater Geelong Street Access Committee identified the need to improve physical access to the breast screening clinic in Geelong.[37]

These approaches to improving early identification of physical and mental health concerns for people with disability focus on greater collaboration and raising awareness among general practitioners, mental health clinicians, community care, disability services, people with disability and their families.

Inquiry participants also emphasised the need for a collaborative approach to improve health promotion for people with disability. Some recommended the following:

- a greater focus on the role of general medical practitioners (GPs) as the first point of contact for many people with disability, including ensuring that GPs have are familiar with community services and supports[38]

- a coordinated approach between community health care services and the disability service sector[39]

- improved coordination between mental health services and disability service providers to help identify the onset of mental illness for people with disability[40]

- working with carers on communication skills and on proactive health care that does not rely on people coming to the doctor when they are feeling unwell but rather reaches out to people and encourages a proactive approach to pick up disease and disorders at an early stage and provide preventive health and health promotion interventions.[41]

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34   Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014.* Melbourne, DHS, pp.12–13.
35   *Submission S017*, City of Stonnington, p.3.
36   *Submission S116*, Geelong City Council Disability Advisory Committee, p.6.
37   *Submission S116*, Geelong City Council Disability Advisory Committee, p.6.
38   *Submission S097*, Whitehorse City Council, p.12.
39   *Submission S097*, Whitehorse City Council, p.12.
40   *Submission S097*, Whitehorse City Council, p.12.
41   *Transcript of Evidence,* Centre for Developmental Disability Health Victoria, p.2.

The *State disability plan 2013–16* has committed to address some of these issues through its strategies and implementation actions. For example, one action in the Plan is to 'encourage health, community care and disability services to work together to get the best support and care for people with disability and complex health needs.'[42] However, the Plan does not provide specific details about how it will achieve these actions and how success will be measured.

Health promotion initiatives and education

In addition to preventative health screening and early identification of health concerns, Inquiry participants supported education initiatives specifically targeted to maintaining good health. For example, Disability Sport and Recreation commented that the work it does in promoting sport and recreation is all about 'better health outcomes for Victorians with disability'. It suggested there would be value in raising awareness amongst people with disability of the health benefits of engaging in sport.[43] It also recommended that people with disability are included in awareness campaigns that seek to promote physical activity in the community.[44]

The Municipal Association of Victoria (MAV) provided an example from Yarra City Council of the Yarra Leisure Community Membership Program, which provides low cost gym memberships to community health centres. By targeting residents in public housing and rooming houses (many of whom have disability and experience exclusion) and by working in collaboration with a MetroAccess Officer, this program allows many people with disability to practice a healthy lifestyle.[45]

The Committee acknowledges that the *State disability plan 2013–16* includes a commitment to improving the health literacy of people with disability. For example it has made a commitment to conduct health literacy and consumer involvement activities for people with disability, their families and carers to:

• empower them to control their own healthcare

• increase their awareness of when to get help and who to get help from.[46]

However, this does not appear to include promoting the benefits of physical activity and lifestyle choices for people with disability to maintain good health.

As discussed in Section 4.3.2 of Chapter 4, Inquiry participants identified that there is a need for better sexual and reproductive health education for people with disability. For example, Women's Health West explained:

> Relative to women without disability, women with disability are less likely to have access to sexuality education and health services, are more likely to experience pressure to terminate pregnancies as well as lack of timely access to their choice to termination of pregnancy, limited parenting support and a disproportionate representation in child protection cases.[47]

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42   Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014*, p.13.

43   *Transcript of Evidence,* Disability Sport & Recreation, pp.2, 5.

44   *Submission S055*, Disability Sport & Recreation, p.4.

45   *Supplementary evidence*, Response to Questions on Notice, Municipal Association of Victoria, 8 April 2014, p.2.

46   Department of Human Services (2012) *Victorian state disability plan 2013–2016. Companion document*, p.13.

47   *Submission S071*, Women's Health West, p.3.

The Committee heard that misconceptions about the sexuality of people with disability can contribute a lack of focus on education in this area. Women's Health West recommended the inclusion of 'ability and sexuality' learning in the current sex education curriculum:

> In addition to adapting learning environments and resources, sexuality education should promote inclusive standards by representing the sexuality of people with disability in a positive way … we recommend the inclusion of 'ability and sexuality' as a key learning concept in the section of the curriculum that covers sexuality education. This could be supported with the inclusion of scenarios and activities in Catching On Early and Catching On Later that positively represent intimacy, sexual expression and parenting for people with disability. Facilitating discussion around ability and sexuality is important for all students regardless of their current ability, as it will inform their attitudes towards people with disability who might be friends, family, clients or lovers, and prepare them for potential changes in their own ability.[48]

5.1.3.   Educating health professionals

The Committee considered that building the capacity of mainstream services is particularly important in the context of Tier 2 of the NDIS, the aim of which is to connect people with disability to mainstream services. Chapter 2 discusses the NDIS and Tier 2 in greater detail. Inquiry participants supported the need for healthcare professionals to have better skills in promoting the health of people with disability.[49] For example, CDDHV identified the importance of educating health professionals in the following areas:

- the implications of disability for health, and the implications of health for disability

- the barriers to healthcare encountered by people with disability and strategies to address these barriers

- the knowledge and skills required to provide high quality care to people with disability

- the responsibilities of service providers to make reasonable adjustments required for equitable access to health services by people with disability.[50]

Educating health professionals about how to encourage preventative health and lifestyle choices such as involvement in sport and physical activity can have a significant influence on physical and mental health of people with disability. The Chief Executive Officer of Disability Sport and Recreation, Mr Rob Anderson, suggested that organisations such as VicHealth could play an important role in health promotion initiatives for people with disability.[51]

The Committee also heard that there needs to be better education about the mental health of people with disability. Participants told the Inquiry that many health professionals can struggle to understand mental health and mental illness in the context of disability. For example, in a study of health service providers Dr Jane Tracy from CDDHV observed that there was 'a misunderstanding as to what intellectual disability was, and mixing up intellectual disability and mental

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[48]   *Submission S071*, Women's Health West, p.5.
[49]   *Submission S114*, Dental Health Services Victoria, p.4.
[50]   *Submission S108*, Centre for Developmental Disability Health Victoria, p.7.
[51]   *Transcript of Evidence,* Disability Sport & Recreation, p.9.

health was quite common.'[52] Dr Tracy explained that health professionals who have education specifically in this area are often able to understand and address these issues more effectively:

> … you do not know what you do not know, and if somebody is behaving a bit differently, I think sometimes people have not had the opportunity to step through the kinds of ways that mental illness and intellectual disability might manifest. To know the questions to ask might be a little bit hard for people to work out. I think that with appropriate training and education, yes, people understand it, and they get it straightaway. Without that, I think there can be a little bit of confusion when people are seen to behave differently—how do we understand that behaviour?[53]

As discussed in Chapter 8, including people with disability in community education and efforts to raise awareness is associated with positive outcomes. Dr Tracy's experience of involving people with intellectual disability in teaching young health professionals supports this:

> One of the terrific teaching sessions we have at Monash is that we employ people with intellectual disabilities as teachers—as tutors for our medical students. For those young people with intellectual disability, part of their learning goals are to develop confidence, public speaking and being part of contributing to community, just as the medical students have their learning goals of getting better at communicating and not using long medical jargon words. Bringing together those two groups of young people who each have learning needs that can be met in the same forum has been a really useful exercise for both sides of that equation.[54]

The *State disability plan 2013–16* includes actions to improve awareness and training for general practitioners and staff in health services to improve health outcomes for people with disability. These actions are outlined in Table 5.1.

Table 5.1: *State disability plan 2013–16*—strategies and implementation actions to improve the response to lifelong health needs, 2013–14

Implementation actions
• Improve the ability of staff in health services to support people with disability by:
♦ providing guidelines and information
♦ promoting professional development modules.
• Raise the awareness of general practitioners and health services about health conditions relevant to people with disability.

Source: Department of Human Services (2012) *Victorian state disability plan 2013–16. Implementation plan 2013 and 2014.* Melbourne, DHS.

No specific targets or explanations are identified in the Plan to indicate how these actions will be achieved and which professionals (other than general practitioners) the measures will target.

Finding 5.2

In the context of the National Disability Insurance Scheme, mainstream health services will need to be accessible and build capacity to support people with disability.

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[52] *Transcript of Evidence,* Centre for Developmental Disability Health Victoria, p.9.
[53] *Transcript of Evidence,* Centre for Developmental Disability Health Victoria, p.9.
[54] *Transcript of Evidence,* Centre for Developmental Disability Health Victoria, p.5.

> **Recommendation 5.1**
>
> That the Victorian Government incorporate into future State Disability Plans specific strategies, actions and targets that aim to:
>
> - improve health promotion efforts for people with disability
>
> - ensure accessible health information
>
> - identify and respond to the causes of mental health issues that people with disability experience.

5.2. Quality specialist supports

The Committee heard that many people with disability require support to achieve their aspirations in life, to be independent and to improve their opportunities for social inclusion. The WHO recognises that support for many people with disability is essential. In its *World report on disability*, the WHO states that 'for many people with disability, assistance and support are prerequisites for participating in society.'[55]

Some Inquiry participants explained that the provision of necessary supports and equipment can facilitate economic independence and reduce reliance on income support.[56] The Department of Human Services (DHS) acknowledged the importance of support as an essential need:

> … people with disability have told us they need support and skills—from education and training to health care and safe and reliable transport—to really access and participate in community life.[57]

Support to people with disability is sometimes provided by family and other times by specialist services. The WHO has stated that 'the lack of necessary support services can make people with disability overly dependent on family members—and can prevent both the person with disability and the family members from becoming economically active and socially included.'[58] It has also identified the importance of diversity in service provision, highlighting that:

> No one model of support services will work in all contexts and meet all needs. A diversity of providers and models is required.[59]

5.2.1. NDIS and self-directed funding

As outlined in Chapter 2, in its 2011 report on disability care and support, the Productivity Commission determined that 'current disability support arrangements are inequitable, underfunded, fragmented, and inefficient and give people with disability little choice.'[60] In response to this it recommended a national disability scheme with a focus on self-directed funding for individuals:

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[55] World Health Organization (2011) *World report on disability*, p.137.

[56] *Submission S001*, Mrs Brenda Rawlins, p.4; *Transcript of Evidence*, Vision Australia, Melbourne, 31 March 2014, p.3.

[57] *Transcript of Evidence*, Department of Human Services, Melbourne, 3 March 2014, p.2.

[58] World Health Organization (2011) *World report on disability*, p.137.

[59] World Health Organization (2011) *World report on disability*, p.137.

[60] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*. Canberra, Commonwealth of Australia, p.5.

> The evidence strongly suggests a wide range of positive wellbeing outcomes from self-directed funding for people with disability and their carers, including higher satisfaction with life, more independent living, better continuity of care and lower levels of abuse and neglect. Self-directed funding appears to cost no more than traditional models of care, and may well cost less.[61]

This approach is designed to give people with disability the capacity (but not the obligation) to 'make choices about how to spend their individualised budget' and subsequently to give them greater autonomy.[62]

In line with the findings of the Productivity Commission, the Committee heard that there are shortcomings in a range of areas of disability support. These included aids and equipment, communication and facilitation aides, personal care, supported accommodation, and respite.

In view of the transition to the NDIS, the Committee does not discuss these service system shortcomings, as the Victorian Government will not hold ongoing responsibility for the provision of support to people with severe functional limitations. In this chapter the Committee considers:

- the scope of disability services that will be provided under the NDIS (Section 5.2.3)

- the interaction of support and living arrangements for people with disability (Section 5.3.4)

- supports to achieve financial security (Section 5.4).

Support requirements for informal carers is discussed in Section 4.3.1 of Chapter 4, and supports to facilitate participation in education and employment are discussed in Sections 6.3 and 6.4 of Chapter 6.

5.2.2.   Person-centred approaches and individualised funding

Until 2006, Victoria provided 'block funding' to disability support providers that enabled them to deliver services based on how they identified the needs of clients.

In 2007, Victoria moved to an individualised approach to disability service provision. In 2013, this person-centred approach became national with the NDIS being appointed to change the way that disability services are provided and ensure people with disability have greater choice and control in how they access the services they need.

> **Block funding**—*is the process by which governments directly fund service providers with lump sum payments. These payments are then used by the providers to deliver support services.*

The *Disability Act 2006* (Vic) changed the way the disability service system operates in Victoria. It introduced an individualised approach to service provision, establishing Individual Support Packages (ISPs) for people with disability to choose and purchase disability related supports to assist them to achieve their goals.

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[61]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.343.
[62]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.226.

ISPs enable people with disability to:

- direct the planning process to support their choices

- plan in a way that respects the needs of family members and carers and their role in the person's life

- be assisted to identify goals and the way these can be achieved

- explore supports that are flexible and wide-ranging.[63]

'Individualised' or 'self-directed' funding—*is where government funds can be given directly to service users to then purchase services. This would mean service providers receive funding only after being approached (chosen) by the service user.*

ISP funding is generally for on-going costs but can include initial funds for one-off costs to purchase equipment to assist with establishing independent living arrangements. The funding may complement existing informal support arrangements from family and friends and/or generally available community services.

Many Inquiry participants explained that in Victoria individualised support provides people with disability greater choice and control over the services they purchase.

Box 5.1: Person-centred approaches

The concept of 'person-centred' and 'independent living' approaches originated in North America in the late 1980s. It is based on the view that people with disability should be recognised as active participants in the community, needing support to achieve their lifetime goals based on their strengths:

> The person-centred approach creates a team of people who know and care about the individual with disability, who come together to develop and share a dream for the person's future, and who work together to organize and provide the supports necessary to make that dream a reality.

One way of distinguishing personalised systems from service-centred approaches is to think about how people ordinarily make decisions. Most people have the chance to live lives that are largely determined by their own decisions, within the limits imposed by their ability, local environment and budgets. They think about what they might want from life and make decisions that help them get there. They decide where they might like to live, who they would like to live with, and what job and employer they would like. They decide how to spend their leisure time, where to buy things from and the role they will play in the community and as citizens.

That is not so for many people with disability (or their carers) because others make and fund so many decisions central to their lives. In a survey of Australians with disability, the Julia Farr Association found that 51 per cent of people had no choice about who provided personal support and 28 per cent had no choice about where they lived.

The intention of person-centred approaches is to maximise, as much as reasonably possible, the capacity for people with disability to take control of their lives. People with disability and carers can be given more power in many ways. They include—the obligation

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[63] Department of Human Services *Individual support packages.* DHS. Accessed on 1 August 2014 from http://www.dhs.vic.gov.au/for-individuals/disability/individual-support-packages.

Box 5.1: Person-centred approaches

of providers and others to treat them with respect; genuine opportunities for employment and other forms of social participation; challenging stereotypes and other attitudes that marginalise people; packages of support that suit the person (as for any other consumer); and the appropriate allocation of funding to meet their support needs.

Source: *Submission S123*, Northern Support Services, pp.2–3.

The Association for Children with a Disability told the Inquiry that the shift to funding people with disability on an individual basis rather than block funding to deliver services has created 'a greater degree of freedom and flexibility for many.'[64] The Association went on to explain:

> People with disability have been able to firstly identify how they want to live their lives and secondly purchase the services and supports to make their goals a reality. Naturally this has created challenges for many who have been floundering as they try to shift their mindset from being a passive recipient of care to become drivers of their own destiny—such a quantum leap. Recognition that such a transition cannot occur without support to build individual capacity took some time, but the benefits of nurturing peer support opportunities and developing communities of support are now unequivocal. The broader community also needed to make adjustments so that public places and spaces were more accessible.[65]

In its submission, Life Without Barriers expressed the view that increasing people's social inclusion in a way that accounts for their individual disability and experience 'firstly requires people being able to access a sufficient range of supports that facilitate inclusion within the community.'[66] By way of illustration, it provided the following example:

> … to engage in meaningful employment, an individual may firstly require adequate supports to assist them to get out of bed; or proximity to accessible public transport. These additional supports will be unique for each person.[67]

5.2.3.   Range of specialist disability supports

The Productivity Commission considered the nature of specialist supports that people with disability require on a daily basis to have the autonomy to live their lives the way they choose. It identified two types of relevant support and assistance:

- specialist disability supports, such as attendant care, community access and home and vehicle modifications

- generic or 'mainstream' services and assistance available to the whole population, including health, housing, transport, education and employment services.[68]

The Committee recognises that not all supports required by people with disability will be provided by the NDIS. Table 5.2 outlines the supports that will be provided under the scheme.

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64   *Submission S122*, Association for Children with a Disability, p.6.
65   *Submission S122*, Association for Children with a Disability, p.6.
66   *Submission S109*, Life Without Barriers, p.2.
67   *Submission S109*, Life Without Barriers, p.2.
68   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.226.

Table 5.2: Specialist disability supports provided by the NDIS

Supports	Description
Aids and appliances	A range of products to improve functioning, enable a person to live at home and in the community, and enhance independence. These would range from low to high-tech aids and encompass toilet supports or hand-held showers, continence aids, wheelchairs, hearing aids, mechanical lifters, electronic communication devices, equipment to support the use of Braille, and artificial limbs.
Home modifications	Modifications to the structure, layout or fittings of a home to enable an individual to utilise the home's standard fittings or facilities.
Vehicle modifications	Modifications which allow individuals to access, travel as a passenger or drive a motor vehicle.
Personal care	Supports that enable an individual to take care of themselves in their home and community. These include help with showering, bathing, dressing, grooming, personal hygiene (including bowel and bladder care/toileting), assistance with eating and/or drinking, mobility and transfers, health maintenance (such as oral hygiene, medication use or regular and routine exercises and stretches). This would also include nursing care when this was an inextricable element of the care of the individual (for example, when meeting the care and support needs of a ventilated quadriplegic).
Community access	Supports to provide opportunities for people to enjoy their full potential for social independence—the intention is to allow people a lot of choice and innovation in this area. Supports would focus on learning and life skills development, including continuing education to develop skills and independence in a variety of life areas (for example, self-help, social skills and literacy and numeracy). Supports would also focus on enjoyment, leisure and social interaction. The supports would: • include facility and home-based activities, or those offered to the whole community • include supervision and physical care • range from long-term day support to time-limited supports.
Specialist accommodation support	Such as group homes and alternative family placement encompassing support for clients to carry out essential activities of daily living (net of the standard contribution from a person's income for rent). The NDIS would not necessarily own the 'bricks and mortar' but the funding it provided would cover the cost of capital.
Domestic assistance	To enable individuals to live in the community and live on their own, such as meal preparation and other domestic tasks; banking and shopping; assistance with selecting and planning activities and attending appointments.
Transport assistance	Provision or coordination of individual or group transport services, including taxi subsidies.

Supports	Description
Orientation and mobility training	To increase the independence of individuals to move safely around their environment and build confidence in using public transport or crossing roads.
Employment support	Supported employment services and specialist transition to work programs that prepare people for jobs.
Therapies	Such as occupational, speech and physiotherapy, counselling, and specialist behavioural interventions.
Local area coordination and development	Broad services, including individual or family-focused case management and brokerage (disability support organisations), as well as coordination and development activity within a specified geographical area. They aim to maximise people's independence and participation in the community.
Crisis / emergency support	Following, say, the death of a family member or carer, including emergency accommodation and respite services.
Guide dogs and assistance dogs	Including the reasonable costs of being assessed for the dog, the dog itself, user training and veterinary costs.
Whole-of-life personal planning	For those who need more wide ranging or intensive assistance with planning in order to achieve more personal aspects of well-being such as with relationships, aspirations and achievements, employment, financial security as well as succession planning.

Source: Productivity Commission (2011) *Disability care and support. Volume 1, report no.54.* Canberra, Commonwealth of Australia, pp.227–28.

Finding 5.3

A range of disability specific supports are required to meet the diverse needs of people with disability and the move to individualised support is increasing their choice and control over the nature of supports they purchase.

Aids and assistive technology

The Committee heard that many people with disability depend on essential equipment and accessibility supports in order to achieve independence and to be socially included. For example, Post-Polio Victoria explained:

> Mobility aids and other assistive technology are essential to people, with some level of muscle weakness, so they can be as independent as possible and to carry out their social responsibilities.[69]

Mr Carl Thompson of the Victorian Aids and Equipment Action Alliance illustrated the importance of choice and its effect on independence and inclusion in his evidence to the Inquiry:

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[69] *Submission S016*, Post Polio Victoria Inc, p.3.

> Talking about the automatic door example, I have got one in my room now and that was funded through my ISP as well, which meant that I have had to reduce my personal care hours, but looking forward it has meant that I can now enter and exit my room independently. If there is a fire, I do not have to die … I do not have to ring a bell.[70]

The Committee heard that customisation of equipment can be effective in enabling social inclusion for those who cannot access equipment that meets their unique requirements. Solve Disability Solutions, for example, works with volunteers who engineer and construct equipment specifically tailored to individual needs. This enables them to engage in activities of their choosing when appropriate items are not available. Solve provided numerous examples such as a modified bicycle scheme that adjusts standard children's bicycles in order to enable children with physical disability to ride a bike. One story demonstrated the benefits that such tailored equipment can bring to the daily lives of people with disability:

> This young lady is 11, she has cerebral palsy and it was just fantastic. She learnt she was independent at riding a bike and she said to her mum, 'can I take myself to school?'. Her mum said, 'you can, but to get around at school you need to use your crutches'. So they immediately came back and asked us to do a modification so that Alicia could take her crutches to school with her. What we did … is attach those PVC piping tubes to the framework. Her crutches go in there and she rides to school with her peers. She is absolutely independent.[71]

Women with Disabilities Victoria (WDV) indicated that there is a need for improved enabling equipment for mothers with disability, such as 'visual alerts for a child's cry for the mother who is deaf; or a modified cot which assists a mother with poor balance to lift and cuddle her child.'[72] Vicdeaf also provided examples of the value adaptable alarms for people with hearing impairment can provide, such as baby crying monitors or smoke alarms that are wired to turn lights on and off or vibrate furniture to alert the person with disability.[73]

In the context of employment, some Inquiry participants explained that the provision of necessary supports and equipment to enable people with disability to work would be economically viable as it would reduce reliance on income support.[74]

Interpreters and communication aides

For many people with disability, access to interpreters is a critical aspect of communication. Deafblind Victorians, for example, explained the importance of highly trained and experienced Auslan interpreters and tactile interpreters for the inclusion of people with vision impairment 'as equal members of the community':

> For people who are deafblind accessing Auslan interpreters and tactile interpreters is the same as a person who is in a wheel chair and requires a ramp to enter a building. Without a ramp a person in a wheelchair is not able to enter the building. In our case if we do not have access to Auslan tactile interpreter/guides, we are excluded from society. In other words our ramp to communication and to inclusion in the community is our interpreters who make it possible for us to be included in society. [A lack of] appropriate funding to have this type of support will leave us all out in the cold.[75]

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70   *Transcript of Evidence*, Victorian Aids and Equipment Action Alliance, Melbourne, 20 March 2014, p.3.
71   *Transcript of Evidence*, Solve Disability Solutions, Melbourne, 20 March 2014, p.5.
72   *Submission S051*, Women with Disabilities Victoria, p.14.
73   *Transcript of Evidence*, Vicdeaf, Melbourne, 17 March 2014, p.8.
74   *Submission S001*, Mrs Brenda Rawlins, p.4; *Transcript of Evidence,* Vision Australia.
75   *Submission S113*, Deafblind Victorians, pp.1–2.

Communication access is currently supported by the Communication Access Network Program which operates in Victoria. This program is designed to lead, support and coordinate local and statewide initiatives to assist people with complex communication needs to communicate effectively and participate in their own communities.[76]

The North East Primary Care Partnership noted the benefits of this service for aiding people with communication difficulties to be understood in their communities. However, it suggested the service is 'stretched to meet the full range and number of communication needs across the region.'[77]

National Disability Services (NDS) Victoria informed the Inquiry that emerging technologies are proving increasing effective as communication tools:

> Rapid changes in the use of Internet enabled technologies can empower people with disability… The expanding use of digital technologies, such as tablets, has enabled more people with disability with communication and/or hand movement limitations, to use this equipment to express their choices.[78]

Similarly, the North East Primary Care Partnership noted the profound effect that assistive communication technology can have on the ability of some people with disability to communicate:

> The ability to communicate your thoughts and feelings, to be understood is fundamental to social inclusion. People with complex communication needs either cannot speak or have speech that is difficult to understand. Some people may also have difficulty understanding spoken language. Assistive communication technologies and resources are thus fundamental to people being able to participate in the civic life of the community.[79]

The importance of communication and access to information and the impact of emerging technologies on accessibility are discussed in Chapter 7.

Assistance with personal care

Assistance with personal care can be critical for some people with severe or profound core activity limitation. The Victorian Aids and Equipment Action Alliance provided its perspective on the importance of personal care in the context of social inclusion. It explained that 'many Victorians don't fully participate in the community due to a lack of basic supports. For example, limited personal care may mean only having one shower per week.'[80]

Many people with disability receive personal care and care in the home through informal supports such as family. However, people with disability can access personal care support through their individualised service packages, and some may be eligible for assistance through the Home and Community Care (HACC) Program. The Department of Human Services (DHS) explained to the Inquiry that there is no publicly available data regarding the number of disability service clients that also receive HACC services.[81]

The Committee recognises that responsibility for personal care support and some of the HACC services will be transferred to the Australian Government under

76 Scope (Vic) Ltd *Communication Access Network (CAN).* Accessed on 8 June 2014 from http://www.scopevic.org.au/index.php/site/whatweoffer/communicationresourcecentre/communicationaccessnetwork.
77 *Submission S079*, North East Primary Care Partnership, p.8.
78 *Submission S045*, National Disability Services Victoria, p.12.
79 *Submission S079*, North East Primary Care Partnership, p.7.
80 *Submission S011*, Victorian Aids and Equipment Action Alliance, p.2.
81 *Supplementary evidence*, Response to Questions on Notice, Department of Human Services, 24 March 2014, p.5.

the NDIS. In May 2013, the Victorian Government agreed to transfer the responsibility of HACC services for older clients to the Australian Government from July 2015. HACC services for younger clients will remain the responsibility of the Victorian Government.[82]

Victorian reform—Services Connect

The Committee recognises that DHS has recently introduced the Services Connect model of service delivery and is currently navigating the interaction of this model with the NDIS. The model seeks to simplify service navigation by replacing multiple case managers with one key worker to help people with disability navigate the service system. While it is unclear whether there will be an ongoing role for this program in the long term, DHS advised that the Victorian Government 'intends Services Connect to work closely with the National Disability Insurance Agency (NDIA) to ensure coordination of services for people with disability eligible under a NDIS.'[83]

It advised that a model is currently being trialled in Barwon that places the management of the Services Connect Client Support teams and case management of NDIA disability clients under the same structure.[84] Travellers Aid Australia pointed out that in order for the Services Connect model to work, case managers and key workers will need to be very knowledgeable and understand the all aspects of Victoria's disability service system and entitlements for people with disability (including, for example, the service system of transport).[85]

5.3.   Living arrangements

Access to secure, appropriate and affordable housing is essential for all people to feel safe and comfortable in their environment and contributes to increased social inclusion. People with disability are no different. However, accessibility, economic disadvantage and support requirements can lead to barriers in securing housing that meets the needs of people with disability. Having little or no control about living arrangements can have a profound impact on a person's physical and mental health. It can also impact on the capacity and desire to participate in other domains of life.

Suitable living arrangements in the community are vital to enable people with disability to pursue their goals in life and experience social inclusion. Northern Support Services, for example, explained the importance of stable and affordable living arrangements:

> … as people gain stable affordable housing, develop community connections and have roles that they value within that community their support needs stabilise. They can then direct their own supports which builds resilience and empowerment. People thrive when given the opportunity to have their own home and live independently.[86]

Like others in the community, people with disability live in diverse types of housing and accommodation, and like all members of the community their living

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[82]   Australian Institute of Health and Welfare (2014) *People using both disability services and home and community care in 2010–11.* Canberra, AIHW, p.2.

[83]   *Supplementary evidence*, Response to request for information, Department of Human Services, 27 June 2014.

[84]   *Supplementary evidence*, Response to request for information, Department of Human Services, 27 June 2014.

[85]   *Transcript of Evidence*, Travellers Aid Australia, Melbourne, 24 March 2014, p.4.

[86]   *Submission S123*, Northern Support Service's My Place-KeyRing Program, p.14.

arrangements depend on their particular circumstances. For people with disability, however, inability to access appropriate support or housing can limit their options. Some may live independently (alone, with a partner or with friends). Others live with their parents or other family members. Some live in disability service accommodation, such as shared supported accommodation or residential facilities.

Victorians with disability are more likely to live in public housing, compared with other people in the community. Those people with disability living in the private rental market often have fewer options as a consequence of lower income levels. Further, the limited accessibility features of many properties often means that people with disability cannot live in them, even if they could afford to.[87]

According to the ABS, people with disability are less likely to live independently than other community members. Like everyone, people with disability are diverse in their needs and requirements, in their willingness and ability to live independently, and their housing preferences. However, they generally have fewer options to enable them to choose the living arrangements that will meet their needs if their goal is to live independently. Demographic data from ABS identified in the Victorian Government's *Companion document* to the *State disability plan 2013–16* is shown in Figure 5.1. This data shows the diversity of living arrangements of people with disability. The *Companion document* identified that ABS data shows that in 2009 an estimated 1 per cent of people with disability lived in a non-private dwelling, such as a group home.

Figure 5.1: Estimated proportion of people's housing tenure by population subgroup in Victoria in 2009
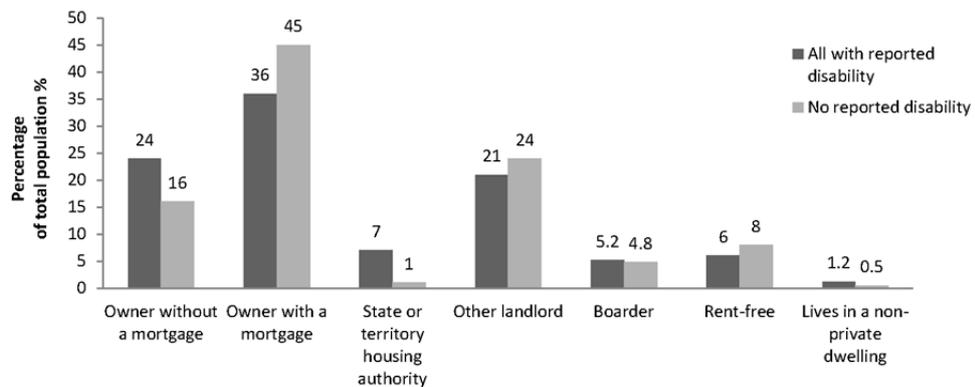
Source: Department of Human Services (2012) *Victorian disability plan 2013–16. Companion document.* Melbourne, DHS, p.18.

The location of housing is also important. In order for people with disability to be socially included, they need to live close to accessible facilities and their social networks.[88] Frankston City Council explained to the Inquiry the importance of locating housing close to low barrier community facilities:

> Suitable locations for accessible and appropriate housing affects social inclusion for people with disability in a number of ways; it affects the ability of people with disability to access

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[87] *Submission S126*, Victorian Council of Social Service (VCOSS), p.16.
[88] See, for example *Submission S046*, MICH Inc Manningham Inclusive Community Housing, pp.1–2.

transport, public spaces like libraries and parks, and private spaces such as cafes, churches and other people's homes. Where people have mobility or transport issues, housing must be located appropriately in relation to low-barrier community sites such as these if people with disability are to be involved and engaged in their communities.[89]

Finding 5.4

Factors such as location, appropriate support and housing design are key considerations to ensure housing contributes to social inclusion.

5.3.1.   The NDIS and Victoria's social housing strategy

Some Inquiry participants identified the need for clarity regarding the application of the NDIS to accommodation opportunities for people with disability.[90] Although the precise scope of the application of the NDIS to housing is not clear, the Productivity Commission report recommended that the NDIS have a significant role in supported accommodation and home modification.[91] In its factsheet titled *Housing and independent living*, the NDIA states that the supports and services to be provided through the NDIS will assist people with disability to live independently. This includes:

- supports that build people's capacity to live independently in the community —such as living skills training, money and household management, social and communication skills and behavioural management

- home modifications to the participant's own home or private rental property

- support with personal care—such as assistance with showering or dressing

- domestic assistance around the home where the participant is unable to undertake these tasks due to their disability.[92]

The factsheet also states that the NDIS may also contribute to the cost of accommodation in situations where a participant has a need for specialised housing due to their disability. It explains that the NDIS will only contribute to costs in situations where the cost is higher than the standard rental cost that the participant would otherwise incur.[93]

In August 2014, the NDIA Chair, Mr Bruce Bonyhady, acknowledged the role of the NDIA in housing affordability and accessibility:

> Early action on affordable and accessible housing is essential. While the Agency is not responsible for housing for participants, which remains a responsibility of States and governments' affordable and public housing strategies more generally, the NDIS can be a catalyst for significant new housing investment for participants. This will be the subject of a housing discussion paper that the Agency will issue later this week.[94]

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[89]   *Submission S106*, Frankston City Council, p.9.
[90]   For example, see *Submission S052*, Moonee Valley City Council, p.4.
[91]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, pp.299–30.
[92]   National Disability Insurance Scheme *Mainstream interface: Housing and independent living*. NDIS fact sheet. Accessed on 27 August 2014 from
http://www.ndis.gov.au/sites/default/files/documents/fact_sheet_supports_ndis_fund_housing_ind_living.pdf.
[93]   National Disability Insurance Scheme *Mainstream interface: Housing and independent living*. From http://www.ndis.gov.au.
[94]   B. Bonyhady (2014) 'The NDIS vision: Delivering the Plan' (Speech delivered at St Laurence National Conference: The NDIS one year on, Deakin University, Geelong, 11–12 August 2014). At the time of the Committee adopting its report on 1 September 2014, the housing discussion paper had not been released.

The Committee acknowledges that the Victorian Government has developed a social housing strategy. In 2014 the Victorian Government released *New directions for social housing: A framework for a strong and sustainable future.* This followed a statewide consultation on the future of social housing in Victoria that sought the views of tenants, service providers and the community concerning issues in social housing.

The Framework outlines the steps the Victorian Government will take to create a more sustainable social housing system that supports the most vulnerable Victorians now and into the future. It commits to building better communities, delivering better opportunities to tenants and developing better social housing assets.[95]

Issues relating to housing are being worked through during the trial phase of the NDIS. The transition to the NDIS will occur between 2016 and 2019. In the interim, the Victorian Government's actions in this context remain important.

Recommendation 5.2

That the Victorian Government negotiate with the National Disability Insurance Agency to establish an online forum for the disability service sector to ensure up-to-date and clear information about the services available to people with disability and their families in Victoria, in order to ensure a smooth transition between Victorian supports and supports to be provided under the National Disability Insurance Scheme.

5.3.2.   Choice in living arrangements

A consistent theme in evidence to the Inquiry was that people with disability want the freedom to choose their own living arrangements—including where they live, who they live with, and the type of home they live in. In his evidence, Mr Bil Hurley explained his perspective on housing and his choice to live independently:

> I am looking forward to having privacy. Where I live now, there is no lock and the dogs bust open the sliding door, morning and night, just to say 'G'day'. When I move, it will be my castle, my kingdom. I need space to paint, and my mind needs silence—freedom to live the life of an artist, not having to explain why there is paint on the furniture. The city will only be 15 minutes away, and I will be surrounded by art. I can restock what I need to keep my creative juices flowing. I will be able to live within myself. Living on my own will be like living on an island, but with a speedy boat for company when I want it. If I am lucky, I might meet someone down the track. If not, I will just keep flirting.
>
> For most people, it is easy to make a decision and move house. For me it has not been easy at all. The difference has been money and finding a suitable house, end of story. What others have the freedom to do, I do not.[96]

Similar findings were made in 2000 in a study undertaken by Millward Brown Australia and the Department of Human Services (DHS) on aspirations. For

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[95]   Department of Human Services *New directions for social housing: A framework for a strong and sustainable future.* Accessed on 28 August 2014 from http://www.dhs.vic.gov.au/about-the-department/plans,-programs-and-projects/plans-and-strategies/new-directions-for-social-housing.

[96]   *Transcript of Evidence,* Summer Foundation Ltd, p.4.

example, a young man with disability stated that 'I'd like to be able to live independently, perhaps share a flat with someone.' He went on to state, however, that his 'thing is not having the guts to do it. Fear of the unknown, I suppose.'[97]

In its submission, Annecto advised the Inquiry that the community needs to ensure that:

> … persons with disability have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.[98]

However, the Committee heard that housing choices for people with disability are limited by their financial means, the level of accessible support for their needs, and the availability of affordable and appropriate accommodation that is close to their family and social networks. As noted earlier, the NDIS will resolve some financial barriers to living independently for some people with disability, however others may not be eligible for support under the NDIS.

Choice in living arrangements is interlinked with housing availability. Like many people in the community, an inability to access affordable housing can limit choices. For people with disability a number of other factors impact on availability. The availability of universal housing can determine whether living independently is a realistic option. The availability of specialist supports to provide personal care, support for household tasks, and other assistance in the home can influence the type of living arrangements a person with disability can choose from.

The Committee determined that a range of housing options is necessary to ensure there are sufficient opportunities for people to choose where and how they live, and with whom. Chapter 4 discusses the implications of housing options on the choices people with disability are able to make about who they live with.

Melba Support Services told the Inquiry that there needs to be greater flexibility in funding to enable greater choice in living arrangements for people with disability:

> At the moment government provides organisations like us with funding and says, 'We want you to provide accommodation to four or five or six people living in a group home with the funds you receive'. Funding does not go to individuals to allow them to exercise choice, and I think that will be a great driver of additional supply—if people can take funding that is rightfully theirs and make decisions about whether they want to live in a group home or if they would like to live somewhere else.[99]

The organisation went on to explain that the Disability Housing Trust[100] established in 2006 to address housing shortages for people with disability had enabled some of their clients to secure independent housing.[101] The NDIS is intended to provide such flexibility. Yet how it will do this is unclear at this stage of the transition.

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97   DisAbility Services Victoria, Department of Human Services (2000) *The aspirations of people with a disability within an inclusive Victorian community. Summary report*. Melbourne, DisAbility Services Victoria, DHS, p.25.
98   *Submission S104*, Annecto - the people network, p.5.
99   *Transcript of Evidence*, Melba Support Services Inc, Melbourne, 26 May 2014, p.10.
100   Now incorporated into Housing Choices Australia.
101   *Transcript of Evidence,* Melba Support Services Inc, p.10.

Despite the importance of housing location, many people with disability have little choice over where they live and ensuring they are close to accessible facilities and social networks. Yarra City Council explained to the Inquiry that:

> Housing which is close to community amenities such as public transport, medical facilities, shopping precincts and other community facilities, is often unaffordable for people who rely solely on pensions or other government benefits. Being forced to live in a more remote area, away from one's regular networks, contributes to social isolation.[102]

5.3.3.   Accessibility and universal housing

The Committee heard that universal housing design has great potential to enable people with disability to have more independence, choice and control in their lives, which all contribute to improved social inclusion opportunities. It can lead to increased housing options and can improve their chance of finding accommodation that will meet their current and future needs. It can enable the opportunity to visit the homes of friends and relatives who also live in universal housing.

However, Inquiry participants stated that access to such housing is limited. Yarra City Council, for example explained:

> In instances where people with disability are able to afford to live alone, accessible housing is hard to find. People with physical disability often incur extra costs of modifying their homes to ensure appropriate physical access.[104]

Universal housing design—
means designing Australian homes to meet the changing needs of home occupants across their lifetime. It recommends the inclusion of key easy living features that aim to make homes easier and safer to use for all occupants including: people with disability, ageing Australians, people with temporary injuries, and families with young children.[103]

This scarcity has a significant effect on the social inclusion of people with disability. Ms Shaunagh Stevens, for example, explained the impact that inability to access the homes of friends and family has had on her social inclusion:

> Since birth my social life has mainly consisted of visiting family, friends and acquaintances at their homes. For a number of years I have required the use of a wheelchair and have been unable to access most homes leaving me isolated and lonely. Sadly my home has become more like a prison than a home.[105]

The Committee acknowledges an increased focus on universal housing by governments. At the national level, in 2010 the Dialogue on Universal Housing Design (the Dialogue) developed the *Livable housing design guidelines*. The Australian Government convened the Dialogue in 2009 and it comprised representatives from all levels of government, key stakeholders groups from the ageing, disability and community support sectors and the residential building and property industry.

In 2010 The Dialogue released a Strategic Plan followed by a 10 year implementation plan. The Dialogue describes universal housing as a policy

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[102]   *Submission S118*, Yarra City Council, p.6. See also *Submission S106*, Frankston City Council, p.9.
[103]   Australian Department of Social Services (2012) *National dialogue on universal housing design — strategic plan.* Accessed on 12 May 2014 from http://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-strategy/livable-housing-design/national-dialogue-on-universal-housing-design-strategic-plan?HTML.
[104]   *Submission S118*, Yarra City Council, p.6. See also *Submission S106*, Frankston City Council, p.9.
[105]   *Submission S090*, Ms Shaunagh Stevens, pp.2–3.

aimed at encouraging Australian homes to be designed to meet the changing needs of occupants across their lifetime. It states that a universally designed home should be:

- easy to enter

- easy to move in and around

- capable of easy and cost effective adaptation

- designed to anticipate and respond to the changing needs of home occupants.[106]

The *Livable housing design guidelines* seek to achieve housing that is 'designed and built to meet the changing needs of occupants across their lifetime.'[107] The guidelines outline three 'performance levels' for livable housing design—Silver, Gold and Platinum.

The Strategic Plan established a target that all new homes would achieve the Silver level by 2020. The seven core design elements for Silver level are outlined in Box 5.2.

Box 5.2: Livable housing design guidelines–Silver level

- A safe continuous and step free path of travel from the street entrance and/or parking area to a dwelling entrance that is level.

- At least one, level (step-free) entrance into the dwelling.

- Internal doors and corridors that facilitate comfortable and unimpeded movement between spaces.

- A toilet on the ground (or entry) level that provides easy access.

- A bathroom that contains a hobless (step-free) shower recess.

- Reinforced walls around the toilet, shower and bath to support the safe installation of grabrails at a later date.

- A continuous handrail on one side of any stairway where there is a rise of more than one metre.

Source: Livable Housing Australia (2012) *Livable housing design guidelines.* Sydney, LHA, p.13.
Accessed on 30 July 2014 from
http://livablehousingaustralia.org.au/library/help/Livable_Housing_Design_Guidelines_Web1.pdf.

There are currently no mandatory requirements for housing to follow the *Livable housing design guidelines.* Inquiry participants supported amending Victoria's building regulations to include a requirement that new dwellings meet some minimum requirements for accessibility. The Victorian Council of Social Service (VCOSS) suggested that adopting minimum requirements would be a cost effective way of expanding accessible housing for people with disability and

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[106] Australian Department of Social Services (2012) *National dialogue on universal housing design — strategic plan.* From http://www.dss.gov.au.

[107] Livable Housing Australia (2012) *Livable housing design guidelines.* Sydney, LHA, p.8. Accessed on 30 July 2014 from http://www.livablehousingaustralia.org.au/library/help/Livable_Housing_Design_Guidelines_Web1.pdf.

preparing for an ageing society.[108] Furthermore, VCOSS told the Inquiry that the cost of installing these features in homes during construction is much cheaper than subsequently retrofitting.

The Committee heard that taking a voluntary market driven approach to the adoption of livable housing design is likely to slow the extent to which houses become compliant with universal housing requirements. Frankston City Council, for example, stated that there are currently insufficient mechanisms to enforce a minimum supply of universal housing developments in and around activity centres and public transport hubs and routes.[109] It told the Inquiry that market forces are insufficient to ensure adequate supply of such housing:

> Due to the strong correlation between disability and financial disadvantage, the current reliance on market mechanisms to achieve optimised goals for land use fails to ensure that accessible housing is appropriately located.[110]

Given that new housing development comprises only a small proportion of development, the Committee identified that the Victorian Government needs to consider how existing housing stock could be adapted to incorporate universal design principles.

The Committee acknowledges that the *State disability plan 2013–16* has a strategy to make houses easier and safer to live in. The Victorian Government has committed to encouraging the building industry, councils and supported residential services to incorporate the *Livable housing design guidelines* in housing design to make housing easier and safer for people with disability to live in.

Yet the Plan is not specific regarding how it will implement the actions and measure success. The actions are:

- Encourage the building industry and councils to incorporate *Livable housing design guidelines* into projects by supporting the key projects of Livable Housing Australia.

- Encourage social housing providers to incorporate *Livable housing design guidelines* in the construction of new housing.

The question of what incentives are needed to ensure there is sufficient accessible housing for people with disability was identified as a 'major challenge'.[111] The Committee considered that the Victorian Government could introduce incentives to encourage the development of affordable livable housing. An example is the National Rental Affordability Scheme (NRAS), which awarded incentive grants to approved medium and large developers of affordable housing between 2008 and 2013. Inclusion of livable housing design features formed part of the eligibility criteria for these NRAS grants. The Victorian Government could consider the use of stamp duty and other concessions to encourage the inclusion of livable housing design features in affordable housing development in Victoria.

108   *Submission S126*, Victorian Council of Social Service (VCOSS), p.12.
109   *Submission S106*, Frankston City Council, p.9.
110   *Submission S106*, Frankston City Council, p.9.
111   For example, see *Transcript of Evidence*, National Disability Services, Melbourne, 3 March 2014, p.8.

Recommendation 5.3

That the Victorian Government is more specific about its intentions to encourage the building industry, councils and social housing providers to incorporate the national *Livable housing design guidelines* and introduces specific incentives to encourage the development of affordable housing that meets livable housing design guidelines.

5.3.4. Flexible living arrangements—support and housing

For many people with disability, flexible housing options are vital to enable independent living. Flexible housing options can allow people with disability to be supported ways that enable them to live as independently as possible. Support can vary greatly. It might involve having someone living nearby who can be called on for help or it might be more direct assistance with daily living activities. Support can be provided informally by family or others in the community. Or it can be more formal supports provided by specialist disability and other service providers.

The Committee heard that flexible living arrangements can ensure that people with disability receive quality supports that are tailored to their needs. The Research Program Leader and Deputy Chair of the Academic Board at La Trobe University, Professor Christine Bigby emphasised that the quality of supports is vital and that small-scale living arrangements can deliver good outcomes if they have good support and supervision.[112] She explained to the Inquiry:

> It is actually the type of support you get once you have got a house that makes the critical difference. We are hopefully going to have much more dispersed housing and much more dispersed support, so we need to create a culture of excellence of support. We know what good support practice looks like: it is about enabling and facilitating people to be engaged in their own lives in both the house and the community.[113]

In the provision of formal disability services, support and accommodation have traditionally been linked. In its 2011 report on disability care and support, the Productivity Commission explained that:

> Typically, the provision of supports is tied to a particular residence — the 'bricks and mortar'. But tying support to accommodation unnecessarily restricts the choices people with disability have.[114]

It went on to suggest that the approach proposed in the NDIS 'could effectively unbundle the support from the accommodation.'[115]

The Committee heard that the opportunity to access resources through individual support packages could pave the way for greater opportunities to establish more innovative and flexible housing options. For example, Ms Geraldine Fowler of Northern Support Services suggested that the availability of resource-sharing models like KeyRing (discussed later in this section) could be supported by the introduction of the NDIS.[116]

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[112] *Transcript of Evidence*, Professor Christine Bigby, La Trobe University, Melbourne, 20 March 2014, p.10.
[113] *Transcript of Evidence,* Professor Christine Bigby, p.9.
[114] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.231.
[115] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.231.
[116] *Transcript of Evidence*, Northern Support Services, Melbourne, 20 March 2014, p.7.

Box 5.3 outlines some examples of existing and more innovative supported living options for people with disability.

Box 5.3: Specialist disability housing and support

- Dispersed housing—a spread of supported properties throughout the community, including the KeyRing model.

- Intentional communities—housing that groups people together with similar philosophies and preferences. For example the *Getting a life—intentional community cooperative* in the ACT.

- Supported accommodation / group homes—shared accommodation with shared live-in supports, including the Abbeyfield model.

Source: Compiled by the Family and Community Development Committee.

Residential facilities and de-institutionalisation

As outlined in Chapter 1, supported living arrangements for many people with disability in Victoria were historically provided in large residential institutions. Since the early 1980s, these institutions have been gradually closed and replaced by alternative supported accommodation. Yet there remains a legacy from the era of institutions that continues to adversely affect the social inclusion of people with disability today.

Person-centred approaches to service delivery and the NDIS are transforming the way that people with disability are socially included. Inquiry participants emphasised the need to persist with changes to cultural attitudes and service practices. For example, the Association for Children with a Disability highlighted that:

> Achieving individual choice and control is reliant on more than the dismantling of block funded supports. It requires attitudinal change and adjustments to structures and practices within our community that still constitute barriers to social inclusion. Replacing the old system where people with disability and families were passive recipients of care, requires greater investment in encouraging them to participate in all aspects of community life. Unless this occurs and professionals adopt family centred and person centred approaches when supporting self-determination and encouraging consumer choice and control, the only change will be the furniture and the colour of the walls—social isolation will persist.[117]

Many Inquiry participants argued strongly for the closure of remaining residential facilities in Victoria—Colanda, Sandhurst Residential Services and Oakleigh Centre. The Committee acknowledges that the Victorian Government is currently in the process of closing each of these residential facilities and assisting residents with the transition to alternative housing and, where appropriate, the NDIS.[118]

Research studies on the closure of Kew Cottages, a residential facility for people with intellectual disability, show that improvements in quality of life can occur when people move from institutions to small group supported living options in

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[117] *Submission S122*, Association for Children with a Disability, p.4.
[118] Premier of Victoria (2 May 2014) *Media release: Oakleigh disability institution to close.* Accessed on 13 May 2014 from http://www.premier.vic.gov.au/media-centre/media-releases/9798-oakleigh-disability-institution-to-close.html.

the community.[119] The individualised approach the NDIS has adopted to delivering disability services will contribute to ongoing cultural change in the provision of disability supports and the ways in which people with disability will access them.

Shared supported accommodation

Since the 1990s, shared supported accommodation has been the main form of housing and support in Victoria's disability service system. This type of accommodation is often referred to as a 'group home' and typically consists of four or five unrelated adults with disability living together with a support worker.

DHS informed the Inquiry that as at December 2013 there were 1 374 people recorded on the Disability Support Register who required supported accommodation. In 2011, the Productivity Commission drew attention to the fact that many people with disability are on waiting lists to be housed in either public housing or supported accommodation for years and forced to live in inappropriate housing due to a lack of alternative options.[120] In its 2014 progress report, the Joint Standing Committee on the NDIS identified that in the Barwon trial site there is no longer a Disability Services Register or a waiting list for Early Childhood Intervention Services.[121]

The Committee heard that there are mixed views about the suitability of shared supported accommodation as it is currently provided in Victoria. Some Inquiry participants emphasised the benefit of this accommodation for people with high support needs.

However, others indicated that supported accommodation is generally not suited to the needs of people with disability and that for people living in this type of accommodation their opportunities for social inclusion can be limited.[122] For example, Occupational Therapy Australia (OTA) referred to research undertaken by Monash University. The research was conducted by Senior Occupational Therapy Lecturer, Dr Rachael McDonald. She identified low levels of contact by residents with friends or outsiders, stating that 76 per cent of supported accommodation residents surveyed 'had occasional, or no known contact with friends and outsiders.'[123] This is consistent with other research the Committee reviewed and outlined in Chapter 4.

The Committee acknowledges that the *State disability plan 2013–16* contains specific strategies and actions to address issues relating to shared supported accommodation. Table 5.3 outlines these actions.

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[119] C. Bigby, B. Cooper, & K. Reid (2012) *Making life good in the community: Measures of resident outcomes and staff perceptions of the move from an institution*. Melbourne, Department of Human Services, p.3.

[120] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, pp.117–18.

[121] Joint Standing Committee on the National Disability Insurance Scheme (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme*. Canberra, Commonwealth of Australia, p.15.

[122] See, for example *Submission S015*, Lifestyle in Supported Accommodation (LISA) Inc, pp.1–2.

[123] *Submission S101*, Occupational Therapy Australia, p.8.

Table 5.3: *State disability plan 2013–16*—strategies and implementation actions to improve housing and accommodation choices, 2013–14

Strategies and implementation actions
Strategy: Improve supported accommodation services

• Strengthen the disability accommodation service system to:
   ♦ increase resident choice
   ♦ provide portability of funding
   ♦ support people with complex support needs.

• Deliver new supported accommodation options through the Victorian State Budget and the Commonwealth's Supported Accommodation Innovation Fund (SAIF).

Source: Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014*. Melbourne, DHS.

KeyRing housing model

KeyRing is an example of the way in which flexible housing can help people with disability achieve independent living. The housing model originated in the United Kingdom (UK), where it has been operating for around 20 years. Its objective is the provision of independent living accommodation for nine people with disability within a small local area, with a local volunteer providing them with flexible support.

In 2013, an evaluation of the program in the UK demonstrated that community support arrangements under this model have been sustainable. In addition, the model has been trialled and found to be a cost effective housing alternative for people who are transitioning from residential care.[124] Box 5.4 provides an overview of the KeyRing model.

Box 5.4: KeyRing housing model

Nine individuals (members) comprise a KeyRing with support provided to them by a community volunteer (with reimbursement). The nine members live in a specifically identified geographical area, whereby living close to one another they can easily maintain contact with each other, either by walking or using public transport systems (ie train, local bus network). With everyone living in the same community people can access the same facilities and resources and build locally based networks. People live in the arrangement of their choosing for example, they may choose to live alone, or share with a friend(s) or partner. People also live in a variety of housing options; public housing, community / social housing, private rental, own home, rooming house etc.

The volunteer either lives in the same community or has strong links to that community and the aim is that with support, members will make connections with one another and within their local community. The relationship members develop with the volunteer is pivotal and quite unique as this person assists them manage their relationships with one another and within the broader community. The volunteer and members receive back up support from paid staff positions–a manager and coordinator, who, depending on each member's

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124   Alder (2013) *Evaluation of keyring networks plus in Walsall*. Kent, England, Alder.

Box 5.4: KeyRing housing model

individual circumstances, can provide higher level and more intensive support to as the need arises.

The volunteer provides support across three areas: housing and tenancy, community access and inclusion, Social support and development of locally peer based friendship support network.

The volunteer provides the following:

- One support visit per week to each member—1 hour

- Telephone call once per week to each member

- Access to 2 hours of telephone back up support weekly

- Support to members to organise and attend monthly social get togethers which the volunteer attends.

Source: *Submission S123*, Northern Support Services, pp.2–3.

In Victoria, this type of housing model is available through Northern Support Services and Merillac House. Northern Support Services commended this model to the Inquiry as a 'very flexible, low cost, innovative housing and support model that supports people with disability to live in the community.'[125] Northern Support Services explained that although their KeyRing housing predominantly accommodates people with mild intellectual disability, it also supports people with 'quite complex and often more significant disabilities' including physical, sensory and mental health issues.[126]

Northern Support Services explained that the unique features of the KeyRing model include its flexibility and capacity to assist people with disability to form social connections in their community:

> What makes the KeyRing model unique is its ability to be flexible in the delivery of supports. Visit times are arranged between each member and the volunteer and visits can change depending on what the member may need. For example—If someone doesn't want a visit one week they don't have to have one, alternately they may want a 2 hour visit the following fortnight. The supports delivered also vary as the volunteer can respond to every day matters as they arise and focus on what the person needs at the time. However what really makes KeyRing unique is its focus on establishing a peer support friendship network between members and its ability to assist people make connections within their local community.[127]

The KeyRing model has benefits for increasing the social connections of people with disability, which is discussed in Section 4.5.3 of Chapter 4.

Supported apartment living

Supported apartment living is a recent innovative example of flexible housing that can enable people with disability to live independently.

This housing type has been developed to better meet the needs of people with disability under 65 years who continue to live in residential aged care facilities due to a lack of alternatives for people with high support needs. While their ages

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[125] *Transcript of Evidence,* Northern Support Services, p.2.
[126] *Transcript of Evidence,* Northern Support Services, p.2.
[127] *Submission S123*, Northern Support Service's My Place-KeyRing Program, pp.4–5.

may vary from their 20s through to their early 60s, people in these circumstances are often referred to as 'young people in nursing homes'. The Executive Manager of the Summer Foundation, Mr Tom Worsnop, outlined the current situation to the Inquiry:

> … being admitted into an aged-care nursing home is a major hurdle for a young person if they are wanting to become part of a socially included life. It is a very isolating experience, and that is what people report. There are very few alternative appropriate housing options currently available for the group of young people with high-level disability, as you are also probably aware. Annually more than 200 people under 50 are still being admitted into nursing homes across Australia. There are about 6000 people under 65 in nursing homes across Australia as it stands at the moment. Victoria has about one-third of that population.[128]

In 2005, Youngcare was established to address the issue of young people living in residential aged care under the age of 65 years. In its submission it highlighted the extreme social isolation experienced by these young people:

> Research shows that the residential aged care (RAC) is no place for a young person. Young people in RAC face extreme social isolation. Around 82 per cent will never go and visit friends, around half never get so far as going to the shops, movies, sporting events—things the rest of us take for granted. The life expectancy of people in aged care is brief, but when young people end up there they have reached the final destination in their lives where they are left for not a few years, but decades. Amongst young people who end up in this situation and their families, a recurrent theme is that it amounts to 'captivity'.[129]

In collaboration with the Transport Accident Commission (TAC), the Summer Foundation is currently trialling a housing demonstration project for people living in, or at risk of entering, residential aged care in view of their requirements for 24-hour on-call support. The project consists of two self-contained units located in a mixed private and affordable housing development in Abbotsford. The housing incorporates the use of smart technology to enable people to be as independent as possible, and decrease their reliance on paid staff. This technology enables residents with severe physical disability to use smart phone or tablet technology to unlock and open doors, open and close the window blinds, control the air conditioning and turn lights off and on. Communications technology enables residents to notify staff when they need help and contact staff in the event of an emergency. The Summer Foundation explained that:

> The model of support for the Abbotsford demonstration project will not operate like a typical shared supported accommodation service. Individualised support will be provided based on the specific needs and preferences of each resident. However, the service provider will also be able to capitalise on the potential efficiencies created by the close proximity of the apartments. There is a small staff office on site that will enable support workers to sleep over where required.[130]

Chapter 7 discusses advances in technology in greater detail and how this has potential benefits for people with disability that can be explored.

The Committee also acknowledges that the *Implementation plan 2013–14* for the *State disability plan 2013–16* has identified the need to continue to address the needs of young people in nursing homes. Table 5.4 outlines the specific actions listed in the plan.

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128   *Transcript of Evidence,* Summer Foundation Ltd, p.2.
129   *Submission S072*, Youngcare, p.1.
130   Summer Foundation Ltd *Housing demonstration project: Abbotsford.* p.2. Accessed on 14 May 2014 from http://www.summerfoundation.org.au/wp-content/uploads/Housing-Demonstration-Project.pdf.

Table 5.4: *State disability plan 2013–16*—**implementation actions to improve housing and accommodation choices, 2013–14**

Implementation actions
• Improve the hospital and discharge experiences of younger people with disability at risk of entering residential aged care.
• Prioritise younger people who live in, or are at risk of entering, residential aged care for broader disability supports in addition to the dedicated my future my choice services
• Monitor the number of younger people with disability in residential aged care.

Source: Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014.* Melbourne, DHS.

A National injury insurance scheme that provides no-fault lifetime care and support for catastrophic injuries was recommended by the Productivity Commission as part of its measures to address disability support.[131] The details of this scheme are not yet known, but it will have implications for the care and support of people who have a disability resulting from a serious injury, such as an acquired brain injury (ABI) or spinal cord injury (SCI).

Intentional Communities

An intentional community is a type of mixed housing where people with disability and people without disability live together in a community. Some of the homes have a shared living arrangement whereby a person without disability provides practical assistance and companionship for the people with disability, and has free or reduced rent.

Formal and informal support is also provided. The aim of this housing type is to form a network of friendship and social connectedness around people with disability in the community through informal interactions and community gatherings.

An example of this type of housing is the *Getting a life* intentional community in Phillip in the Australian Capital Territory (ACT). As part of this 25-residence housing and community building project, three houses have been set aside for young people with disability. The remaining 22 are allocated to existing Housing ACT tenants by application. The development was the first housing project in Canberra to be initiated and developed by families of people with disability.

In addition to ensuring security of tenure for the people with disability, the model seeks to ensure the necessary paid support and the potential of unpaid supports through relationships and networks which develop through the community model.

5.3.5.   Maximising social inclusion benefits of housing

In 2013, the Australian Housing and Urban Research Institute (AHURI) undertook research on the effect of housing assistance on social inclusion for people with disability. AHURI concluded that housing assistance has a clear

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[131]   Productivity Commission (2011) *Disability care and support. Volume 2, report no. 54*. Canberra, Commonwealth of Australia.

'social inclusion dividend', providing stability and reducing the risk of homelessness for people with disability. AHURI identified a number of steps that governments can take to maximise the social inclusion benefits arising from housing assistance. Table 5.5 outlines these steps.

Table 5.5: Maximising social inclusion benefits from housing assistance

Steps	Description
Focus on sustaining tenancies	Social inclusion outcomes for tenants living with disability will remain sub-optimal if actions to sustain tenancies are not promoted. This is clearly a concern for those with mental health issues in particular.
Additional supply	Targeted provision of housing assistance for people with disability will have positive impacts. People with disability should remain a priority group in the housing allocation processes of social housing providers.
Spread of locations	Social housing provision should avoid creating areas of concentration of people with disability. While acknowledging that the demand for social housing exceeds supply, and that many people living with disability are in need of urgent assistance, grouping large numbers of people with disability in one location has negative effects. The supply of social housing needs to be spread across a range of locations and neighbourhoods as much as possible.
Appropriate housing features	The housing occupied by people with disability needs to meet the circumstances of the individual and their household as closely as possible. This includes modifications to the dwelling and on-going maintenance where the disability may require on-going attention. A pertinent example here is dwellings where a wheelchair user lives.
Access to transport	Housing assistance for people with disability should focus on providing accommodation in places with good access to public transport in order to assist access to both services and employment.
Private rental support	Given the pressure on the social housing sector to house vulnerable people with a range of needs, more needs to be done to ensure that housing assistance received by those in the private rental market genuinely helps to address sustained high housing costs. Lessons can be learned from existing private rental support programs assisting people living with disability. For example, private rental support programs—such as that offered by Karingal in Geelong— successfully assist with securing and sustaining tenancies.
Training and community development	Housing assistance programs can be used as a vehicle for delivering training and community development programs that help people with disability to find their voice.[132]

Source: Australian Housing and Urban Research Institute (February 2013) 'What effect does housing assistance have on social inclusion and people with disabilities?'. *AHURI Research & Policy Bulletin,* no. 159, pp.3–4.

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[132] Australian Housing and Urban Research Institute (February 2013) 'What effect does housing assistance have on social inclusion for people with disabilities? '. *AHURI Research & Policy Bulletin*, No. 159, pp.3–4.

As outlined earlier, the Committee acknowledges that the *State disability plan 2013–16* has a specific strategy to reform the Victorian social housing system through the development of 'a Victorian Social Housing Framework to ensure public and community housing is both sustainable and fair.'[133] In the context of the roll out of the NDIS, the Committee recognises that responsibilities across States, Territories and the Commonwealth are currently in negotiation.

Finding 5.5

People with disability need to choose the living arrangements that are suitable to their lifestyles and generally have the following options:

- living in the community (own home, renting, or living with a partner, family or friends)

- living in communities with specialist disability support (such as KeyRing models and supported living arrangements)

- living in government funded disability accommodation (such as shared supported accommodation).

Recommendation 5.4

That the Victorian Government negotiate with the National Disability Insurance Agency to ensure resourcing for flexible housing models that have proven success in promoting the social inclusion of people with disability.

5.4.   Financial security

Achieving financial security provides people with disability greater choice and opportunities to pursue their aspirations and achieve social inclusion. Many Inquiry participants emphasised the importance of financial security as a foundation for being included in the community. For example, Whittlesea Disability Network expressed the view that:

> Income security is an essential precursor to equitable participation in society and the life of our community … Our vision of fulfilling our goals, dreams and aspirations requires an adequate income as a starting point/'launching site'.[134]

The Committee heard, however, that people with disability often experience difficult financial circumstances. Many have limited financial resources to fund their choice of accommodation and lifestyle, including the additional costs of securing disability aids, supports and equipment. For example, the Victorian Coalition of ABI Service Providers (VCASP) explained the implications of economic insecurity in the context of social inclusion for people with acquired brain injury (ABI):

> The effect of income deprivation upon the lifestyles and social inclusion of people with ABI is profound, often incapacitating the opportunities for real social and communal connection. Financial limitations prevent people being able to access many community activities and fail to contribute to social inclusion for many reasons including transport

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[133]   Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014*, p.10.

[134]   *Submission S037*, Whittlesea Disability Network, p.6.

costs, registration or attendance fees, activity costs, funding for support staff, amongst others.[135]

Due to poor employment outcomes, the income distribution among people with disability is markedly different from other people in the community. People with disability are often financially disadvantaged, with many reporting a government pension or allowance as their main source of income (see Figure 5.2). Reliance on a government pension or allowance increases according to the severity of disability. In contrast, people who do not experience a core activity limitation are more likely to receive their main source of income from wages or salaries.

Figure 5.2: Main source of personal income for Victorians with disability 2012 aged 15 years and over, living in households
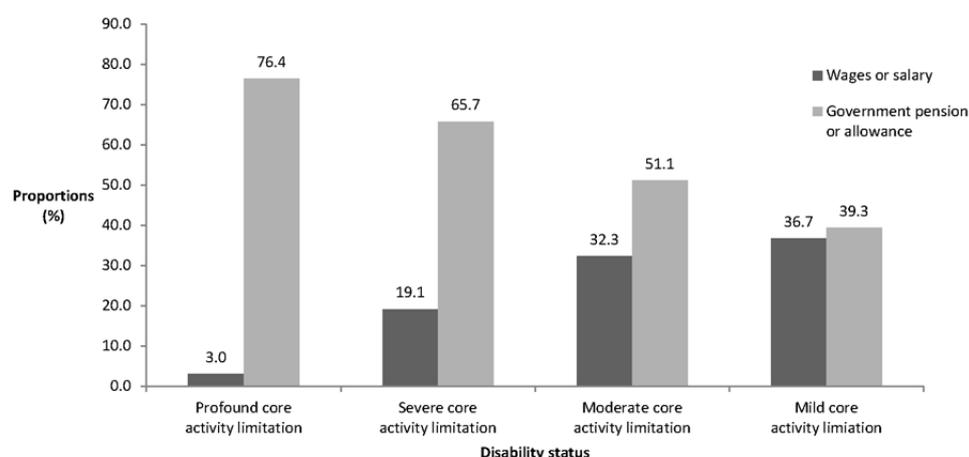
Source: Compiled by the Family and Community Development Committee based on Australian Bureau of Statistics (2012) *44300DO002—2012 Disability, ageing and carers, Australia: Victoria, 2012 (Table 8).* Accessed on 10 July 2014 from
http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02012?OpenDocument.

In its evidence to the Inquiry, the ABS provided further information about the economic wellbeing of people with disability who rely predominantly on government pensions and allowances. Using a process of equivalising,[136] the ABS examined the extent to which people have 'command over economic resources, that is the income and wealth available to them to support their consumption of goods and services.'[137] Based on 2012 data, 22 per cent of Victorians with disability had an equivalised weekly gross household income in the lowest quintile. This is significantly lower than the national figure of 8 per cent for people without disability with a weekly income in the lowest quintile.[138] Figure 5.3 demonstrates these differences by income quintile.

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[135] *Submission S069*, Victorian Coalition of ABI Service Providers Inc (VCASP), p.12.
[136] The process of equivalising uses a scale to measure a lone-person household irrespective of how many people live in a household, allowing a comparison across different household sizes.
[137] *Transcript of Evidence*, Australian Bureau of Statistics, Melbourne, 17 March 2014, p.4.
[138] *Transcript of Evidence,* Australian Bureau of Statistics, p.4.

Figure 5.3: 15–64 year olds gross weekly equivalised household income, Victoria 2012
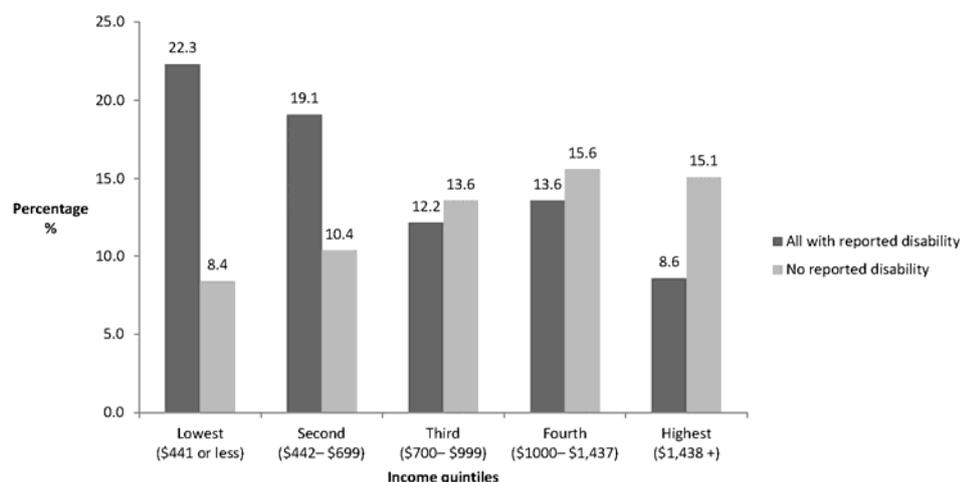
Source: Adapted from *Supplementary evidence*, Hearing presentation, Australian Bureau of Statistics, 17 March 2014.

The Committee recognises that these figures potentially understate the financial difficulties people with disability experience, often due to the additional costs of living associated with disability.[139] Other factors create further financial pressures. For example, housing stress is common among people with disability. Evidence to the Inquiry suggested that about three in ten persons who rely on government pensions and allowances allocate more than 30 per cent of their gross household income on rent.[140] In its submission, Women with Disabilities Victoria (WDV) highlighted that limited employment opportunities and low income can adversely affect the capacity of people with disability to live independently:

> Even now as a mature woman, my parents still exert control over my life … I feel it is time for me to move out and break away from their stranglehold. If I could find employment then I could gain the income I need to rent and live an independent life. I believe having a disability really affects employers' attitudes. This really makes a difference to how I manage my disability and the costs associated with it. I have chronic pain since birth but can't afford to pay for [treatment].[141]

Internationally, Australia has been identified as lagging behind most counties in the Organisation for Economic Coordination and Development (OECD). Australians with disability are 2.5 times more likely to live in or near poverty compared with others in the population, and more than double the (OECD) average of 22 per cent. The OECD average for relative poverty risk is 1.6, which means that people who have disability are 1.6 times more likely to live in poverty compared with the wider population. In Australia the poverty risk for people with disability is 2.7, making it 'the worst performer on this indicator, ranking 27th out of 27 OECD countries.'[142]

The cost of disability increases the importance of financial security for people with disability. It is well known that the cost of disability is high. The

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[139] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.116.
[140] *Submission S111*, Melbourne City Mission, p.19.
[141] *Submission S051*, Women with Disabilities Victoria, p.17.
[142] PricewaterhouseCoopers (2011) *Disability expectations: Investing in a better life, a stronger Australia*. Canberra, PwC, p.11.

Committee heard that many people with disability pay significantly more to be able to access services, maintain employment and do other activities that other people in the community take for granted. For example, Whitehorse City Council stated that:

> Participation in the life of the community can be quite costly especially for people with limited disposable income. It is not expected that the NDIS or other funding services will meet all costs associated with participating in the community, rather there needs to be consideration within policy and service directions of the cost implications for the person with disability and their family.[143]

Ms Stella Young (quoted in the WDV submission) expressed the view that:

> It's very hard to be out and about in the community if you're poor. You might not have a mobility aid that suits your needs. You might be limited to using taxis (a very expensive option for daily travel) because the public transport in your area is inaccessible to you. Or you might just feel, because of the access and attitudinal barriers you know are out there, that you are not allowed a place in your community.[144]

Moonee Valley City Council emphasised that the challenges in securing employment can exacerbate the financial difficulties for people with disability. It told the Inquiry that:

> Perhaps the most significant barrier to meaningful social inclusion for people with disability is lack of economic independence. In most cases, this is caused by limited education and employment opportunities, and the costs associated with living with one or more impairments.[145]

The Committee heard that many people with disability consider employment to be a key avenue to self-reliance and financial security, despite its potential to have an impact on their income support payments. The Summer Foundation, for example, provided the following comments from people with disability on securing employment to achieve financial independence:

> I know there's gonna be money taken off from me, but I think being financially independent would outweigh that. (Jason)

> That thing of self-reliance, the satisfaction of earning that money as opposed to receiving that money far outweighs DSP. In the future I want to get a full-time job and wean myself off DSP. I'd theoretically earn more than what I get from DSP so I see it as a positive. (Kirrily)[146]

People with disability are often in a position where they need to rely on government income support when they would rather work. The introduction of the NDIS is anticipated to better fund access to services, assistance and equipment for those who need them. It also has a strong focus on the need to improve opportunities for employment. Chapter 6 discusses the importance of participating in employment and how this needs to be achieved in Victoria.

5.5. Access to justice

A number of Inquiry participants drew the Committee's attention to the barriers that many people with disability encounter in attempting to attain equality before the law, particularly in the criminal justice system. These barriers exist for both victims and perpetrators of crime.

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143   *Submission S097*, Whitehorse City Council, p.10.
144   *Submission S051*, Women with Disabilities Victoria, p.26.
145   *Submission S052*, Moonee Valley City Council, p.2.
146   *Submission S121*, Summer Foundation Ltd, p.11.

In 2014, the Australian Human Rights Commission released its report, *Equal before the law: Towards disability justice strategies*, the purpose of which was to guide all Australian jurisdictions to develop a Disability Justice Strategy. It noted:

> People with disability do not enjoy equality before the law when they come into contact with the criminal justice system in Australia. Whether a person with disability is the victim of a crime, accused of a crime or a witness, they are at increased risk of being disrespected and disbelieved. If a victim, their disability may be seen to mitigate the offender's guilt; if a perpetrator, their disability makes incarceration more likely.[147]

Mr Ian Parsons from the Centre for Rural Regional Law and Justice, School of Law, Deakin University explained that access to justice services is vital for ensuring that people with disability can address concerns about experiences of discrimination or disadvantage because of their disability:

> Whether they are issues of discrimination, whether they are issues of consumer law in terms of dealing with the purchase of goods and services, whether they are criminal justice issues, planning issues, any of those areas have a legal component to them. So if a person is experiencing some area of difficulty, disadvantage or exclusion because of their disability in those areas and they wish to use the law to address those problems, the relevance of and the accessibility of legal systems in their communities will become vital.[148]

In July 2014, the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) published its report on access to justice for people with disability titled *Beyond doubt: The experiences of people with disabilities reporting crime*.[149] The VEOHRC found that people with disability were more likely to experience violent and sexual crime, but were less likely to report it because they fear they will not be believed, will be seen as lacking in credibility or fear negative consequences.[150] It explained that people with disability are routinely denied access to justice 'because police and other sections of the justice system are ill equipped to meet their needs.'[151] The report identified negative and discriminatory attitudes, gaps in training and development and inconsistency in police responses to reporting of crime by people with disability. In some cases, it suggested that police members refused to accept reports and in others there was a failure to make reasonable adjustments to facilitate communication.[152]

The treatment of people with disability who are victims of family violence is of significant concern, and is discussed in more detail below.

In its submission, NDS Victoria drew on findings of a 2011 Victorian study that found 42 per cent of male prisoners and 33 per cent of female prisoners had an ABI. This compared with 2 per cent of the Victorian population with an ABI.[153] The Victorian Council of Social Service's (VCOSS) submission also highlighted

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147 Australian Human Rights Commission (2014) *Equal before the law: Towards disability justice strategies*. Sydney, Australian Human Rights Commission, p.8.

148 *Transcript of Evidence*, Centre for Rural Regional Law and Justice, Deakin University, Melbourne, 6 March 2014, p.2.

149 Victorian Equal Opportunity and Human Rights Commission (2014) *Beyond doubt: The experiences of people with disabilities reporting crime*. Carlton, VEOHRC.

150 Victorian Equal Opportunity and Human Rights Commission (2014) *Beyond doubt: The experiences of people with disabilities reporting crime*, p.36.

151 Victorian Equal Opportunity and Human Rights Commission (2014) *Beyond doubt: The experiences of people with disabilities reporting crime*, p.5.

152 Victorian Equal Opportunity and Human Rights Commission (2014) *Beyond doubt: The experiences of people with disabilities reporting crime*, pp.43– 44.

153 *Submission S045*, National Disability Services Victoria, p.3. See also *Submission S050*, Australian Community Support Organisation (ACSO), p.4.

that the over-representation of people with disability in the corrections system 'points to systemic failures earlier in life where they did not receive appropriate support.'[154] VCOSS explained that 'people with disability are likely to have worse outcomes from the justice system, be more vulnerable to crime, and more fearful of becoming a victim.'[155]

Access to diversionary criminal justice programs is particularly problematic in rural and regional areas. Mr Parsons identified that this often leads to people being dislocated from their communities in order to access particular programs, which in turn exacerbates the problems. He provided the following example:

> … if a person has offended, they may because of having disability need access to fairly specialised diversionary programs and they might not be available locally. The person either then misses out on those services altogether or they are dislocated from their community in order to get them. Local community identity is often a very critical part of social inclusion in regional communities, so the person's sense of dislocation leads to further problems and can give rise to further offending, which keeps the cycle going.[156]

He also explained that there are anomalies in distribution of justice services across the state, pointing out that because there is no Legal Aid office in Mildura, people needing legal aid in Mildura have to travel to Bendigo.[157] Mr Parsons suggested that successful solutions should draw on local community infrastructure that is often 'incredibly good' in rural and regional settings. He drew the Committee's attention to a new program being auspiced by the Goulburn Valley Community Legal Centre in Shepparton:

> They are looking at ways of using local community infrastructure to assist people who are appearing in the Magistrates Court in a whole range of ways, from helping them through the court process to providing some sort of legal problem solving for people before they appear before the magistrate to come up with alternatives to custodial sentencing, and so on. It is drawing on the people already in the community, bringing them together to try and find alternatives to the more disastrous outcomes that sometimes happen when you do not have access to diversionary services and community based sentencing options.[158]

In 2013 the Victorian Parliamentary Law Reform Committee (VPLRC) conducted an *Inquiry into access to and interaction with the justice system by people with an intellectual disability and their families and carers*. The VPLRC acknowledged that efforts have been made by police, the courts and the legal profession to recognise the needs of people with intellectual and cognitive disability.

The Committee acknowledges that the Victorian Government has committed to considering and responding to these recommendations. However, it identified that more can be done to raise awareness of their needs and to improve processes, services and supports in order to improve their access to and experience of the justice system.[159] A case study that illustrates some of these issues was provided by WDV and appears in Box 5.5.

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154   *Submission S126*, Victorian Council of Social Service (VCOSS), p.18.
155   *Submission S126*, Victorian Council of Social Service (VCOSS), p.18.
156   *Transcript of Evidence,* Centre for Rural Regional Law and Justice, Deakin University, p.3.
157   *Transcript of Evidence,* Centre for Rural Regional Law and Justice, Deakin University, p.5.
158   *Transcript of Evidence,* Centre for Rural Regional Law and Justice, Deakin University, p.3.
159   Law Reform Committee (2013) *Inquiry into access to and interaction with the justice system by people with an intellectual disability and their families and carers*. Melbourne, Parliament of Victoria, p.xxi.

Box 5.5: Alia's experience—Sunshine Magistrates Court 2013

Alia arrived at court to take out an intervention order because her partner was abusive. The Registrar's counter was above the height of her scooter. The Registrar got frustrated listening to Alia's stroke affected voice and referred her to the Applicant Support Worker (ASW) …

The Court's lift was too small to fit Alia's scooter. Alia returned to court with a smaller, borrowed manual wheelchair which required her to hire a disability support worker for the trip. In the courtroom, the only wheelchair accessible space was where the door swung back and forward into her and people stepped over her. The witness box was not accessible, so Alia spoke from the floor.

Various factors served to undermine Alia's communication with the court. The community lawyer had no training or experience working with clients with communication difficulties. No communication assistant was called for by the court.

Source: *Submission S51*, Women with Disabilities Victoria, p.13.

The introduction of the NDIS has raised questions about who is responsible for disability services for people who have come into contact with the justice system. The Australian Community Support Organisation (ACSO) suggested in its submission that this may depend on whether the supports are related to a person's disability or the perceived risk to the community.[160]

The *State disability plan 2013–16* outlines a number of strategies and actions to improve access to rights and justice for people with disability. It also commits to improving services for people with complex needs or behaviour of concern in justice custodial settings.

Table 5.6: *State disability plan 2013–16*—strategies and implementation actions to improve access to rights and justice responses, 2013–14

Strategy and implementation actions
Strategy: Improve services for people with complex support needs or behaviours of concern
• Strengthen partnerships across human services, education and youth justice custodial settings to: ♦ promote positive behaviour support approaches   ♦ reduce the use of restrictive interventions
• Further develop the **Positive practice framework** (DHS 2012) for utilisation across human services and youth justice custodial settings
• Develop and implement a monitoring framework for behaviour support services to strengthen monitoring and evaluation
• Develop a statewide disability forensic practice framework to drive consistent approaches and evidenced-based practice
• Strengthen the disability forensic service system to improve outcomes for young people and adults with disability involved in the justice system, with a focus on early intervention and contemporary approaches

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[160] *Submission S050*, Australian Community Support Organisation (ACSO), p.8.

Strategy and implementation actions
• Provide specialised prison and community-based programs for people with disability to address their offending behaviour
• Continue and further develop specialised services to offenders with an acquired brain injury

Source: Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014.* Melbourne, DHS.

The Department of Justice *Disability action plan 2012–2016* also addresses some of the barriers to justice identified in this section. The plan identifies a range of strategies that focus on improving responsiveness across the justice system to people with disability, including:

• provision of accessible information and advice and appropriate support to enable people with disability to access the justice system

• improved responsiveness of agency staff to people with disability that takes into account their diversity

• accessibility of justice systems and processes

• improved access to physical facilities.[161]

The Committee considers that ongoing monitoring is needed to ensure that these strategies benefit people with disability in accessing and interacting with the justice system.

Family violence

The Committee heard that women with disability are at higher risk of exposure to violence in their intimate relationships. In its submission, WDV highlighted this risk and explained the experience of violence in their home setting and the consequences on their lives:

> Evidence supports that women with disability are at higher risk of violence. Causes for this increased risk include negative attitudes … and social exclusion …
>
> The extent of controlling behaviour that defines family violence is often described as being like terrorism in the home. Lack of control one's place of residence can have powerful effects on social inclusion due to ongoing anxiety, insecurity, low self-esteem and social isolation. Long periods of anxiety and insecurity and the lack of supportive relationships are damaging in many ways.[162]

WDV also explained that 'women with disability can experience violence in the diversity of places they reside, such as private homes, group homes and hospitals.'[163]

For women with disability, the nature of the violence can involve additional dimensions specific to their disability. For example, WDV explained that:

> … perpetrators can choose to exert additional types of control over women with disability, for example, withholding aids, withdrawing supports, restricting movement, or

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161 Department of Justice (2012) *Disability action plan 2012–2016*. Melbourne, DOJ.
162 *Submission S051*, Women with Disabilities Victoria, p.12.
163 *Submission S051*, Women with Disabilities Victoria, p.12.

> mis-administration of medicines. In comparison to women without disability, women with disability experience violence at a higher rate, for longer periods, from more perpetrators, and in more severe episodes.[164]

One of the examples provided by WDV involved a woman with disability whose partner would 'hide her scooter battery, push her out of her scooter and put important things out of her reach.'[165]

Women's Health West explained that there can also be specific difficulties for women with disability who are trying to escape a violent relationship or home situation that directly relate to their disability:

> For women with disability who experience family violence, limited options in accommodation and disability support are key factors influencing their decision to leave. Many women do not have access to independent finances or alternative disability supports and cannot afford to be in an extended period of transition. Additionally, access to 24 hour attendant support is extremely important for women leaving violence, who have complex needs in decision making, information processing and managing anxiety.[166]

Whitehorse City Council expressed its acknowledgement of the challenges for women trying to leave violent circumstances:

> Women with disability who experience violence in their home are less likely to have the capacity to leave than other women who experience violence. Women with disability may be reliant on the perpetrator of violence for daily care activities, moving out of the area may limit their access to services, financial resources may be limited and women with disability living in supported accommodation may not feel they have any opportunity to move house.[167]

The Committee acknowledges that in the *State disability plan 2013–16*, the Victorian Government has prioritised actions to improve responses to violence and sexual assault under Goal 2 of 'upholding rights and promoting participation'. Table 5.7 outlines the actions committed to under the Plan.

Table 5.7: *State disability plan 2013–16*—strategies and implementation actions to prevent and respond to violence against women with disability, 2013–14

Strategies and implementation actions
Strategy: Better enable people with disability, families and carers to exercise their rights
• Enable people with disability who are victims of crime to exercise their rights in the criminal justice system by: ♦ increasing the awareness of workers in victim services and criminal justice agencies of the information and support needs of people with disability who are victims of crime ♦ developing better processes to identify the individual needs of people with disability prior to attending court ♦ ensuring greater collaboration between disability services and victim support agencies.
• Support people with disability who have become victims of personal crime to access: ♦ legal assistance

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164   *Submission S051*, Women with Disabilities Victoria, p.12.
165   *Submission S051*, Women with Disabilities Victoria, p.13.
166   *Submission S071*, Women's Health West, p.9.
167   *Submission S097*, Whitehorse City Council, p.11.

Strategies and implementation actions

- ♦ protection

- ♦ help to recover from the effects of crime.

Strategy: Improve responses to violence and sexual assault

- • Provide professional development for workers in disability services and agencies about the rights and services available to people with disability who are victims of crime.

- • Support women with disability or women who have a child with disability experiencing or escaping from family violence to access a crisis response or remain safely in their own home.

- • Enable disability support staff to better identify indicators of family violence and sexual assault and refer to specialist support services through:

  - ♦ providing information and resources

  - ♦ training programs.

- • Extend Family Violence Risk Assessment and Risk Management Framework through information and training to the disability sector as a priority.

- • Introduce three additional multidisciplinary centres to provide improved support for survivors of sexual assault and children who have experienced abuse.

Source: Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014*. Melbourne, DHS.

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Chapter 6

Creating opportunities to participate

AT A GLANCE

Background

Participation in social, economic and community life has significant health, social and financial benefits. Victorians with disability make valued and diverse contributions to the social, economic, and civil dimensions of life. While most Victorians expect to be able to participate in education, employment, recreation and other activities, many people with disability face considerable challenges in accessing opportunities to participate in a way that meets their needs, expectations and aspirations.

Key findings

- People with disability participate in a range of mainstream and specialist settings in education, employment and other activities. While mainstream settings are considered ideal for improving belonging and social inclusion, many are not fully inclusive. For some people with disability, specialist settings remain the only viable option for participation. **(Finding 6.1)**

- While there have been efforts to improve the inclusiveness of education in mainstream schools, there remains an inconsistent approach to ensuring accessibility and inclusiveness across all schools in Victoria. Many children with disability continue to experience barriers that result in them having to attend specialist schools. **(Finding 6.2)**

- People with disability have skills, knowledge and experience to contribute to the workforce, and like others want equal opportunity to work in environments where they can add value and be respected for their contribution. In order to allow equal opportunities for people to contribute to the workforce, adjustments need to be made to account for diversity of all employees, including those with disability. **(Finding 6.3)**

- People with disability continue to participate at low levels in the workforce due to negative attitudes and barriers that prevent them from fully contributing to the best of their potential. **(Finding 6.4)**

- People with disability participate in a variety of sports, yet in substantially lower rates than other people in the community despite the valuable health benefits. **(Finding 6.5)**

- People with disability participate in arts and cultural activities, but experience barriers that prevent their full participation due to physical inaccessibility, negative attitudes and lack of information about accessibility. **(Finding 6.6)**

- While people with disability are increasingly participating in advocacy and leadership roles within the disability community, there remain very few people with disability in political, elected and other civic roles in the broader community, such as committees of management and board positions. **(Finding 6.7)**

AT A GLANCE

Recommendations

That the Victorian Government

- Establish measurable outcomes and targets in future State Disability Plans and implementation plans that relate to increasing participation by people with disability in education, employment, sports and recreation, cultural activities, and political and other elected roles. . **(Recommendation 6.1)**

- Undertake a study of children with disability who progress from early childhood education into schools over the next five years to identify the extent to which mainstream schools provide inclusive environments for children with disability. **(Recommendation 6.2)**

- Commission a review of reverse integration approaches to assess their value and potential to provide exposure and increased awareness for children of all abilities to the diversity of children with disability. **(Recommendation 6.3)**

- Consider the feasibility of introducing a partnership program between the school and Vocational Education and Training sectors and the Victorian and Australian governments to promote open employment within school communities with the intention of supporting a smooth transition from school to real work for students with disability. **(Recommendation 6.4)**

- Develop a job shadowing program to assist young people with disability to gain experience in the workplace and to provide employers with exposure to the contributions that people with disability can provide. **(Recommendation 6.5)**

- Develop a strategy on access to elected office for people with disability. **(Recommendation 6.6)**

Participation in social, economic and community life can provide avenues for social interaction, learning and developing skills, and pathways to financial security. Members of the community, including people with disability, can benefit considerably from the experience of participating in society. In turn, there are also valuable returns for local communities, the economy and society generally.

The ways that people participate in the community vary enormously, and people with disability contribute to society in equally diverse ways.

However, the Committee also heard that many people with disability experience daily challenges in their efforts to engage in activities or pursue a career or other ambitions. Inaccessibility, negative attitudes, and limited or segregated opportunities can prevent people with disability from contributing to society and pursuing their aspirations.

Due to the advocacy of people with disability and other supporters, recent decades have seen efforts by governments and others to improve opportunities for participation. While progress has been achieved, the Committee identified that there is an ongoing need to address practical and attitudinal barriers to meaningful participation.

In this context, the Committee received considerable evidence about participation in the context of education and employment. Yet Inquiry participants also made reference to the diversity of contributions people with disability make to society—including civic pursuits such as leadership and advocacy. They also highlighted the need for increased opportunities to participate in sport, recreation and cultural activities.

6.1.   Contributing to society and fostering increased participation

As for all people in the community, when people with disability participate in society there are important benefits for them as individuals, for society, for local communities, and for the economy:

- Individual benefits—health and wellbeing, social inclusion and improved quality of life.

- Societal and community benefits—contribution of diverse skills and experience, improved attitudes towards and treatment of people with disability and acceptance of diversity.

- Economic benefits—consuming goods and services, participation in the workforce, reduced reliance on financial supports.

Chapter 1 discussed the difference between social inclusion and participation. Some people with disability feel that their contributions to society are valued and respected, which contributes to a sense of belonging and inclusiveness. Yet for others, their participation in the community does not always reflect their expectations, needs or aspirations. Participation does not always lead to experiences of social inclusion.

6.1.1.   Contributions of people with disability

In its Submission Guide, the Committee sought input from participants about the ways in which people with disability contribute to their communities and society more broadly on a day-to-day basis. The Darebin Disability Advisory Committee explained that people with disability are no different from any other person in the community and contribute to society in all its dimensions:

> People with disability participate in all areas of economic, social and civil dimensions like every other Australian. People with disability are parents, employees and employers, students, educators, performers, consumers, advocates and policy makers just to name a few.[1]

The Centre for Rural Regional Law and Justice made the same point, and emphasised that just because someone has disability, this should not limit the areas of social life they choose to participate in:

> People with disability participate in the economic, social and civil dimensions of society in all the same ways that other Victorians do … the dimensions of participation do not need to be different or limited simply on the grounds of having disability.[2]

In a story provided to the Inquiry, Aaron, a person with disability, expressed the importance of contribution:

> I love having a purpose, having somewhere I can go to be productive and achieve something while also getting to help others. And for me, with my operation setting my life back three to four years, it's a great feeling to be able to support others in their recovery.[3]

Whitehorse City Council told the Inquiry that a drawback of social inclusion policy has been a tendency to focus on participation in the workplace over other ways that people with disability contribute to society. It explained that 'economic participation has had a primary focus on employment ignoring the many other ways people with disability contribute to the economic viability of a community.'[4] The Council went on to emphasise that 'people with disability are; consumers of goods and services; provide employment for many people and are volunteers.'[5]

A member of Women with Disabilities Victoria (WDV), Shaunagh, also drew the Committee's attention to the emphasis on employment, stating that:

> Discussions on 'social inclusion' always focus on employment. It is important not to forget all the unpaid work of women—volunteering, parenting and caring.[6]

Another woman who participated in the WDV submission explained the diversity of her contribution to the community:

> I'm involved in local community groups like Whitehorse Disabilities Advisory Group and the Alfred Community Advisory Group. I volunteer, talking to people in hospital who may be about to or who have just undergone limb amputation, and serve in medical research Committees.[7]

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[1]   *Submission S041*, Darebin Disability Advisory Committee, p.5.
[2]   *Submission S013*, Centre for Rural Regional Law and Justice, Deakin University, p.9.
[3]   *Submission S111*, Melbourne City Mission, p.11.
[4]   *Submission S097*, Whitehorse City Council, p.6.
[5]   *Submission S097*, Whitehorse City Council, p.6.
[6]   *Submission S051*, Women with Disabilities Victoria, p.14.
[7]   *Submission S051*, Women with Disabilities Victoria, p.7.

The level of diversity in the contributions that people with disability make in the social, economic and civil dimensions of society was stressed by many Inquiry participants. Monash Health provided a detailed example of this diversity beyond economic participation:

> The importance of diversity and prevalence of participation of people with disability cannot be underestimated. Many people with disability often provide the hugely important role of carers for grandchildren, aged relatives or others with disability. They are often involved in creative self-expression and the arts, the not for profit sector—community radio, boards and committees, or local council in an advisory capacity on disability issues. Many do significant amounts of voluntary work in areas as diverse as consumer representatives in health care, board members, retail assistance in opportunity shops, community visitors to aged and nursing care homes, administration roles within clubs, presenters on community radio, delivery workers for meals on wheels, interviewers and receptionists for citizens advisory boards and resource centres, outdoor and garden workers, and pet walkers.[8]

The Committee also heard people with disability participate 'in every way, in not enough ways.'[9] This simple statement summarised the views of many perspectives provided in the Inquiry evidence. Box 6.1 outlines some additional views on the limited opportunities for people with disability to contribute more to society.

Box 6.1: Contributions and society's missed opportunity

- Victorians with disability do participate in the economic, social and civil dimensions of society … However society is missing out on a huge knowledge base and massive contribution from people with disability and their life experiences. People with disability would participate in a wider range of economic, social and civil dimensions of society if the access barriers were removed. (*Submission S007,* Deaf Victoria, p.2)

- People with disability participate on many levels locally (working in cafés, heard on local radio, given the chance to provide input for a skatepark redevelopment, exhibit in art shows) however the opportunities are limited or short lived / one off. (*Submission S036,* Mansfield Support Group, p.2)

- People with disability contribute to the economic, social and civic fabric of society however the barriers they experience impacts on the level and way in which people are able to contribute to society. (*Submission S097,* Whitehorse City Council, p.7)

- People with disability already participate in the economic, social and civil dimensions of society in exactly the same way as every citizen, albeit in greatly reduced numbers. But there are fewer people with disability engaged in more valued and responsible activities and roles. (*Submission S104,* Annecto, p.9)

- Victorians with disability, like all other Victorians, make valuable contributions to all aspects of the economic, social and civil dimensions to society. However, like other marginalised groups, they face significant barriers to access, participation, inclusion and achievement. (*Submission S111,* Melbourne City Mission, p.25)

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[8] *Submission S068*, Monash Health, pp.9–10.
[9] *Submission S012*, Office of the Public Advocate, p.20.

The Committee heard that there is vast potential for society to benefit from people with disability increasing their contribution to social, civic, and economic life. In this context, Monash Health told the Inquiry that it is:

> … important to ensure that people with disability are active participants and are provided with the opportunity to give back to their community. Many people living with disability are 'stuck' being the receiver of services or assistance and not provided with the opportunity to contribute or give back to community.[10]

Associate Professor Paul Ramcharan provided insights about how thinking needs to change for the community to recognise the opportunity it is missing as a result of the limited participation of people with disability. In considering how people can contribute more extensively in ways that benefits both them and society more generally, he explained that there is a need to focus on people with disability as 'active citizens' and 'equal citizens', which is:

> … based on the idea that people have something to contribute to their community, that they bring gifts. It is an extraordinarily strong argument on moral grounds that the respect for diversity, autonomy, choice and citizenhood are at the very core of people contributing to their communities. However, it relies a great deal on the public to change their attitudes.[11]

The Committee considers that changing attitudes is essential to increasing the opportunities for people with disability to contribute. This is discussed throughout this chapter and in Chapter 8. Part of changing attitudes is ensuring greater inclusiveness in mainstream settings, as the next section discusses.

6.2.   Mainstream and specialist settings for participation

As Chapter 1 outlined, a history of marginalisation and institutionalisation has resulted in a legacy of segregation that persists in Victoria today. Since the 1970s, Victoria has been gradually moving away from segregated approaches to disability.

The Committee heard that greater integration into mainstream participation is not a linear process. For example, residential institutions have been closed, but people with disability continue to participate in segregated day programs. The number of children with disability in mainstream schools fluctuates as parents and young people make decisions to change schooling arrangements at varying points. Given the diversity of activities people with disability engage in, it is difficult to measure the extent to which participation is mainstream or segregated.

The Committee recognises that there continues to be divided opinion about the benefits of segregated environments such as schools, employment and recreation. Opinion is equally divided on the advantages of people participating solely in mainstream settings.

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[10]   *Submission S068*, Monash Health, pp.4–5.
[11]   *Transcript of Evidence*, Associate Professor Paul Ramcharan, Centre for Applied Social Research, RMIT University, Melbourne, 3 March 2014, p.3.

The debate over mainstream and specialist environments for participation is complex, challenging and emotional. Those engaged in the debate are varied. People with disability themselves have views that are as diverse as they are individuals. Informal carers and those who are empowered to make decisions on behalf of a child or an adult with disability have varying perspectives. Disability advocates, academics and policy makers also have diverse opinions.

The Committee identified that in the context of social inclusion, the issue regarding mainstream and segregated settings has both societal and personal perspectives. From a societal perspective, segregated environments represent social exclusion from the community. From a personal perspective, a sense of belonging and connectedness contributes to social inclusion.

The complexity of achieving a fully inclusive experience is demonstrated when the following questions are asked about what represents an experience of social inclusion:

- Is a person socially included if they are participating in a mainstream environment but feel isolated, lonely and disconnected?

- Is a person socially included if they are participating in a segregated setting and feel a sense of belonging and connectedness?

The Committee heard that in an ideal world, social inclusion would be when a person feels a sense of belonging and connectedness while participating in mainstream settings. As Victoria continues its gradual move away from segregated environments, increasing numbers of people with disability feel connected and included in the mainstream community. Yet participants told the Inquiry that for many people with disability participating in either segregated or mainstream settings does not immediately lead to personal feelings of connectedness and belonging.

Figure 6.1 provides a simplistic matrix representation of four possible experiences of exclusion and inclusion in mainstream and segregated settings. While Victoria is generally moving towards greater inclusion in mainstream environments, the Committee heard that people with disability do not experience feelings of belonging and inclusion in a linear progression.

The Committee heard that experiences across these settings can be very fluid. People might move across the quadrants outlined in the matrix in one area of their life or activities, while be stable in one quadrant in another area of participation. For example, a person might live in shared supported accommodation, work in open employment and participate in a disability football league. In each of these areas their experience of inclusion and connectedness might be different. Another example might be a child with disability who moves multiple times across mainstream schooling and specialist schooling and experiences different degrees of social inclusion at a personal level.

Figure 6.1: Matrix representation of four possible experiences of exclusion and inclusion in mainstream and segregated settings
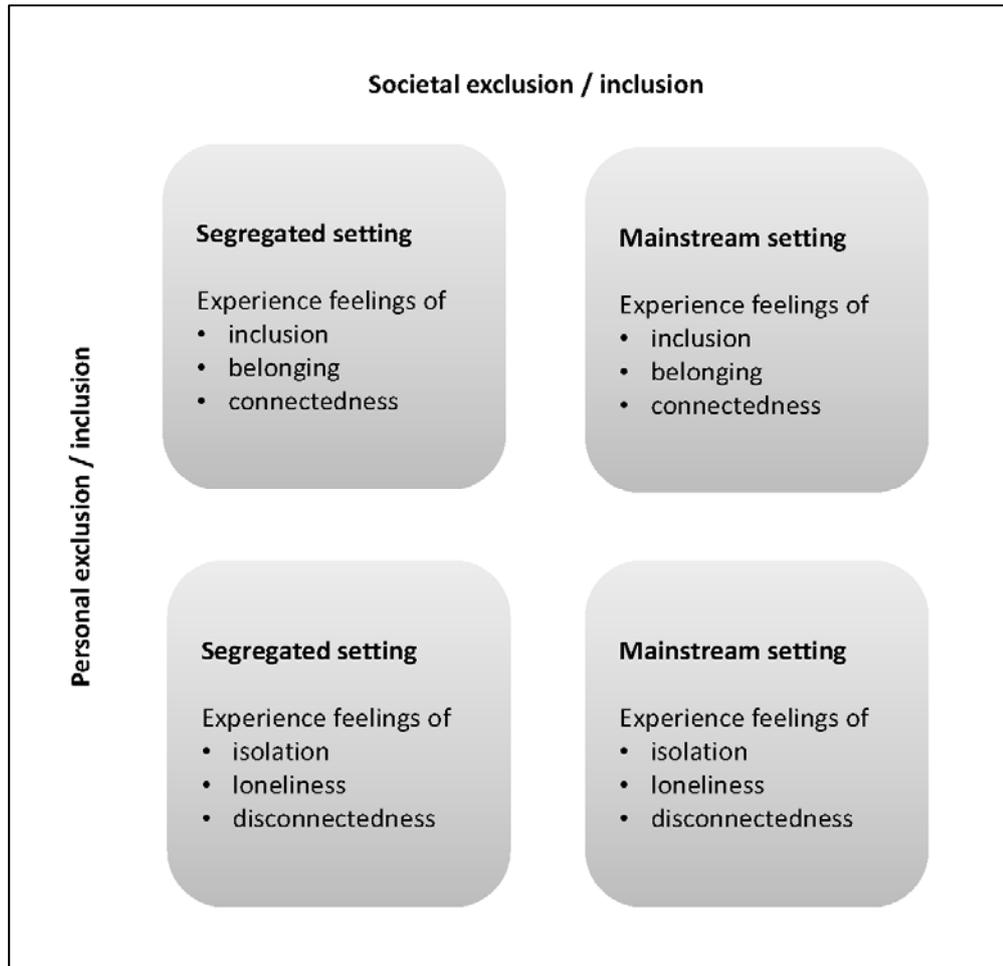
Source: Complied by the Family and Community Development Committee.

6.2.1.   Educational settings

The Committee considered the issue of participating in segregated and mainstream environments in the context of education. It heard strong and divided opinion regarding the value of inclusive education in mainstream schooling and the benefits of specialist schooling. Education is a complex space given that in general children do not have complete control over their decision making—parents make the majority of decisions based on varying degrees of consultation with their child.

In Victoria, the companion document to the *State disability plan 2013–16* reported that in 2012, 55 per cent of students with disability attended mainstream schools, with the other 45 per cent attending one of Victoria's 76 specialist schools.[12] In evidence it provided to the Inquiry, the Victorian Department of Education and Early Childhood Development (DEECD) advised that its

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[12]   Department of Human Services (2012) *Victorian state disability plan 2013–2016. Companion document*. Melbourne, DHS, p.14.

preferred way of engaging Victorians with disability in the education system is through mainstream settings.[13]

Inquiry participants supported the inclusion of children and young people with disability in mainstream educational settings. For example, Dr Jane Tracy, Director of the Centre for Developmental Disability Health Victoria (CDDHV) at Monash University, told the Inquiry there are benefits in mainstream schooling for promoting social inclusion among young people. She explained that peers of young people with disability in mainstream schools:

> … learn about diversity in the community. They learn about the richness that diversity brings. They learn about the ways in which we are all different—skin colour, racial or religious background and the ability to move around and think. We are all on the spectrum somewhere.[14]

STAR Victoria is a strong advocate for ending segregated schooling. A board member for the organisation, Dr Philip Graves, told the Inquiry that progress was strong in the 1970s and 1980s but had regressed in the past decade or so:

> We used to be leaders here in Victoria back in 1974. In the *Education (and Handicapped) Children Act 1970* we said that all children, regardless of their level of ability were educable, and that was pretty progressive. Then in 1984 in the review of educational services for children with disability, we again in Victoria—and it was more you— produced a report that said that all children regardless of ability should have the right to go to mainstream schools, and that was very progressive. But we now have more children excluded today than we had back in 1984. We have about twice as many children in Victoria excluded from mainstream schools—that is as a percentage of the total—than we had back then in 1984.[15]

It informed the Inquiry that it believes:

> … that inclusive education is the foundation and a fundamental part of achieving community inclusion. We are not suggesting for one moment that if we get inclusive education right, all the rest of it will fall into place, but it is the starting point.[16]

Other Inquiry participants provided a different perspective, stating that in view of current attitudes in the community and the education system, they do not feel they can send their child to a mainstream school. For example, the Association for Children with a Disability explained to the Inquiry that:

> … there are people who believe that all specialist schools should be closed and that would force mainstream to step up. But we have families who say, 'that's fine as an aspiration. I don't want my child to be a sacrificial lamb right now in 2014'.[17]

Mr Matthew Potocnik also expressed his concerns that a mainstream school would not be able to support the needs of his son, but also indicated that if those needs were met it might lead to greater inclusion for children with disability:

> Inclusion, to my son is being able to go to a specialist school, with others. It is probably best that way because a mainstream school would not be able to support his needs as well. But perhaps it should?[18]

The Committee sought the perspective of a specialist school and heard from Mr John Burt, Principal of Ballarat Specialist School. He explained to the

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13 *Transcript of Evidence*, Department of Education and Early Childhood Development, Melbourne, 3 March 2014, p.2.
14 *Transcript of Evidence*, Centre for Developmental Disability Health Victoria, Melbourne, 6 March 2014, p.7.
15 *Transcript of Evidence*, STAR Victoria Inc, Melbourne, 5 May 2014, p.4.
16 *Transcript of Evidence,* STAR Victoria Inc, p.3.
17 *Transcript of Evidence*, Association for Children with a Disability, Melbourne, 17 March 2014, p.6.
18 *Submission S125*, Mr Matthew Potocnik, p.1.

Inquiry that the school provides regular education based on individual education plans and also more specialist services, such as its therapy program:

> We have a therapy section consisting of 19 people who are occupational therapists, physiotherapists, speech pathologists, chaplains, school nurses—and so it goes on. They are a significant group within our population. Many of our students are receiving, for example, hydrotherapy perhaps two or three times a day, and for them it is much more relevant than reading, writing and arithmetic.[19]

He made the point, however, that the school is 'bursting with numbers'. He suggested to the Inquiry that there needs to be consideration of how to address the burgeoning numbers, stating that one option might be to increase the number of students with disability that mainstream schools will take:

> What we have to do at Ballarat is either set up an annex to take further numbers in our area or start looking at the real possibilities of students being maintained in regular schools.[20]

He explained that around 60 to 100 students attending the Ballarat Specialist School 'should be able to be maintained in regular schools' and identified that 'mainstream schools can be far more adaptable and flexible to cater for the needs of many students' than they currently are.[21]

6.2.2. Social and employment settings

As discussed in section 4.5.2 of Chapter 4, specialist settings can allow people with disability to establish social connections through engaging with peers. Specialist sporting facilities, for example, can allow people with disability to engage in sports competitions with similarly abled peers.

For some people with disability, specialist settings can offer opportunities for participation that may be difficult for them to access in the broader community. For example, some social enterprises have been established specifically to create employment opportunities for people with disability, recognising that they are often excluded from the open labour market. Some specialist settings can cater in a more individualised way to the needs and aspirations of people with disability. For example, Marriott Support Services explained:

> In recent times there has existed a strong federal government push for the almost 415 current Australian Disability Enterprises (ADEs) which provide supported employment to an estimated 22,000 people with disability, to move towards social enterprise models and to move increasing numbers of supported employees towards open employment. The reality of ADEs over the last 20 years is that while they have not always provided the same opportunities as open employment for individuals to mix with a wide range of people with different interests and experiences, they have provided meaningful work—a purpose—in a supported environment for many who would otherwise find employment difficult to achieve and maintain. We believe that this has often not been recognised in the thrust towards open employment and social enterprises – a thrust sometime led by people with little hands-on experience of the realities of the world of ADEs.[22]

19 *Transcript of Evidence*, Ballarat Specialist School, Melbourne, 26 May 2014, p.2.
20 *Transcript of Evidence,* Ballarat Specialist School, p.4.
21 *Transcript of Evidence,* Ballarat Specialist School, p.4.
22 *Submission S020*, Marriott Support Services, p.6.

6.2.3.   The need for more inclusive mainstream settings

The Committee concluded that mainstream environments in which people experience a sense of belonging and inclusion are the ideal circumstances for people with disability to participate, assuming that is their preference. But there are circumstances in which people with disability participate in mainstream settings that leave them feeling isolated and excluded. These experiences vary across a diverse range of social, economic and civil dimensions, and it is currently not possible to determine how many people with disability engage in segregated settings.

The Committee determined that increasing the inclusiveness of mainstream settings needs to be an ongoing priority. It is important that people with disability have greater opportunity to choose the domains in which they prefer to participate and contribute. Central to these efforts are addressing negative attitudes and providing the necessary supports for people with disability who choose to participate in mainstream settings.[23]

Finding 6.1

People with disability participate in a range of mainstream and specialist settings in education, employment and other activities. While mainstream settings are considered ideal for improving belonging and social inclusion, many are not fully inclusive. For some people with disability, specialist settings remain the only viable option for participation.

Recommendation 6.1

That the Victorian Government establish measurable outcomes and targets in future State Disability Plans and implementation plans that relate to increasing participation by people with disability in education, employment, sports and recreation, cultural activities, and political and other elected roles.

6.3.   Engaging in quality education

Education provides people with the opportunity to fulfil their potential and to build a strong future for themselves and their families. It also contributes to developing an individual's sense of identity and their place in the world.[24] Inquiry participants emphasised that children and young people with disability desire the same opportunities in education available to students in the broader community. Yet the Committee heard that in reality the education system often fails to effectively cater for and respond to the needs of students with disability.

In its 2011 *World report on disability*, the World Health Organization (WHO) identified that participation in education influences important outcomes for children with disability and fosters a culture of inclusiveness in the broader population:

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[23]   See for example, *Submission S080*, Melba Support Services Inc, p.6.
[24]   National People with Disabilities and Carer Council (2009) *Shut out: The experience of people with disabilities and their families in Australia*. Canberra, Commonwealth of Australia, p.47.

> For children with disability, as for all children, education is vital in itself but also instrumental for participating in employment and other areas of social activity. In some cultures, attending school is part of becoming a complete person. Social relations can change the status of people with disability in society and affirm their rights. For children who are not disabled, contact with children with disability in an inclusive setting can, over the longer term, increase familiarity and reduce prejudice. Inclusive education is thus central in promoting inclusive and equitable societies.[25]

Many Inquiry participants emphasised the importance of education for people with disability. For example, in its submission to the Inquiry, STAR Victoria stressed that inclusion in education is a 'fundamental and critical pathway to lifelong social, economic, and civil inclusion.'[26] It identified preschool, primary and secondary schooling as the first environments for the development of 'lifelong learning communities contributing to a fully inclusive society, a skilled workforce and a pathway out of the poverty cycle.'[27] Chapter 4 discusses the link between social connections and education in greater detail.

The WHO *World report on disability* identified that inclusion in education can be seen in the broad sense of providing access to education in a range of settings:

> The sense of inclusion is that the education of all children, including those with disability, should be under the responsibility of the education ministries or their equivalent, with common rules and procedures. In this model education may take place in a range of settings—such as special schools and centres, special classes in integrated schools or regular classes in mainstream schools—following the principle of 'the least restrictive environment'. This interpretation assumes that all children can be educated and that regardless of the setting or adaptations required, all students should have access to a curriculum that is relevant and produces meaningful outcomes.[28]

The report also explained that education provides opportunities for children and young people with disability to be included in regular classrooms with students of their own age:

> A stricter sense of inclusion is that all children with disability should be educated in regular classrooms with age-appropriate peers. This approach stresses the need for the whole school system to change. Inclusive education entails identifying and removing barriers and providing reasonable accommodation, enabling every learner to participate and achieve within mainstream settings.[29]

The WHO observed that countries vary widely in the degree to which children and young people with disability attend mainstream or segregated schools, and determined that no country has a fully inclusive system. It emphasised the importance of a flexible approach to placement, and that educational needs must be assessed from the perspective of what is best for the individual and the available financial and human resources within the country context.[30]

In early childhood settings, Noah's Ark recommended inclusion to involve the 'active participation and meaningful involvement' of children with disability in the same early childhood education and care programs as children in the broader population.[31] Furthermore, it recommended that programs have the same high expectations for their learning and development and suggested that establishing

25   World Health Organization (2011) *World report on disability*. Geneva, WHO, pp.205–06.
26   *Submission S028*, STAR Victoria Inc, p.2.
27   *Submission S028*, STAR Victoria Inc, p.1.
28   World Health Organization (2011) *World report on disability*, p.209.
29   World Health Organization (2011) *World report on disability*, pp.209–10.
30   World Health Organization (2011) *World report on disability*, p.210.
31   *Submission S102*, Noah's Ark, p.13.

common outcomes for all children is important in fostering aspirations for the participation of children with disability in education. These outcomes include that children:

- have a strong sense of identity

- are connected with and contribute to their world

- have a strong sense of wellbeing

- are confident and involved learners

- are effective communicators.[32]

In the context of achieving inclusion in quality education, the Committee supported the sentiment of the United Kingdom (UK) Department of Education in its 2011 Green Paper *Support and aspiration: A new approach to special educational needs and disability* which stated that:

> Every child, whether in a mainstream or special setting, deserves a world-class education to ensure that they fulfil their potential.[33]

6.3.1.   Transitioning into and through education

A number of participants highlighted the significance of the transition experienced by children with disability from early childhood education and care into the formal schooling system. Early Childhood Intervention Australia (Victorian Chapter) identified a need for children to be effectively supported through this time of transition:

> Much of the work the Government and community puts into helping children with disability and developmental delays to feel supported and included can be lost if these children are not properly assisted in their transition from ECEC [Early Childhood Education and Care] to school. For these transitions to be successful 'it is important that discontinuities around learning, relationship building and support systems are minimised.'[34]

Down Syndrome Victoria expressed its view that while government grants are helpful to those eligible to receive them, there are inconsistent experiences in the transition from early education to school:

> DEECD funding has been given to students starting Prep in a government school or transitioning to a new government school and has been gratefully utilised by schools with a student with Down syndrome meeting the eligibility criteria. Unfortunately ineligible students are required to pay $1800 to receive this service. Many school and families are not in a position to afford this beneficial but costly service.[35]

Melbourne City Mission also suggested the theory of providing support to transition by providing grants is good, but in practice it is less effective. Box 6.2 provides an extract from an example about the parents of two children with autism and their experience during this time of transition.[36]

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[32]   *Submission S102*, Noah's Ark, p.4.
[33]   United Kingdom Government, Department for Education (2011) *Support and aspiration: A new approach to special educational needs and disability. A consultation*. Manchester, Department for Education, p.8.
[34]   *Submission S040*, Early Childhood Intervention Australia (Victorian Chapter), p.6.
[35]   *Submission S026*, Down Syndrome Victoria, p.1.
[36]   See also *Submission S058*, Ms Elizabeth Gillespie, p.2.

Box 6.2: Starting school—Thomas' experience

Thomas had a rocky start [at the first school he attended]. We didn't expect it. The principal presented well. We were impressed about his ideas about transitioning and the school had a long transition period for Preps, which was good.

What we learnt is that there's a difference between people knowing a little bit of information [about autism] and actually having knowledge. And there's a difference between being present and participating, and between participating and being included.

Thomas was being included at first.

For example, the teacher recognised that Thomas wasn't coping in the playground, so she began to take Thomas into the classroom for half an hour at lunchtime. She would pull in some other kids, so that there was a social group interacting together. It was going well, but the principal said it wasn't sustainable.

We had the 'perfect storm'—a controlling and defensive principal and a classroom teacher and an aide who [for different reasons] were not able to challenge what was going on.

The aide was meant to be there for Thomas [and another child] but was regularly directed to work with other kids.

It had been so hard to get that funding in the first place. The process is horrific. You have to downplay your kids' strengths to get support at a mainstream school.

Source: *Submission S111*, Melbourne City Mission, p.13.

The Committee acknowledges that there is a considerable amount of work being done to raise awareness of educators about schooling and autism spectrum disorders.

Some of the evidence provided to the Inquiry (such as the evidence shown in Box 6.2) suggests that some families can face difficulties with the process of establishing eligibility for educational support. In response to the Committee's request for further information, DEECD explained that the eligibility and determination of supports and adjustments under the Program for Students with Disabilities should be a collaborative process between the school and parents. However, it acknowledged that some schools and parents struggle to work positively together and that the Department is developing resources to support positive partnerships:

> In terms of what support is determined, this is done by the school with parents and others as appropriate. The appropriate and reasonable adjustments are determined for the student to participate on the same basis as their peers and address their disability related challenges. This should be true for all students with disability not just those who are funded under the PSD.
>
> Most of the time schools and parents work positively together or reach a shared view, but there will be times when schools and parents struggle and DEECD is working with the Association for Children with a Disability Victoria (ACD) to develop an online resource for parents about Effective Dispute Resolution. The purpose of this is to provide families and schools with information and support to create positive partnerships, and procedures and strengthen common understandings and knowledge.[37]

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[37]   *Supplementary evidence*, Response to Questions on Notice, Department of Education and Early Childhood Development, 25 March 2014, pp.6–7.

While the education system has a key role, the Committee heard that parents are also central in helping to support their child with disability through this transitional phase. Noah's Ark suggested there would be value in 'helping parents of children with additional needs with smooth transitions in their child's early years.'[38]

The Committee considered that there would be value in providing practical information and coaching for parents navigating the educational support system.

Recommendation 6.2

That the Victorian Government undertake a study of children with disability who progress from early childhood education into schools over the next five years to identify the extent to which mainstream schools provide inclusive environments for children with disability.

6.3.2.   Participation levels and inclusive education

The Committee heard that in the context of education, people with disability continue to leave school earlier than other students in the community. It acknowledges that the Victorian Government has identified this issue and has developed strategies to improve the experience of schooling for students with disability. Yet it considers there remains a long way to go.

Progress has been made in improving access to education for people with disability. Under the national *Disability standards for education 2005* education providers in Victoria are required to ensure inclusion and access for people with disability. Discrimination against students with disability is prohibited under the *Equal Opportunity Act 2010* (Vic) (EO Act), which also requires education providers to make reasonable adjustments to facilitate their inclusion.

However, outcomes for children with disability are still poorer than for children in the broader population. As shown in Figure 6.2, around a third of young people with disability completed year 12 in 2012 (38.6 per cent), compared to 62 per cent of young people without disability. The rate of completion varied to some degree depending on the extent of disability, with 31.2 per cent for people with profound or severe core activity limitation completing year 12 compared with 36 per cent of people with specific limitations or restrictions. Further, there was a greater number of people with disability who completed year 10 as their highest level of educational attainment (21.3 per cent), compared to people without disability (13.2 per cent).[39]

The Australian Bureau of Statistics (ABS) told the Inquiry that although there have been improvements in year 12 completion rates across the years for everyone regardless of disability, the gap between those with and without disability has not closed over those years.[40]

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[38]   *Submission S102*, Noah's Ark, p.10.
[39]   These figures are affected to a small degree by variation between people with varying levels of core activity limitation. For example 20.6 per cent of students with a profound or severe core activity limitation completed year 10 as their highest level of schooling, compared with 21.4 per cent of students with specific limitations or restrictions.
[40]   *Transcript of Evidence*, Australian Bureau of Statistics, Melbourne, 17 March 2014, p.3.

Figure 6.2: Highest level of high school attainment by disability status (2012)
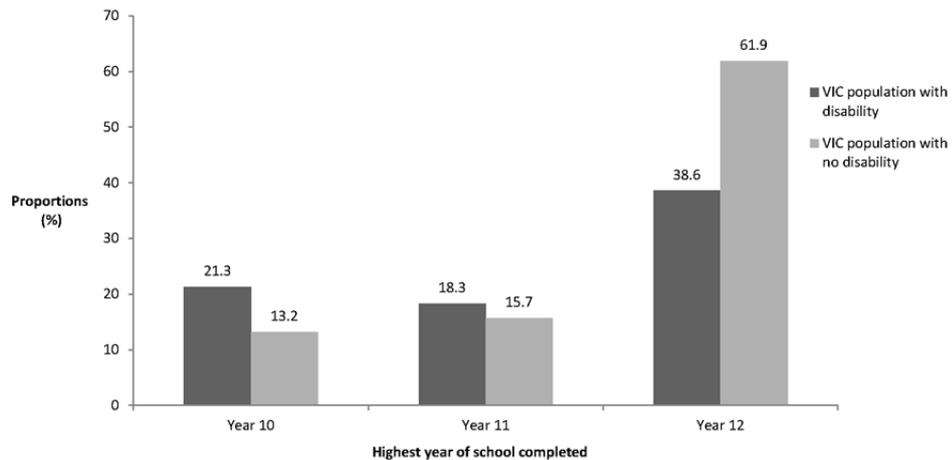
Source: Australian Bureau of Statistics (2014) *Disability, ageing and carers, Australia: Victoria 2012 (Table 7).* cat. no. 44300DO002, Canberra, ABS. Accessed on 14 August 2014 from http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02012?OpenDocument.

These are significant findings as 'early school leavers are more likely to be unemployed for longer periods, earn lower incomes and accumulate less wealth over their lifetime compared to those who complete Year 12 and/or pursue tertiary qualifications.'[41]

In the context of vocational education and training (VET), the Committee heard that people with disability have reasonable access to opportunities for further training in Victoria. As shown in Figure 6.3, there are similar attainment levels for diploma qualifications among people with and without disability.

Figure 6.3: Higher education completion by disability status (2012)
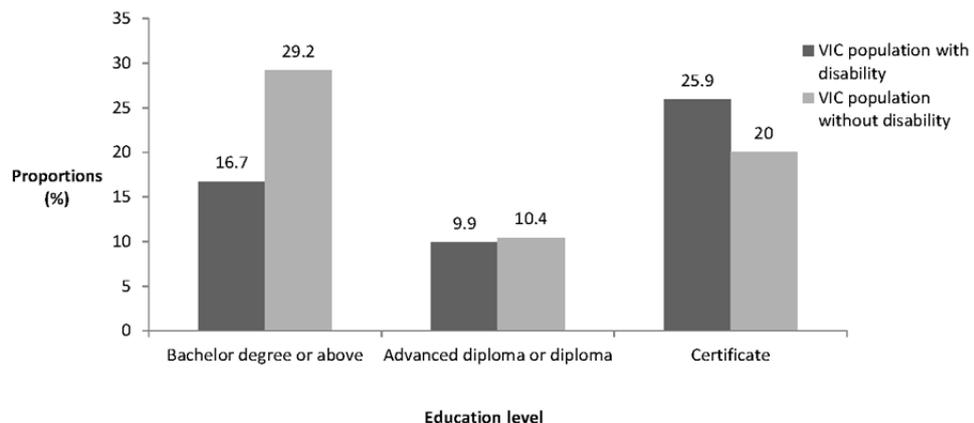
Source: Australian Bureau of Statistics (2014) *Disability, ageing and carers, Australia: Victoria 2012 (Table 7).* From http://www.abs.gov.au.

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41   *Submission S122*, Association for Children with a Disability, p.3.

Experiences of inclusiveness in the Victorian education system

In its submission to the Inquiry, the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) provided a copy of its 2012 report *Held back: The experience of students with disabilities in Victorian schools*. In this report the VEOHRC found that while progress has been achieved in some areas over the past decade, overall discrimination on both individual and systemic levels is still encountered for students with disability. Of the 584 parents of children with disability surveyed for the report, 53 per cent reported that their children were unable to fully participate in education. The VEOHRC observed that 'this is a serious infringement of their human rights, and works against social inclusion.'[42] The *Held back* report investigated the issue of social inclusion of people with disability in schools, finding that despite some successful examples of inclusive school communities, experiences varied between individual schools and teachers.[43]

In 2012 the Department of Education, Employment and Workplace Relations (DEEWR) released a *Report on the review of disability standards for education 2005*. It identified that across Australia there continues to be a lack of awareness and ongoing discrimination against students with disability in mainstream settings. Some of the evidence provided to the DEEWR Review included:

> Every promise of support and modification has yet to be delivered.

> My son was never given the opportunity to reach his full potential.

> My child is clearly not quite as entitled to education as the kid next door.

> Sometimes the hardest thing about disability is expecting support but ending up with yet another time consuming fight.

> I don't have anything good to say about our son's education except it gave the family 'free child care'.[44]

A submission by a disability advocate to the DEEWR Review identified typical messages encountered by families of children with disability who seek to enrol in mainstream schools:

> Many parents are told by staff at mainstream schools that special schools are a better option for their child. For vulnerable parents, this is rejection. The message can be 'we don't want to take your child, but will enrol him if you insist', or 'we can only take him for the number of hours per day for which he is funded' or 'we are not suitable and will not enrol him'. Excuses given for the latter can be 'we are not trained', or 'we can't guarantee your child's safety'. It is a very determined and brave parent who chooses to enrol their child under such circumstances.[45]

Evidence to the Inquiry also indicated that improvements are required to create a more inclusive experience for students with disability. In her evidence, Dr Jessie Mitchell, Manager of Policy and Projects at the Youth Affairs Council of

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[42] *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.7.

[43] Victorian Equal Opportunity and Human Rights Commission (2012) *Held back: The experiences of students with disabilities in Victorian schools*. Carlton, VEOHRC. Referenced in *Submission S021*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, p.9.

[44] Department of Education, Employment and Workplace Relations (2012) *Report on the review of disability standards for education 2005*. Canberra, DEEWR.

[45] Department of Education, Employment and Workplace Relations (2012) *Report on the review of disability standards for education 2005*.

Victoria, highlighted the broad consequences of discrimination in education for young people with disability:

> This leads to a range of poor personal and health outcomes and has serious ramifications for young people's future employment prospects. Here we would also stress the need for all young people to be supported to be able to access sustainable, gainful and meaningful employment.[46]

Participants explained that the education system is not sufficiently responsive to the needs of parents of students with disability. Members of the Whittlesea Disability Network, for example, reported 'not feeling consulted, not being aware of resources which may assist their children with disability and not feeling involved in overall assessment of their child's progress and future planning.'[47]

Inquiry participants suggested that options for inclusion of young people with disability in post-secondary education are limited. The Committee heard that while options for inclusion can be broader in early years, they tend to narrow as children progress through the education system. For example, the Acting CEO of Noah's Ark, Ms Val Johnson, explained that:

> Many children do go to special schools. It appears to me that it is relatively easy in primary school to be included but it becomes extremely difficult in secondary schools. Even for people who are very committed to inclusion it just gets too hard.[48]

Mrs Maureen McLeish, the mother of a daughter with disability, explained how their expectations of social inclusion in post-secondary education were not met when she was offered a place in a specialised program:

> Educational and vocational training is an opportunity for everyone. The TAFE section sold us their version of inclusion yet they segregated our daughter into a disability program that the TAFE called 'inclusion'![49]

Similarly, Wellington (Local Government Area) Community identified that limited lower level (Certificate I, II and III) qualification options present a significant barrier to post-secondary education for students with disability. It explained that these options are important for some people with disability who may be unable to undertake higher level studies due to:

- the level of knowledge required

- demanding timeframes for progressing through a higher level course

- outcomes requirements.[50]

Wellington Community further explained that some people with disability are disadvantaged by the restriction on funding for study at an equivalent level to a course previously completed, as it discourages ongoing study at lower levels, which may be appropriate for some students with disability. An example from its submission is provided in Box 6.3.

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[46] *Transcript of Evidence*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, Melbourne, 20 March 2014, p.2.

[47] *Submission S037*, Whittlesea Disability Network, p.5.

[48] *Transcript of Evidence*, Noah's Ark, Melbourne, 31 March 2014, p.7.

[49] *Submission S006*, Mrs Maureen McLeish, p.1.

[50] *Submission S083*, Wellington (Local Government Area) Community, p.12.

Box 6.3: Post-secondary education example

A student with a neurological condition was interested in coming to TAFE as they had completed his secondary schooling. As a result of their condition and its impact on study a Certificate II level was appropriate, the student had an interest in building and as a result was enrolled in the Building Studies area. The student completed the majority of the course however there were reasonable concerns of their ability to work in the building industry. As the student was interested in gaining employment a discussion was held with the Building studies teacher, the student, a family member and the Disability Liaison Officer of their ability and understanding of what it was like in the Building industry. The student indicated they wished to look at other options and demonstrated an interest in Horticulture. Because the Horticulture certificate was at the same certificate level the student would be required to pay higher fees if he was awarded the Building Studies certificate. The student chose not to complete the building studies course and moved in to Horticulture. They have also secured a traineeship and done very well in this new area of study. However the student has no record of the hard work and dedication they showed completing the majority of the building studies course.

Source: *Submission S083,* Wellington (Local Government Area) Community, Appendix 2, p.13.

Finding 6.2

While there have been efforts to improve the inclusiveness of education in mainstream schools, there remains an inconsistent approach to ensuring accessibility and inclusiveness across all schools in Victoria. Many children with disability continue to experience barriers that result in them having to attend specialist schools.

Education is also discussed in Chapter 4 in the context of establishing social networks and connections.

Victorian Government and inclusive education

The Committee acknowledges the Victorian Government has developed the *State disability plan 2013–16* that incorporates strategies and actions to recognise the Victorian Government can do more to improve access to quality education for children and young people with disability. It contains strategies and actions aimed at improving opportunities in education and early childhood development, including those outlined in Table 6.1.

Table 6.1: *State disability plan 2013–16*—strategies and implementation actions to improve opportunities in education and early childhood development services, 2013–14

Strategies and implementation actions
Strategy: Support educational and early childhood development settings to be more inclusive.
• Strengthen the focus on inclusion in leadership programs provided for professionals in education and early childhood development services.
• Provide information and advice to support disability action planning by education providers so as to improve participation and outcomes.

Strategies and implementation actions
• Increase access of the non-government sector to Department of Education and Early Childhood Development professional learning about building a culture of inclusion.
• Build understanding and competence in implementing evidenced-based inclusive practice in all education and early childhood development services.
• Support early childhood services and schools to provide educational settings that assist children and students with disability to access and meaningfully participate in these environments.
• Support services and early childhood professionals to implement the practice principles in the Victorian Early Years Learning and Development Framework, particularly those regarding principles of equity and diversity, family centred practice, and high expectations for all children.
• Support professional learning of the Disability Standards for Education 2005 for Department of Education and Early Childhood Development staff and leaders to positively influence the culture of inclusion in education and care communities.

Source: Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014.* Melbourne, DHS.

The *State disability plan 2013–16* is supported by a comprehensive *Disability action plan 2013–16* developed by the Department of Education and Early Childhood Development (DEECD). The DEECD Plan outlines goals, strategies and actions to improve educational outcomes and post-school transitions for people with disability. It has a strong focus supporting the education sector to be more inclusive and to better meet the needs of people with disability.

In 2011 the Victorian Government introduced the Abilities Based Learning & Education Support (ABLES) program. According to DEECD's 2011 *ABLES Introductory guide for Victorian Government schools*, ABLES is designed to strengthen Victoria's approach to better meet the educational needs of students with disability. ABLES provides schools with resources to define learning pathways, evidence based strategies and guidance that encourages teachers to support learning progress and online tools and strategies. The program aims to ensure that:

• schools are supported and have the capacity to respond to the individual needs of students with disability and additional learning needs

• students with disability and additional learning needs can access and participate in education on the same basis as their peers

• parents have confidence in a government school system that measures the progress of their child's learning and focuses on their successful completion of schooling whilst making adjustments to facilitate access to, and participation in, appropriate curriculum.

The DEECD *Disability action plan 2013–16* states that one of the actions is to provide the ABLES tool to all government schools in 2013–14 and non-government schools by 2015 to enhance learning accountability.

In 2012 the Victorian Auditor-General released a report into *Programs for students with special learning needs*. It acknowledged that DEECD has policies and guidance to help schools support students with disability and provides funding to support students with disability in education. However, it identified that there is an ongoing need to monitor and oversee educational outcomes of students with special learning needs. It identified that:

> Schools are not implementing DEECD's policies consistently or effectively. As a result, the quality and type of support provided to students with special learning needs is not equitable.[51]

The Committee requested information about the effectiveness of increasing awareness and responses to disability in education, and the effectiveness of professional development in improving interactions with students with disability. DEECD advised that it monitors the uptake of professional learning and capability building initiatives. In addition, it advised that it has evaluations in place that 'indirectly' measure the effectiveness of professional development. DEECD advised that:

- the number of students assessed through ABLES indicates the effectiveness of the resource and the training

- the 'prevalence' rate schools identify through the Nationally Consistent Collection of Data on School Students with Disability (NCCD) indicates the effectiveness of the online course in the *Disability Discrimination Act 1992* (Cth) and national *Disability standards for education 2005*.[52]

The Committee considers that these 'indirect' measures do not appear to contribute to monitoring outcomes relevant to ensuring equitable access to education for people with disability. DEECD also advised that it is working to establish the necessary data sets to enable benchmarking for future evaluative processes such as measuring and benchmarking valid data indicators for access, participation and achievement of people with disability on the same basis as their peers. DEECD did not specify how this data will be collected or used to monitor outcomes to ensure equitable access to education for people with disability.[53]

6.3.3.   Attitudes towards children with disability in education

Negative attitudes towards children and young people with disability in education can hamper their learning and their aspirations for participation. Such attitudes can result in higher levels of segregation in education. Experiences in educational settings can affect children's self-confidence, the bonds and social networks they form, and their opportunities in later life.

The Committee heard that children and young people with disability can often be seen by educators and parents of other children as a burden or inconvenience in mainstream education settings. They often have to overcome a multitude of barriers that negative attitudes create. These include low expectations and higher

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[51]   Victorian Auditor-General (2012) *Programs for students with special learning needs*. Melbourne, VAGO, p.viii.

[52]   *Supplementary evidence*, Response to request for information, Department of Education and Early Childhood Development, 27 June 2014, pp.2–3.

[53]   *Supplementary evidence*, Response to request for information, Department of Education and Early Childhood Development, 27 June 2014, pp.2–3.

risk of exposure to bullying. They also relate to overly protective attitudes and the concerns of teachers and parents about class disruption.[54] The Committee heard that attitudes often lead to an increased likelihood of children with disability being educated in specialist settings. In her submission, the mother of a child with disability, Ms Michele Denham, stated that:

> We have an inherent fear of the unknown. The kinder mums, who shunned my son, were not bad people. They, (like me prior to having my son), have been denied exposure to intellectually disabled individuals. Those with disability were kept segregated and institutionalised when I was growing up. The only thing that has changed is the disabled now live with their families. For the most part, they are sent off to institutions which cater specifically for their special needs during the day. They are segregated from a society which doesn't understand them and who will never learn to understand them or accept them, through lack of exposure.[55]

In its evidence, Noah's Ark provided the Inquiry with its 2012 publication *Participating and belonging: Inclusion in practice.* This resource contains materials for early childhood educators and consultants that assist them to adopt practices that support the inclusion of children with disability. It includes information, research and literature, tips to guide best practice and checklists in three areas of inclusive practice:

- inclusion readiness—emphasises the importance of leadership, quality programs, enrolment, full participation and parent involvement

- resources to support inclusion—articulates the role of families, consultants, training, mentoring and support, funding programs

- program practices to support inclusion—focuses on planning for transitions, individualised programs, physical environment, equipment and toys, children's relationships and inclusive staff teams.[56]

The Principal of the Ballarat Specialist School, Mr Burt, expressed his view to the Inquiry that lack of inclusion of children with disability in mainstream schools often relates to attitudes and fear of challenging behaviours. He also outlined the role of the Ballarat Specialist School in providing information and advice to mainstream schools in the local area:

> **Reverse integration—** *the process whereby people without disability are integrated into activities that previously were limited exclusively to people with disability.*

> Moving on to what we need to do in mainstream schools to accommodate these people, again it is an attitudinal thing. Some people believe it is just too hard, and it is not too hard at all. As a specialist school within our area —and we are more than just a school in Ballarat; we have become a regional resource—we are more than prepared to go out and assist staff from regular schools in dealing with autism, physical disability, muscular dystrophy or whatever it might be.[57]

Mr Burt told the Inquiry about an approach known as 'reverse integration' that the school is involved in with a private, mainstream school in Ballarat. Box 6.4 outlines an approach that the two schools have adopted.

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54   For example see *Submission S102*, Noah's Ark, p.8.
55   *Submission S092*, Ms Michele Denham, pp.2–3.
56   A. Webster & J. Foster (2012) *Participating and belonging: Inclusion in practice* Malvern, ECII.
57   *Transcript of Evidence,* Ballarat Specialist School, p.5.

Box 6.4: Changing attitudes through reverse integration

There is a private school in Ballarat that runs an excellent program … Part of the arrangement we have with that school is we have reverse integration, so the students of prep age within that school come and work with our entry-age kids one afternoon a week, which is Wednesday afternoon. We have Ballarat parents within our community saying, 'our kids will go to this private school providing they get the opportunity to interact with Ballarat Specialist School on Wednesday afternoon'. That comes back to your question of whether over the next decade we are going to be able to change that attitude. Yes, we are, providing we do those sorts of things. Reverse integration is something I am very interested in. The focus does not always necessarily have to be on the disability. It has to be on us—on those who are considered regular or normal, whatever that means, also.

Source: *Transcript of Evidence,* Ballarat Specialist School, Melbourne, 26 May 2014, p.8.

As outlined in Chapter 8, research has shown that targeted and experiential learning can overcome negative attitudes of peers towards children with disability. Attitudes towards people with disability and their treatment by others are discussed in greater detail in Chapter 8.

In the context of changing attitudes in the educational sector, the Committee heard that the Victorian Government is focusing particularly on improving the workforce capacity of educational professionals through multiple methods. Table 6.2 outlines the strategies and implementation action in the *State disability plan 2013–16*. The DEECD disability action plan outlines a range of measures for improving workforce capacity, including online learning, leadership programs, transition planning training, Autism Spectrum Disorder Inclusion Support Program trials and raising awareness of the national *Disability standards for education 2005*.

Table 6.2: *State disability plan 2013–16*—strategies and implementation actions to improve workforce capacity to meet the learning and development needs of children and students with disability, 2013–14

Strategies and implementation actions
Strategy: Improve workforce capacity to meet the learning and development needs of children and students with disability
• Improve early assessment of learning and development and appropriate referral to specialised supports available to children and students.
• Provide early childhood professionals with learning opportunities to assist with the application of the Victorian Early Years Learning and Development Framework and Practice Principles and strengthen assessment, curriculum, reporting and effective teaching and learning approaches.
• Support the development of individual learning plans for students with disability by providing staff in the Department of Education and Early Childhood Development (DEECD) with a comprehensive set of tools through the Abilities-Based Learning and Education Support resource.
• Provide professionals in early childhood education and care settings, primary and secondary schools with learning opportunities that will enable them to better assist transitions and planning for children and students with autism spectrum disorders.

Strategies and implementation actions

- Continue to support the development of a consistent approach to planning of support and service provision in early childhood intervention services that is responsive to individual child and family needs.

- Support professionals to collaborate and share information about children's learning and development to assist with continuity of learning and to support transitions.

Source: Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014*. Melbourne, DHS.

Recommendation 6.3

That the Victorian Government commission a review of reverse integration approaches to assess their value and potential to provide exposure and increased awareness for children of all abilities to the diversity of children with disability.

6.3.4. Quality supports and adjustments for education

In order to achieve their full potential, some children and young people with disability require quality teaching and other supports and adjustments in order to access education. Some may require physical modifications and equipment to enable them to attend classes and complete tasks, others may require the curriculum to be modified and tailored to their abilities, needs and requirements and still others may require aides or personal care supports to realise their full potential.

Teaching and educational supports are provided through the mainstream school and post-secondary education system to assist people with disability. These can include facilitating access, providing learning assistants and learning aids, making reasonable adjustments to curriculum and built infrastructure and providing transport for excursions.

For young children, the early childhood system provides 'inclusion supports' under the Kindergarten Inclusion Support Package (KISP). These supports aim to enable services to meet a child's needs through increased staff to child ratios and to enable staff to attend disability specific training. They also support children with disability by adapting educational programs and making reasonable adjustments to the built environment and providing transport for excursions.

The Productivity Commission is currently undertaking a review of childcare and early childhood learning. In July 2014 it released draft report on this review. The report proposes a block funded *Inclusion support program* for children with additional needs, including children with disability. The Productivity Commission proposed that this program expand the existing inclusion programs to provide once-off grants to early childhood providers to build their capacity to provide services to additional needs children. This could include modifications to facilities and equipment and training for staff to meet the needs of children

with disability and other children with additional needs.[58] The Productivity Commission emphasised that, if adopted, this program would be in addition to supports provided under the National Disability Insurance Scheme (NDIS):

> The extent to which the National Disability Insurance Scheme (NDIS) will meet the needs of children with disability when participating in ECEC is unclear to the Commission at this stage. However, the Commission's proposed ECEC assistance arrangements for children with additional needs is in no way intended to replace whatever support is provided under the NDIS.[59]

Currently, the NDIS is in a trial and co-design phase, and therefore the scope of supports to foster inclusion in education under the NDIS has not been fully developed. However, fact sheets issued by the National Disability Insurance Agency (NDIA) indicate that the NDIS will provide disability specific supports in addition to the state-based supports provided through the based education and early childhood system. For school students, this will include assistance with self-care, specialist transport, mobility and communication aids and specialised or intensive supports to transition between school and to post-school options.[60] In addition, the NDIS will fund early interventions, allied health or other supportive therapies and individualised supports to enable a child to attend an early learning service.[61]

The *State disability plan 2013–16* outlines a range of actions to improve access to aids and equipment generally, which may benefit students with disability to better access education opportunities.

Educational supports that foster inclusion of Victorian students with disability in education are summarised in Table 6.3. The table also makes reference to proposed NDIS supports.

Table 6.3: Supports and adjustments that foster inclusion in education in Victoria

Target of support	Support type
Victorian Government–funded kindergarten	*Kindergarten inclusion support package*—support for children with disability and high support needs in government-funded kindergartens, including modifications, specialist training and consultancy and additional kindergarten staffing. (Victorian Government funding)
Victorian Government schools	*Student resource package*—makes up the school's total budget which schools use to make adjustments for students for personalised learning and support needs. (Victorian Government funding) *Program for students with disabilities*—provides additional funding for children with disability who have moderate to high needs, based on assessment at the commencement of primary school and at the completion of grade 6. (Victorian Government funding)

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[58] Productivity Commission (2014) *Childcare and early childhood learning, Draft report*. Canberra, Commonwealth of Australia, p.23.

[59] Productivity Commission (2014) *Childcare and early childhood learning, Draft report*, p.24.

[60] National Disability Insurance Scheme *Mainstream interface: Higher education and vocational education and training.* NDIS fact sheet, p.1. Accessed on 15 August 2014 from http://www.ndis.gov.au/node/741.

[61] National Disability Insurance Scheme *Mainstream interface: Early childhood.* NDIS fact sheet, p.1. Accessed on 15 August 2014 from http://www.ndis.gov.au/node/739.

Target of support	Support type
Independent schools	*Program for students with disabilities*—contributes to support of teachers, aides, counsellors and resources, physiotherapy or occupational therapy, minor capital works and/or equipment. (Australian Government funding)
	Specialised services—support for specialist services including a visiting teacher service for students with specific physical, sensory or health needs. (Victorian Government funding)
Post-secondary education	*Disability liaison officer*—assists students who may require reasonable adjustments or other support to fully participate in education. (Victorian Government funding)
Individual support needs in early childhood services	*Proposed NDIS supports*— early interventions, allied health or other supportive therapies and individualised supports to enable a child to attend an early learning service. (Australian Government funding)
Individual support needs in school	*Proposed NDIS supports*—assistance with self-care, specialist transport, mobility and communication aids and specialised or intensive supports to transition between school and to post-school options. (Australian Government funding)

Source: Compiled by the Family and Community Development Committee.

The Committee heard that despite the range of supports outlined in Table 6.3, seeking support is not always easy for parents of children with disability. In 2012, Noah's Ark undertook a review of KISP. It identified that the actual process of applying for support has a strong focus on the disability rather than the ability of the children and that this consequently had an impact on the parents' expectations for the education of their children:

> … several parents spoke of their horror at having to have their first conversation with the kindergarten director be about everything that is wrong with their child and everything their child is not able to do, and to be asked to make out the worst possible case in order to obtain funding. They spoke of this often being the first time when the focus was on what was wrong with their child (with their interactions with ECIS and other professionals usually having a strengths focus) and the impact this conversation had on their expectations of the education system (remembering that this is their first ever formal interaction with the education system in relation to their child). Some spoke of feeling devastated by the conversation and then by having to read what the kindergarten director had said about their child in the report (which they are required to sign) in order to justify the KISP funding.[62]

As identified in Section 6.3.1, the Committee considered practical information and coaching for parents navigating the educational support system is needed.

Participants told the Inquiry that care must be taken to ensure that specialist supports for children with disability in mainstream settings do not inadvertently encourage segregation.[63] In its submission, for example, Noah's Ark indicated that:

> … while DEECD's policy clearly states that KISP funded additional assistants should work with all children and therefore increase the capacity for one to one interaction and

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[62] *Submission S102*, Noah's Ark, p.11.
[63] For example, see *Submission S003*, Ms Elisheva Picker, p.1.

> support for all children from the kindergarten teacher, in practice many KISP funded additional assistants operate as 'aides' working directly with the child with disability. Such an approach can be exclusionary as children with disability interact mainly, or wholly, with the additional assistant (who may be the least qualified staff member in the room) and fail to receive the same level of access to the teacher as other children; and fail to have the opportunity to interact with their peers.[64]

For many students with disability, inclusion in education depends on the ability to make necessary adjustments in educational settings. Ms Ariane Garner-Williams, a member of the Steering Committee for the Youth Disability Advisory Service, provided an account of her experience that illustrates the effect of personal care needs on her ability to participate in education and the need for educators to be skilled in making necessary adjustments to ensure people with disability are not excluded. This is outlined in Box 6.5.

Box 6.5: Experience of post-secondary education

Access to TAFE and university and people's basic human rights. I have a personal story that I will share with you now. I was going to RMIT University and I had to travel for 20 minutes to get to and from the bathroom because they were not allowed to help me at the school. This meant that I was missing out on quite a lot of my class time and missing out on the social inclusion with my friends. The organisation that I was going to use the facilities was Travellers Aid. They said, 'we want to put a Travellers Aid in Melbourne Central, which is right near the RMIT campus near Swanston Street', but they said, 'we can't get the funding from government bodies to do it and we don't have enough funding coming in from donations to even start saving towards it or keeping our other commitments going'. It was really sad for me to hear that because I know that not only am I being disadvantaged but a lot of people in that general vicinity, that has quite a few different universities, including Melbourne University, are being disadvantaged in their learning because it takes them so long to do something as basic as using the bathroom.

The one thing I want to point out within TAFE education is that I had a really good time doing my certificate IV in screen and media. They really understood me and were really willing to help me with any sort of devices I needed. I went into the diploma course but I have had to pull out of it now because they were not willing to make the adjustment I needed to be included in the course or they did not understand how to make the adjustment. They did not understand how to say, 'what do you need?' and then make adjustments to the way they operate to make that possible. They were like, 'I'm not sure we will be able to get that'. When I said, 'I haven't been going to classes because I don't have the time to get there on time with carers' or 'I need more rest because I have back problems', they would go, 'oh, that's fine' but they would not say, 'okay, we'll try and figure out how we can fix it'. When I wanted to apply to get recognition of prior learning I was kind of talked down to. They said, 'are you sure you want to do this? Do you understand what you have to have done to be able to do this? ' It is like, 'yes, otherwise I wouldn't be doing it'. I am thinking about how other people must be impacted by being spoken to and treated like this. If it is driving someone like me out of a course who has been a disability advocate since she was 14, then what is it doing to other people who do not know how to advocate for themselves?

Source: *Transcript of Evidence,* Youth Affairs Council of Victoria & Youth Disability Advocacy Service, Melbourne, 20 March, p.4.

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[64]   *Submission S102*, Noah's Ark, p.12.

The Committee also heard that while the *Equal Opportunity Act 2010* (Vic) (EO Act) requires education providers to make reasonable adjustments to accommodate people with disability, there are still attitudinal barriers to overcome. Ms Garner-Williams told the Inquiry about the experience of another young person with disability. This young person went on to attend high school despite being told in a junior grade that he 'was incapable of learning … because he uses a communication device.'[65]

In supplementary evidence to the Inquiry, DEECD advised that its focus is on ensuring professional development of education professionals through *Inclusion online* courses provided since 2012. DEECD advised this focus on professional development reflects evidence that 'the most effective adjustment for students with disability is a teaching workforce that has the knowledge and skills to ensure students are valued, equal participants and achievers in the learning and social life of their school.'[66]

6.3.5. Transitioning to employment

The Committee heard that moving from education to employment is a key transition point for people with disability. The Inquiry heard that many people with disability do not achieve their employment objectives upon completing their studies. Chapter 3 highlighted that for many people with disability this is a key transition in their lives and, like most people in the country, they have ambitions to pursue a career or work participation of their choosing. As SkillsPlus and BRACE told the Inquiry:

> While a great deal of work has been done to raise the aspirations of young people with disability and their families in areas such as inclusive careers planning, parent workshops and disability awareness training the concern is that a large number of students are not achieving their employment goals once they transition from programs aimed at preparation for employment. Students are often continuing to seek educational programs where available to remain engaged as they have no work opportunities.[67]

The *State disability plan 2013–16* outlines a number of actions to improve transition from school to post-school education, employment and training, which are outlined in Table 6.4.

Table 6.4: *State disability plan 2013–16*—implementation actions to improve transition from school to post-school further education, employment and training, 2013–14

Implementation actions
• Roll out a coordinated communication strategy to better inform young people with disability, their parents and teachers about further education, training and employment options.
• Develop and implement an assessment and planning framework to better match post-school supports to a young person's needs.

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[65] *Transcript of Evidence,* Youth Affairs Council of Victoria & Youth Disability Advocacy Service, p.7.
[66] *Supplementary evidence*, Response to request for information, Department of Education and Early Childhood Development, 27 June 2014, p.2.
[67] *Submission S042*, SkillsPlus and BRACE, p.5.

Implementation actions

- Develop and implement approaches that strengthen the pathway to employment for young people with disability with particular emphasis on improving information provision, planning, and support coordination.

Source: Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014.* Melbourne, DHS.

In this context, the current DEECD *Disability action plan 2013–16* also includes a strategy to 'build skills and work readiness'. It has made a commitment to:

> Develop and implement approaches to build work awareness and work readiness of young people with disability both in school and post-school, with particular emphasis on opportunities to gain work experience in open employment.[68]

As part of this strategy, DEECD has identified a need to 'support specialist schools to develop applications for funding to access new vocational training facilities through the Trade Training Centres in Schools Program.'[69] In addition, the Department of Human Services (DHS) has focused on transitions to employment through two programs—*Futures for young adults* and *Transition to employment*.

The DEECD *Disability action plan 2013–16* identifies a range of government tools and measures for improving transition of people with disability from school to post-school education and employment. In relation to students with disability, the Plan articulates a commitment to building capacity of schools to implement the Victorian Government's careers resources, with a focus on managing individual pathways and planning. It states that DEECD will develop and distribute a customised version of the Engaging Parents in Career Conversations (EPICC) Framework for career practitioners to engage parents of children with disability in their children's career development journey and transition.[70]

SkillsPlus and BRACE identified that discussing 'career' options for young people with disability requires a 'fundamental shift of perception'.[71] It commended to the Inquiry the DEECD's Victorian Careers Curriculum Framework. This Framework and associated practical career planning tools are designed to help school careers staff, professionals and families to support and raise the aspirations of young people with disability. This approach helps to:

- highlight an individual's potential

- value the individual's choices on how they decide to engage on their own terms in what they perceive is meaningful and challenging.

The Framework is underpinned by principles based on the High-Five Principles of Career Development as identified by Canadian researchers Dave Redekopp,

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[68] Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014.* Melbourne, DHS, p.18.

[69] Department of Education and Early Childhood Development (2013) *Disability action plan 2013–2016.* Melbourne, DEECD, p.14.

[70] Department of Education and Early Childhood Development (2013) *Disability action plan 2013–2016.*

[71] *Submission S042*, SkillsPlus and BRACE, p.5.

Barrie Day and Marnie Robb in 1995.[72] The High-Five Principles of Career Development are outlined in Box 6.6.

Box 6.6: High five principles of career development

The High-Five Principles of Career Development are:

- Change is constant—in an environment characterised by change, people need to recognise and value their own fluidity and develop resilience in the face of constant change.

- Know yourself, believe in yourself and follow your heart—people need to be empowered and confident to proactively design and manage their preferred futures.

- Focus on the journey—the development of career competence is a lifelong journey shaped by a wide array of personal, family, social and environmental factors.

- Learning is ongoing—people need to actively engage in learning throughout their lives.

- Access your allies—people will enrich their careers by seeking the support of others and by providing support to others.

Source: *Submission S042,* SkillsPlus and BRACE, p.5.

Despite these types of programs, some participants suggested that young people with disability still do not find it easy to achieve their goals and aspirations when they leave school. For example, Aspect Victoria expressed its view that during 'the life area of transition from secondary school... [m]any teenagers with ASD [autism spectrum disorder] who are nearing leaving school age feel there aren't the pathways out there to keep them included within society and their local communities.'[73]

In its submission, Warrnambool City Council indicated there can be difficulties accessing government programs and suggested that there is a need for:

> A stronger and more supportive range of services in the community increases capacity to respond to the 'bottleneck effect' of programs like Futures for Young Adults by providing opportunities for young people with disability to have more choice of postschool options that includes mainstream community services and activities.[74]

The Committee heard that greater opportunities for early intervention and transition to open employment are important. The Able Movement provided the Inquiry with information about a strategy adopted in South Australia based on a partnership approach that is having positive results. It incorporates the theme raised by SkillsPlus and BRACE in regard to planning. It also uses a coaching and mentoring approach for students who might be at risk of leaving school early. Box 6.7 outlines this approach.

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[72] D. Redekopp, B. Day, & M. Robb (1995) *The "high five" of career development.* United States, Eric Digest. Referred to in *Submission S042*, SkillsPlus and BRACE, p.5.

[73] *Submission S029*, Aspect Victoria (Autism Spectrum Australia), p.1.

[74] *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.8.

Box 6.7: South Australia—State Transition Program & Open Employment

Over 85 per cent of school students with identified disability across Australia are defined as having developmental disability. Traditional approaches which channel these individuals to congregate care or supported employment (e.g. Australian Disability Enterprises) do not support economic inclusion. Open Employment offers a successful alternative. By earning wages and enjoying conditions of employment the same as their co-workers without disability, many workers with disability have proven their value as productive and loyal employees over many years.

The State Transition Program is a partnership between the school and VET [Vocational Education and Training] sectors and the South Australian and federal governments to promote Open Employment within school communities. The aim of this early intervention approach is to support a smooth transition from school to real work for students with disability by:

- Mentoring students with disability who are at risk of early disengagement from learning. Commencing in year 9 of secondary school, mentors work with students, families, schools and other relevant services to support goal planning and decision making for the student. A 'vision' of employment and further learning is encouraged and supported among all stakeholders.

- Establishing a clear plan for the transition year. This also assists students who struggle with change due to their disability to prepare for this significant step in life. It also ensures resources from the student's own networks, school based resources and those of the specialist disability employment system are collectively focussed upon this learning pathway to employment and active participation.

- Facilitating/brokering accredited training and workplace experience (via Structured Workplace Place Learning) that assist students in the job market. Labour market competitiveness is improved by enabling students with disability to achieve vocational qualifications as part of their secondary schooling. Practical experiences in real work settings further support the student to make choices about career directions.

- Establishing ongoing relationships between the student, their parents/carers, teachers and post school services early in the transition year. A key element is involving a Specialist Disability Employment Support Worker. Planning is driven by student aspiration, not service/program design. Investments are made into interventions that support personal leadership skills and life goal setting.

- Providing on-going employment support from the service post-school. Long term partnerships with the disability employment support staff ensure that the young person has support with career advancement.

To date, the experience of the State Transition Program has been that as more students, teachers and parents see the pathways taken individuals with disability, aspirations rise about what is both possible and desirable which leads to substantial improvements in economic inclusion and participation.

Source: *Submission S089*, The Able Movement, pp.13–14.

> **Recommendation 6.4**
>
> That the Victorian Government consider the feasibility of introducing a partnership program between the school and Vocational Education and Training sectors and the Victorian and Australian governments to promote open employment within school communities with the intention of supporting a smooth transition from school to real work for students with disability.

6.4.   Engaging in meaningful employment

Inquiry participants emphasised that most people with disability want to work, and that integration in the workforce is a key component of being integrated into the broader community. Chapter 3 explored in greater detail the aspirations of people with disability, including employment. Many participants highlighted the role of employment in people with disability feeling valued and recognised as equal and contributing members of society.

The Centre for Developmental Disability Health Victoria (CDDHV) explained that:

> Work is crucial for many aspects of social and emotional health including feelings of empowerment, social inclusiveness and belonging and a sense of accomplishment.[75]

Paid employment also allows people with disability to support themselves and provides the means to participate in other social and cultural spheres of society. As SkillsPlus and BRACE highlighted:

> The flow on effects of increased employment for people with disability include reduction in poverty, choice as consumers, opportunities for relationship building and identity as valued members of the community.[76]

For many people, their job is integral to their identity and who they are. Kirrily, an Ambassador with the Summer Foundation, expressed her experience of empowerment gained through work and the freedom to be financially independent. She is quoted as stating that:

> I think work in any form all comes back to the empowerment, self-esteem and well being. The increased sense of positive well being, and I suppose that moral highlight of wow, I'm contributing to my community, to my future, I'm contributing. The fact that one is contributing has so many positive aspects.[77]

Anj, also an Ambassador at the Summer Foundation, expressed that having a job is 'absolutely brilliant. 15! (out of 10) Really good, its more of a normal thing to be able to talk about your job because, I mean everyone has a job.'[78] Another Ambassador, Vicki, stated:

> Yay! To be able to be self-employed and work from home and speak with clients and be able to be like normal people and to travel that would be a really great reward.[79]

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[75]   *Submission S108*, Centre for Developmental Disability Health Victoria, p.5.
[76]   *Submission S042*, SkillsPlus and BRACE, p.6.
[77]   *Submission S121*, Summer Foundation Ltd, pp.10–11.
[78]   *Submission S121*, Summer Foundation Ltd, p.11.
[79]   *Submission S121*, Summer Foundation Ltd, p.11.

6.4.1.   Progress on inclusion in employment

It is well established that the employment of people with disability in Australia is substantially lower than the employment of others in the community, and that Australia compares poorly with other countries in the Organisation for Economic Co-operation and Development (OECD).[80]

ABS figures shown in Figure 6.4 indicate that the labour force participation rate for Victorians with disability is significantly less than the rate for Victorians without disability (54 per cent compared to 82 per cent, respectively), reflecting a national trend.[81] In her evidence to the Inquiry, the Victorian Regional Director at the ABS, Ms Judy Henson, advised that there have not been any significant changes in these rates over time, stating that 55 per cent of Australians with disability participated in the labour force in 1993.

Figure 6.4: Victorian labour force participation by disability status (2012)
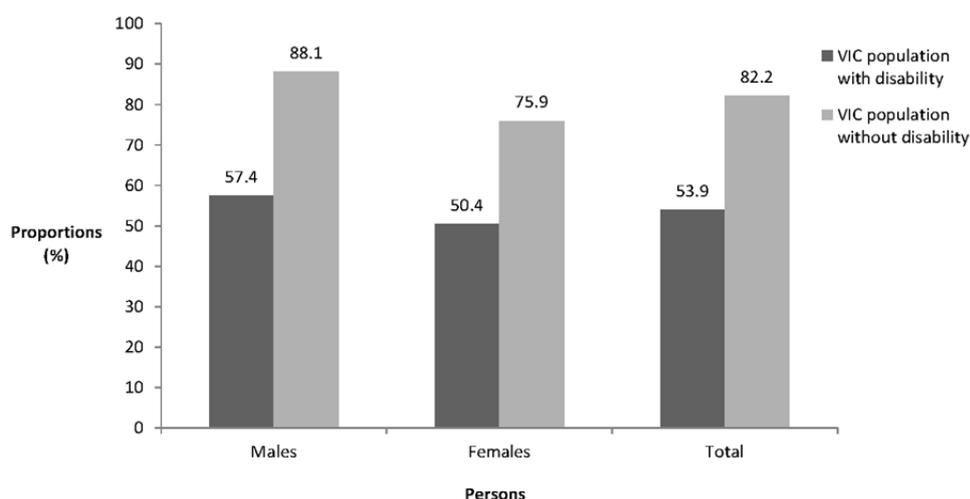
Source: Australian Bureau of Statistics (2014) *Disability, ageing and carers, Australia: Victoria 2012 (Table 9).* From http://www.abs.gov.au.

Belonging Matters explained to the Inquiry that people with disability experience particularly high rates of unemployment. The organisation indicated only 4 people (5 per cent) of all people assisted through their program were working, while 29 people said they wanted to find work.[82]

Research conducted by Vision Australia in 2012 highlights that the rate of unemployment among people who are blind or vision impaired is high. The

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[80]   Deloitte Access Economics (2011) *The economic benefits of increasing employment for people with disability.* Sydney, Access Economics Pty Ltd, p.ii; *Submission S052,* Moonee Valley City Council, p.2.

[81]   Australian Bureau of Statistics (2013) *Disability, ageing and carers, Australia 2012.* cat. no. 4430.0, Canberra, ABS. Accessed on 14 August 2014 from http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0. These figures are affected to a small degree by variation between people with varying levels of core activity limitation. For example, the employment rate for people with a profound or severe core activity limitation in 2012 was 29 per cent compared with 47.6 per cent for people with specific limitations or restrictions. According to evidence to the Inquiry provided by Ms Judy Henson of the ABS, 53 per cent of Australians with disability participate in the labour force, compared to 83 per cent of Australians in the broader population. *Transcript of Evidence,* Australian Bureau of Statistics, p.3.

[82]   *Submission S030,* Belonging Matters, p.3.

research found that 58 per cent of people who are blind or vision impaired of workforce age are unemployed compared with 14 per cent of the wider population.[83]

As highlighted in section 6.3.2, people with disability are less likely to complete school and this also limits their employment options.

Despite the establishment of Disability Employment Services (DES) by the Australian Government, the Committee heard that employment opportunities through DES may not be fulfilling in nature, nor suited to the individual skills, interests or aspirations of people with disability. For example, Belonging Matters told the Inquiry that DES often fail to provide pathways into permanent employment that is meaningful for people with disability:

> Disability Employment Services, for example, often fail to get people with significant disabilities work that is not in a sheltered arrangement. Or the only type of 'work' offered to people with disability is in welfare types of environments e.g. people with disability volunteering in opportunity shops, soup kitchens, nursing homes etc. What is often offered are pre-employment programs/training, with no real assistance to find and secure work. The disability services then become an end in and of themselves, rather than being a means to living a more fulfilling life based in the community.[84]

DES specialise in either open employment services or supported employment services. Annual DES reviews undertaken by the Australian Department of Human Services have shown a gradual increase in the proportion of service users who use open employment services. As illustrated in Figure 6.5, the percentage of service users who use open employment services has increased from approximately 68 per cent in 2004 (67.8 per cent of male and 69 per cent of female service users) to approximately 84 per cent in 2010 (83 per cent of male and 86.4 per cent of female service users).

Open employment services—*services providing employment assistance to people with disability in obtaining and/or retaining paid employment in the open labour market.*

Supported employment services—*services providing ongoing on-the-job employment support within a commercial enterprise.[85]*

However, employment outcomes[86] for Victorians who use supported employment services are significantly higher than for those who use open employment services. For example, between 2004 and 2010 the employment rate for open employment service users was between around 36 per cent and 47.2 per cent. The employment outcomes for supported employment service users in the same years was much higher (ranging from around 84 per cent to apparently full employment in 2010).[87]

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[83]   *Submission S112*, Vision Australia, p.5; *Submission S082*, Blind Citizens Australia, p.3.

[84]   *Submission S030*, Belonging Matters, p.3.

[85]   Department of Families, Housing, Community Services and Indigenous Affairs (2010) *Australian Government disability services census 2008*. Canberra, FaHCSIA.

[86]   'Employment outcomes' refers to those consumers in disability employment services who were employed for some or all of the time during the year. Department of Families, Housing, Community Services and Indigenous Affairs (2010) *Australian Government disability services census 2008*.

[87]   Department of Families, Housing, Community Services and Indigenous Affairs (2010) *Australian Government disability services census 2008*.

Figure 6.5: Service users who use disability employment services, by employment type.
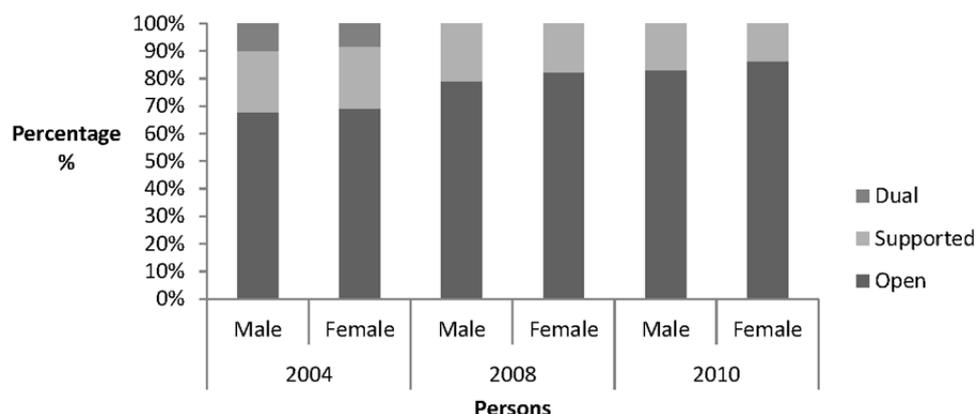
Source: Compiled from the Australia Government Disability Services Reports and data tables of 2004, 2008, 2010.

WISE Employment provided advice to the Inquiry about its strategy of using social enterprises to engage people with disability in the workforce. WISE Employment operates five social enterprises which employ people in labour, cleaning, maintenance and electrical services. It explained to the Inquiry:

> Our social enterprises replicate the conditions of the mainstream workforce but in a supported environment. Support is tailored to meet the needs of the individual and address their barriers towards transition to mainstream employment, which is optional and individuals may choose not to transition to mainstream employment.[88]

WISE Employment identified the key characteristics of successful social enterprises as being:

- a blended workforce of disadvantaged, disability and non-disadvantaged people

- award wage employment

- in-work support

- majority of revenue from commercial sales.[89]

Marriott Support Services explained to the Inquiry that innovative approaches can be successful in employing individuals with disability in open employment. It identified that one such strategy is known as 'job carving'. This approach can provide new employment opportunities by 'creating, modifying or customising job roles, breaking down tasks into individual steps and then rearranging and combining suitable elements into different jobs often requiring varying skill sets or levels.'[90] For example, Marriott Support Services informed the Inquiry that it is currently working with Crown Entertainment in Melbourne to apply this

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[88]   *Submission S044*, WISE Employment, p.5.
[89]   *Submission S044*, WISE Employment, p.5.
[90]   *Submission S020*, Marriott Support Services, p.5.

strategy as part of Crown's commitment to increase employment of people with disability.[91]

Melba Support Services provided an example of how an innovative approach to work can benefit both the person with disability and the wider community, as outlined in Box 6.8.

Box 6.8: Contributions and society's missed opportunity

The Glad Man Delivery Service is the inspiration of Matthew Gladman. Matt, together with his key worker at Melba, Anita, manages a delivery service between the two campuses of St Francis Xavier College, in Berwick and Beaconsfield. Every Wednesday Matt and Anita visit each campus and act as courier between the two sites—but Matt's valued role extends far beyond the delivery of mail.

The Principal of St Francis Xavier College, Paul, is very proud to be a part of Matt Gladman's delivery service. He says, 'for our young people to be seeing Matt … doing the document transport between the two campuses … is great learning for our young people'.

Leah, in the office at Beaconsfield Campus, reflects on the school's fortune in having someone as reliable as Matt as their courier. A lot of staff and teachers have come to know Matt and really enjoy seeing him each Wednesday. Despite whatever sort of day they might be having, staff will stop and have a chat with Matt and smile when he leads them on a walk through the corridors. Matt's work as a courier is undoubtedly increasing his social inclusion.

Source: *Submission S080,* Melba Support Servcies, Inc, p.4.

The Committee identified that innovative employment approaches that identify and support people's individual strengths are not as widespread as they need to be. Positive mainstream employment outcomes often appear to be the result of ad-hoc opportunities frequently driven by families of people with disability. In the context of people with intellectual disability, for example, Belonging Matters expressed its view that 'customised employment initiatives which identify people's strengths, interests and abilities and work over a period of time to secure and support open employment for people with intellectual disability are rare in Victoria.'[92] It acknowledged the role of families in securing employment in mainstream settings for their children:

> We have found that it is usually families who have recognised the multiple benefits of open employment and persist of their own accord and push the boundaries to secure paid employment for their son/daughter.[93]

6.4.2. Role of government in employing people with disability

Inquiry participants called on the Victorian and Australian Governments to do more to employ people with disability, and this is also recognised in the Victorian *State disability plan 2013–16* as identified in Table 6.5. The *State of the service report 2012–13* identified that employment of people with disability

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91   *Submission S020*, Marriott Support Services, p.5.
92   *Submission S030*, Belonging Matters, p.3.
93   *Submission S030*, Belonging Matters, p.3.

in the Australian Public Service declined from 5 per cent in 1999 to 2.9 per cent in 2012.[94]

Melba Supported Services expressed its view that governments can play an important role in employing people with disability in the public service.[95] It suggested the establishment of employment targets by the Victorian Government:

> … government can model the behaviour it seeks to encourage in the private and not-for-profit sectors by employing more people with disability in the public service. Establishing employment targets and benchmarking performance in this area are other strategies worthy of adoption.[96]

WISE Employment emphasised a potential role for the Victorian Government in supporting social enterprises:

> The Victorian government can play a crucial role in supporting the rise of social enterprises as an intermediate labour market. Assisting this employment pathway model will assist the social inclusion aspirations of many people with disability.[97]

In its submission the VEOHRC also referred to the low rates of employment for people with disability in the Victorian public sector, and advocated that this be an area where the Victorian Government could show greater leadership.[98]

Marriot Support Services pointed out that quota systems for employment of people with disability exist in overseas jurisdictions. While acknowledging that such systems may fall short of developing sustainable employment opportunities, they do at least 'force the issue and strongly encourage inclusive practices to be developed in a relatively short time frame.'[99]

The Australian Government has projected that its implementation of the NDIS will increase employment opportunities for people with disability. This is anticipated to be through the direct interventions of the NDIS (in school to work transition programs, supported employment and community engagement) or through changes in broader employment supports (for example, disability employment services, which lie outside the NDIS).[100] In its report recommending the introduction of the NDIS—*Disability care and support*—the Productivity Commission projected that the NDIS would result in an additional 320 000 people with disability being employed by 2050.[101]

In its report, the Productivity Commission proposed a range of initiatives to engage the community and business to improve employment outcomes including referrals and linkages to care and support options outside the NDIS as part of its Tier 2 functions. Tier 2 could include linkages and referrals to mainstream services, community support groups and services, not-for-profit organisations,

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[94]   Australian Public Service Commission (2013) *State of the service report. State of the service series 2012–13*. Canberra, Commonwealth of Australia, p.104.

[95]   *Submission S080*, Melba Support Services Inc, p.6.

[96]   *Submission S080*, Melba Support Services Inc, p.6.

[97]   *Submission S044*, WISE Employment, p.6.

[98]   *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.10.

[99]   Marriot Support Services highlighted that the majority of European countries have some form of a disability employment quota scheme in both the public and private sector. Australian Government (December 2012) *Improving the employment participation of people with disability in Australia. Discussion paper*. Canberra, Commonwealth of Australia. Referred to in *Submission S020*, Marriott Support Services, p.5.

[100] Productivity Commission (2011) *Disability care and support. Volume 2, report no. 54*. Canberra, Commonwealth of Australia, p.958.

[101] Productivity Commission (2011) *Disability care and support. Volume 2, report no. 54*, p.963.

Job Services Australia or mental health services.[102] In its 2014 *Interim report* on the NDIS, KPMG described Tier 2 of the NDIS as the 'gateway to effective diversion from specialist supports'.[103] The Tier 2 function of the NDIS is outlined in more detail in Chapter 2.

The Productivity Commission report also recommended complementary reforms of the Disability Support Pension, additional provision of employment services and appropriate training.[104] The Commission considered that these reforms would provide greater incentives for employment, provide better support for people in jobs, and improve job matching.

The Victorian Government approach to improving pathways to employment is outlined in the *State disability plan 2013–16.* The strategies and implementation actions set out in Table 6.5 indicate an emphasis on providing opportunities for professional development and work readiness and on increasing the role of the Victorian government in creating pathways to employment. The Plan identifies a role for the Victorian Government in employing, retaining and offering professional development to people with disability. As discussed earlier in this section, such a role was supported in evidence to the Inquiry.

DHS advised the Inquiry that the State Services Authority (SSA) released a guide in March 2014 *Recruiting people with disability—getting recruitment right*. The guide was developed in collaboration with DHS and includes practical guidance to deliver a best practice recruitment and selection process.[105]

Table 6.5: *State disability plan 2013–16*—**strategies and implementation actions to build better pathways to employment, 2013–14**

Strategies and implementation actions
Strategy: Build skills and work readiness
• Develop and implement approaches to build work awareness and work readiness of young people with disability both in school and post-school, with particular emphasis on opportunities to gain work experience in open employment.
• Increase professional development opportunities for artists with disability.
• Provide the training market with information that will support them to improve outcomes for learners with disability.
Strategy: Lead the way in the employment of people with disability
• Promote the employment of people with disability through information on the Business Victoria website.
• Explore opportunities to strengthen pathways to employment for people with disability, including people using disability day services.

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[102] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*. Canberra, Commonwealth of Australia, p.18.

[103] KPMG (2014) *Interim report: Review of the optimal approach to transition to the full NDIS*. KPMG, p.8.

[104] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, pp.284, 89.

[105] *Supplementary evidence*, Response to Questions on Notice, Department of Human Services, 24 March 2014. DHS advised that the guide can be accessed at State Services Authority (2013) *Recruiting people with disability: Getting recruitment right*. Melbourne, SSA. Accessed on 1 September 2014 from http://www.ssa.vic.gov.au/products/a-z/view-products/recruiting-people-with-disabilities.html.

Strategies and implementation actions
• Improve the capacity of the Victorian public sector to employ, retain and offer professional development to people with disability.

Source: Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014*. Melbourne, DHS.

6.4.3. Changing attitudes towards people with disability in employment

Many attitudinal barriers prevent people with disability from accessing employment opportunities, including employer attitudes, low expectations of social and economic participation, community and business receptiveness, misunderstanding the cost of and unwillingness to make workplace adjustments and inaccessible application processes.[106] Attitudes towards and treatment of people with disability more generally is discussed in Chapter 8.

The VEOHRC advised the Inquiry that in 2012–13 it received a total of 344 complaints regarding discrimination in employment, based on the attribute of disability. This figure represented the highest percentage of employment-related complaints it received in that period.[107]

There are multiple attitudes that lead to reluctance on the part of employers to engage people with disability. The Committee heard that many have concerns about productivity and the ability of people with disability. Blind Citizens Australia also pointed out that 'there are also often concerns that a person's disability will compromise occupational health and safety policy, making them a liability to employ.'[108]

The Committee also heard that many employers consider they are not equipped to include people with disability in their workplaces or may not be prepared to make sufficient adjustments in order to accommodate them. Cardinia Shire Council, for example, told the Inquiry that 'employers feel ill-prepared to employ people with disability, especially those with a mental illness, although they are more ready to support current employees who acquire a disability.'[109] Belonging Matters observed that employers may have insufficient training hours available for people who take longer to learn a job.[110]

Table 6.6 outlines a range of attitudes highlighted by the National Collaborative on Workforce and Disability for Youth. This is a United States government funded organisation that offers a range of services to integrate youth with disability into the workforce. Its website has identified a range of attitudinal barriers to work. In contrast to the workplace attitudes outlined in the Table 6.6, the reality of people with disability in the workplace is quite different. Many people with disability have skills that make their impairment irrelevant in the workplace.

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[106] Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.115; *Submission S052*, Moonee Valley City Council, p.2.

[107] *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.9.

[108] *Submission S082*, Blind Citizens Australia, p.4.

[109] *Submission S085*, Cardinia Shire Council, p.2.

[110] *Submission S030*, Belonging Matters, p.3.

Table 6.6: Attitudinal barriers to inclusion in the workforce

Attitude	Description
Inferiority	Because a person may be impaired in one of life's major functions, some people believe the individual is a 'second-class citizen.'
Pity	People feel sorry for the person with disability, which tends to lead to patronizing attitudes.
Hero worship	People consider someone with disability who lives independently or pursues a profession to be brave or 'special' for overcoming disability.
Ignorance	People with disability are often dismissed as incapable of accomplishing a task without the opportunity to display their skills.
The spread effect	People assume that an individual's disability negatively affects other senses, abilities or personality traits, or that the total person is impaired. For example, many people shout at people who are blind or don't expect people using wheelchairs to have the intelligence to speak for themselves.
Stereotypes	The other side of the spread effect is the positive and negative generalisations people form about disabilities. For example, many believe that all people who are blind are great musicians or have a keener sense of smell and hearing, that all people who use wheelchairs are docile or compete in paralympics, that all people with developmental disability are innocent and sweet-natured, that all people with disability are sad and bitter.
Backlash	Many people believe individuals with disability are given unfair advantages, such as easier work requirements.
Denial	Many disabilities are 'hidden', such as learning disabilities, psychiatric disabilities, epilepsy, cancer, arthritis and heart conditions. People tend to believe these are not bona fide disabilities needing accommodation.
Fear	Many people are afraid that they will 'do or say the wrong thing' around someone with disability. They therefore avert their own discomfort by avoiding the individual with disability.

Source: National Collaborative on Workforce and Disability for Youth, *Attitudinal barriers for people with disabilities.* Accessed on 4 July 2014 from http://www.ncwd-youth.info.

Like others in the community, people with disability have skills, experience and knowledge to contribute to the workforce, and like others want an equal opportunity to work in environments where they can add value and be respected for their contribution. Research conducted in 2002 by Graffam and colleagues from Deakin University demonstrated that employer attitudes are often unfounded. The research showed that it does not cost employers more to hire a person with disability, as government covers the costs of workplace adjustment, and productivity of workers with disability was equal or greater than other workers in the vast majority of cases. The research also found that most people

with disability had better attendance and lower occupational health and safety incidents than other workers.[111]

The Committee identified that people with disability expect to be held to the same standards as all employees. They expect genuine rewards for making a valued contribution, rather than special treatment for performing day-to-day tasks. However, this can only be achieved by allowing the means of accomplishing the task to be adjusted to account for the diversity of employees. As pointed out by the National Collaborative on Workforce and Disability for Youth, discrimination legislation 'does not require special privileges for people with disability, just equal opportunities.'[112]

Focusing on a person's ability rather than disability can counter prejudicial attitudes and ignorance about what a person with disability is capable of.

Finding 6.3

People with disability have skills, knowledge and experience to contribute to the workforce, and like others want equal opportunity to work in environments where they can add value and be respected for their contribution. In order to allow equal opportunities for people to contribute to the workforce, adjustments need to be made to account for diversity of all employees, including those with disability.

6.4.4.   Supporting pathways into employment

The Committee heard that pathways into employment often do not align with the skills and aspirations of people with disability. Blind Citizens Australia stated, for example:

> In order to increase workforce participation, people need to be provided with the opportunity to seek, work towards and gain meaningful employment that aligns with their individual skills and aspirations.[113]

The Committee heard that there are barriers at all stages of the pathway into employment. Melbourne City Mission told the Inquiry that 'the causes of, and solutions to, these issues are complex and interrelated.' In addition to employer and community attitudes discussed in Section 6.4.3, Inquiry participants identified the following barriers to employment:

- lack of access to pre-vocational and pre-employment training

- lack of appropriate job pathways, e.g. out of supported employment services into competitive employment, or between different career stages

- an inflexible welfare system

- inflexible and inadequate supports for daily living, e.g. transport, assistive technology and attendant care

- short-term approaches to resourcing.[114]

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[111] J. Graffam, K. Smith, A. Shinkfield et al. (2002) 'Employer benefits and costs of employing a person with a disability'. *Journal of Vocational Rehabilitation*, Vol. 17, No. 4 (251–63), p.254.

[112] National Collaborative on Workforce and Disability for Youth *Attitudinal barriers for people with disabilities.* Accessed on 4 July 2014 from http://www.ncwd-youth.info/attitudinal-barriers-for-people-with-disabilities.

[113] *Submission S082*, Blind Citizens Australia, p.3.

The Australian Government provides a range of supports for employment of people with disability. Table 6.7 outlines these services, including the proposed supports to be implemented as part of the NDIS

Table 6.7: Supports and adjustments that foster inclusion in employment in Victoria

Target of support	Support type
Person with disability who is able to work	*Disability Employment Services* (DES), including the following service types: • *Disability Management Service*—temporary assistance for people with disability, illness, or injury who do not expect to need long-term support in the workplace. • *Employment Support Service*—regular and ongoing support in the workplace for people with permanent disability. Services include: • help to prepare for work, including training in specific job skills • job-search support, such as résumé development, training in interview skills, and help in looking for suitable jobs • support when initially placed into a job, including on-the-job training and co-worker and employer support • ongoing support in a job if required • access to vocational training and other employment-related assistance • access to workplace modifications, support services and Auslan interpreting in the workplace.
Person with disability able to work at least 8 hours per week but who cannot benefit from DES	*Australian Disability Enterprises*—supported employment for people with disability, illness or injury who are unable to work in the open labour market. *Proposed NDIS supports*—supported employment, such as services offered by Australian Disability Enterprises.
Employers	*Disability Employment Services*—assists employers with: • recruitment and job matching services • job design for employees with disability • on-the-job or off-site support, including ongoing support if required • disability employment information and awareness training • access to financial support and incentives to fund workplace modifications, assistive technology, mental health first aid training, Auslan interpreting. *Wage Connect Subsidy and Wage Subsidy Scheme*—wage subsidies for employers who employ people with disability.

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[114]   *Submission S111*, Melbourne City Mission, p.36.

Target of support	Support type
People who are not receiving DES and are at risk of losing their job because of illness, injury or disability.	*Job in Jeopardy Assistance*—service to assist people affected by illness, injury or disability to maintain employment.
Awareness	*JobAccess*—information and advice service about the employment of people with disability.
People with disability seeking employment where supports are beyond the requirements of employment services and employers	*Proposed NDIS supports:* • assisting participants who are not eligible for Disability Employment Services (DES) or Job Services Australia (JSA) to build their skills and capacity to participate in employment, as well as assistance to find and maintain employment • personal care or assistance with transport where the participant requires these supports regardless of the activity they are undertaking • assistive technology devices such as wheelchairs, personal communication devices or a hearing aid.

Source: Compiled by the Family and Community Development Committee, based on information from the Australian Government Department of Human Services, accessed on 11 August 2014 from http://www.humanservices.gov.au; and National Disability Insurance Scheme *Mainstream interface: Employment*. NDIS factsheet, accessed on 3 September 2014 from http://www.ndis.gov.au.

The Committee identified that people with disability who have completed training or education can experience difficulties in the pathway to employment. This is acknowledged in the *State disability plan 2013–16* which identified that 54 per cent of people with disability who complete training attain employment compared with 80 per cent of people in the broader population.[115] The Victorian Council of Social Service (VCOSS) expressed concern in its submission that 'people with disability are forced to churn through training programs without them leading to jobs.'[116]

Difficulty with practical aspects also poses a significant impediment to employment. Dr George Taleporos, Manager of the Youth Disability Advocacy Service, has highlighted that workforce inequalities are partly influenced 'if people with disability have sufficient personal assistance and equipment, they are more likely to succeed in the labour market.'[117] Getting to and from work safely was identified as a significant barrier to employment for people with disability. As noted by Mrs Brenda Rawlins:

> Much fanfare is made of the progress made thus far in terms of job creation, training facilities, workplace modification, employer 'education' et cetera. All very worthy, but the

115   Department of Human Services (2012) *Victorian state disability plan 2013–2016. Companion document*, p.17.
116   *Submission S126*, Victorian Council of Social Service (VCOSS), p.17.
117   G. Taleporos (13 January 2014) *Employment and disability: A complex problem with no simple solution*. Ramp Up—Disability, Discussion, Debate. ABC. Accessed on 13 March 2014 from http://www.abc.net.au/rampup/articles/2014/01/13/3922428.htm. Referenced in *Submission S021*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, p.15.

most significant factor and the biggest barrier to the employment of physically or mentally challenged persons is NOT society's view of us or potential employers being big, bad and nasty. It is a factor which I venture to say successive governments have overlooked in their haste to appear to be 'getting us into the workforce.' It is the thing a disabled potential employee needs most and it is known as SAFE AND AFFORDABLE TRANSPORT TO AND FROM WORK.[118]

The National People with Disabilities and Carer Council explained that DES is underutilised by employers. It stated in its *Vision for employment of people with disability* that only 3 per cent of employers use DES when recruiting. It also highlighted that there is currently a 30 per cent success rate of job retention at 26 weeks, indicating that other approaches are required.[119]

The CEO of Disability Employment Australia, Mr Craig Harrison, stated that employment pathways need to focus on 'valued roles and having that sense of aspiration for young people and their families' in order to achieve 'a truly socially inclusive society for people with disability.'[120]

As identified earlier, a number of reforms to improve employment pathways were proposed by the Productivity Commission in its 2011 report on the introduction of the NDIS. Of particular relevance are the Tier 2 NDIS functions that include initiatives to engage the community and business to improve employment outcomes. The NDIS is discussed in more detail in Chapter 2.

The Committee considered that job shadowing initiatives have considerable potential to improve pathways into employment for people with disability. One such initiative is the Disability Mentoring Day (DMD) run by the American Association of People with Disabilities nationally in the United States. DMD promotes career development through hands-on career exploration, job shadowing, and mentoring that often leads to internships and employment. The DMD Program is outlined in more detail in Box 6.9.

> **Job shadowing**—*is an unpaid opportunity to spend part of a day or more observing and interacting with employers in a workplace.*

Job Shadow Day is a similar program that has been successfully implemented in Ireland and will be introduced in parts of Europe in 2015. Job Shadow Day is discussed in Section 6.6.2.

Job shadowing is an unpaid opportunity to spend part of a day or more observing and interacting with employers in an actual workplace. This can provide people with disability an opportunity to explore careers outside of the hiring context and meet employers that are committed to hiring diverse employees. It is an opportunity to strengthen the transition between school and work, evaluate personal goals, explore possible career paths, and develop lasting mentoring relationships.[121]

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[118] *Submission S001*, Mrs Brenda Rawlins, p.3.
[119] National People with Disabilities and Carer Council (July 2013) *Vision for employment of people with disability.* Disability and Carers, Australian Government, Department of Social Services p.2. Accessed on 15 August 2014 from http://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/consultation-and-advocacy/vision-for-employment-of-people-with-disability.
[120] *Transcript of Evidence*, Disability Employment Australia, Melbourne, 20 March 2014, p.3.
[121] NCWD/Youth - The National Collaborative on Workforce and Disability for Youth (4 October 2011) *Disability mentoring day connects job seekers with disabilities to employers nationwide.* Accessed on 1 September 2014 from http://www.ncwd-youth.info/blog/?p=280.

Similarly, job shadowing can positively influence attitudes of employers as it can provide employers with an opportunity to experience the 'talent, enthusiasm, creativity, and work ethic that workers with disability bring to the workplace.'[122]

Box 6.9: United States—Disability Mentoring Day

DMD began in 1999 with 11 students with disability who job shadowed in the White House during the Clinton Administration. The program now connects approximately 20,000 students and job seekers with disability to thousands of employers each year across 300 locations in every US state and territory.

Some of the activities of the DMD include:

- Career Day—local employers and professionals share information about their career areas with students and job seekers with disability at schools, universities, or local Centers for Independent Living.

- Field Trip—visits to local employers' job sites where DMD participants tour businesses, learn about workplaces, and connect with workplace employees.

- On-Site Job Shadowing—students and job seekers with disability are matched to those professionals serving in careers that interest them.

- DMD Passport to Employment Career Fair—students and job seekers explore career opportunities during a coordinated Job Fair. Using the 'DMD Passport', job seekers are encouraged to visit employer booths organised by key career clusters. Using their Passports, DMD participants can stay connected with employers they meet for ongoing mentoring relationships.

The Association of People with Disabilities coordinates DMD nationally through a network of over 350 volunteer DMD Coordinators. Coordinators are responsible for local DMD programs, and they share tips and information about their particular programs online.

Through DMD, participants gain insights into different careers that can help them make informed decisions about their future. The DMD Program can open a gateway of mutual experiences and opportunities for both employers and participants. By getting to know people with disability, employers open their minds to the real talent, enthusiasm, creativity, and work ethic that workers with disability bring to the workplace. Simultaneously, youth and jobseekers with disability are given the opportunity to explore their potential in diverse areas of employment, discover their preferences and talents, and change directions if they wish.

In many cases, DMD is now just one prong of longer-term employment and career exploration programs designed to connect academic learning to employment. Each year students with disability planning for life after high school take advantage of this event as a unique career-building opportunity.

Source: NCWD/Youth—The National Collaborative on Workforce and Disability for Youth (4 October 2011) *Disability mentoring day connects job seekers with disabilities to employers nationwide*. Accessed on 1 September 2014 from http://www.ncwd-youth.info/blog/?p=280.

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[122] NCWD/Youth - The National Collaborative on Workforce and Disability for Youth (4 October 2011) *Disability mentoring day connects job seekers with disabilities to employers nationwide.* From http://www.ncwd-youth.info.

> **Finding 6.4**
>
> People with disability continue to participate at low levels in the workforce due to negative attitudes and barriers that prevent them from fully contributing to the best of their potential.

> **Recommendation 6.5**
>
> That the Victorian Government develop a job shadowing program to assist young people with disability to gain experience in the workplace and to provide employers with exposure to the contributions that people with disability can provide.

6.5.   Sport, recreation and the arts

Participation in sports, recreation and cultural pursuits are part of the everyday lives of Victorians. People with disability are no different in their desire to participate in these activities. There is a range of ways in which people with disability in Victoria can engage in sport, recreation and the arts. The Chief Executive of Disability Sport and Recreation, Mr Rob Anderson, told the Inquiry 'sport and recreation is saturated with opportunities for people to connect, to participate, to be accepted and included, both within peer groups and in the broader community.'[123] As discussed in Chapter 4, participation in sport, recreational and other activities can be very effective in creating opportunities for social interaction and increasing social connectedness.

However, people with disability do not always have the same access to sport, recreation and the arts as the general population. For example, in their submission to the Inquiry, the Youth Affairs Council of Victoria and Youth Disability Advocacy Service identified that young people with disability experience barriers to basic activities that most people take for granted:

> Most young people take for granted that they can access music, entertainment and spaces to be with their friends, but young people with disability face continued barriers of inaccessible premises and lack of reliable information or understanding at venues and events.[124]

The Committee identified that there is a need for opportunities that cater for the diversity of people with disability, their interests and their aspirations. Deaf Victoria, for example, illustrated that access may not necessarily result in inclusion with the following examples:

> … cinema experience: Currently the only way to access captions in a cinema is to use a device called Captiview that allows you to participate in the cinema experience, however does not suit all Deaf or hard of hearing people, particularly tall people, elderly people, people with eye problems and children. An open captioned approach (English captions on screen) will be more socially inclusive, allowing the Deaf and hard or hearing person to be able to feel socially included in the experience.
>
> … sport participation: Technically, Deaf and hard of hearing people are able to participate in their local sporting club, but without being able to take part in the social interaction, and without the communication and understanding needed by the sporting club, the participant will not feel socially included unless communication is made easier and more natural.[125]

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[123]   *Transcript of Evidence*, Disability Sport & Recreation, Melbourne, 20 March 2014, p.4.
[124]   *Submission S021*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, p.21.
[125]   *Submission S007*, Deaf Victoria Inc, pp.3–4.

6.5.1.   Sport and physical recreation

As for all people, sport and physical recreation provides opportunities for people with disability to participate as players, spectators, volunteers, administrators and coaches. Sport and recreation provide an avenue for social connectedness (as discussed in Chapter 4) and provide important health benefits, as emphasised by Mr Anderson in his evidence to the Inquiry:

> … sport and recreation is just seen as a fun thing or a time filler in many respects when we can demonstrate that it is critical to health. It is important for us to educate the disability world on the importance of sport and recreation, purely from the health point of view, so the notion of measuring the physical health outcome, the mental health outcomes. Some of the stats as you guys know are pretty scary when it comes to the mental health issues associated with disability.[126]

In its 2008 report *Harnessing the power of sport for development and peace: Recommendations to governments*, the Sport for Development and Peace International Working Group (SDP IWG) explained that sport changes community perceptions for people with disability by 'focusing attention on their abilities and moving their disability into the background.'[127] The Report goes on explain:

> Through sport, persons without disability encounter persons with disability in a positive context (sometimes for the first time) and see them accomplish things they had previously thought impossible. Their assumptions about what persons with disability can and cannot do are profoundly challenged and reshaped by this experience. As well, the tendency to see the disability instead of the person is greatly reduced, in part because of the common experience of sport that they now share.[128]

Box 6.10 outlines an example of how shared interest areas such as sport can reduce isolation and improve social inclusion.

Box 6.10: Importance of sport—Jeffrey's experience

Jeffrey has an intellectual disability. Before coming to Marriott he was isolated as his family were afraid to encourage him to access the community independently. The risk, they told us, was too great and they felt very protective towards their son. He was isolated within his family home.

Slowly, over three years, staff worked with family and Jeffrey to move him towards travelling on public transport. As confidence built, Jeffrey started to think about what he was interested in. Football was his passion.

Collingwood Football team is his passion so watching them practice at their home ground was incentive enough for him to hone those public transport skills and make the trip every Friday to the training ground.

He found that others shared his passion so friendships were formed and plans made for further social activities within his community.

Source: *Submission S020*, Marriott Support Services, p.1.

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[126] *Transcript of Evidence,* Disability Sport & Recreation, p.5. See also *Submission S095*, Netball Victoria; *Submission S055*, Disability Sport & Recreation; *Submission S024*, Regional Sport Victoria; *Submission S066*, Riding for Disabled Association of Victoria Inc (RDAV); *Submission S099*, South Coast Primary Care Partnership.

[127] Sport for Development & Peace International Working Group (2008) 'Chapter 5. Sport and persons with disabilities: Fostering inclusion and well-being'. *Harnessing the power of sport for development and peace: Recommendations to governments.* Toronto, Right to Play International, p.171.

[128] Sport for Development & Peace International Working Group (2008) *Chapter 5. Sport and persons with disabilities: Fostering inclusion and well-being*, p.171.

The ABS provided the Inquiry with the rates of participation in sport and physical activity, shown in Figure 6.8. According to 2009 ABS data, 24 per cent of Australians with disability participate in sport or physical recreation compared with 65 per cent of Australians overall.[129] The rate of inclusion in sport by people with disability has remained constant over time and does not appear to be increasing.[130]

Figure 6.8: Victorian sporting and physical activity (2012)
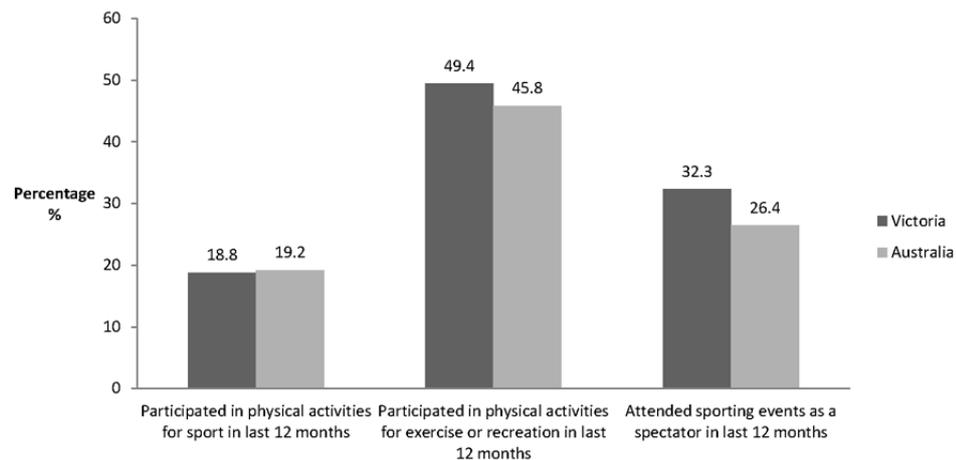
Source: Adapted from *Supplementary evidence*, Hearing presentation, Australian Bureau of Statistics, 17 March 2014.

Many Inquiry participants spoke highly of the Victorian Government's Access for All Abilities (AAA) Program, which has operated in Victoria for over a decade. The program funds organisations to work at a community level to develop inclusive sport and recreation opportunities for people of all abilities. These organisations promote and encourage a range of sport and recreation opportunities across the state, including basketball, cricket, Aussie Rules, soccer, sailing, and lawn bowls. For example, Regional Sport Victoria explained that the AAA Program plays an important role in regional and rural Victoria where it noted that people with disability have 'significantly lower physical activity rates than their metropolitan counterparts':

> Outcomes are achieved under a community development model and based on the utilisation of community sport as environments that are best places to provide inclusive sporting opportunities. With support through the Access for All Abilities Program, community clubs do have the capacity to provide genuine inclusive opportunities of choice.[131]

In 2013 the focus of the AAA Program shifted from funding local councils to funding State Sports Associations (SSAs), Regional Sports Assemblies (RSAs) and disability sports and community based organisations. This change was intended to better build ongoing capacity in local sporting clubs and provide

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[129] Australian Bureau of Statistics (2012) *Sports and physical recreation: A statistical overview, Australia 2012.* cat. no. 4156.0, Canberra, ABS. Accessed on 15 August 2014 from http://www.abs.gov.au/ausstats/abs@.nsf/mf/4156.0.

[130] *Submission S055*, Disability Sport & Recreation, p.4; Australian Bureau of Statistics (2012) *Sports and physical recreation: A statistical overview, Australia 2012.* From http://www.abs.gov.au.

[131] *Submission S024*, Regional Sport Victoria, p.5.

better sport and recreation outcomes for people with disability.[132] However there was some concern expressed by Inquiry participants about whether the recent re-structure of the AAA Program provides the community reach needed to engage people with disability in sport. REAL (Rights, Employment, Accommodation, Leisure) Incorporated explained:

> … one of the best programs for promoting inclusion has recently lost significant levels of funding. The Eastern Recreation & Leisure Service ERLS through the AAA Program worked with local recreation agencies to assist them to develop inclusive policies and practices. This is a great loss to our area. The funding … is no longer benefiting individuals wanting to be included in small, local recreation services.[133]

Although increasing overall participation in sport is important for people with disability as for all Victorians, the Committee considered that there is a need to improve the integration of sporting opportunities for people with disability within mainstream sport. For example, in evidence provided to the Inquiry, Mr Peter Ryan, President and Mr Logan Whitaker, Administration Manager of the Football Integration Development Association (FIDA) spoke about the organisation's strategy of integrating teams that include players with intellectual disability with local football clubs. Mr Ryan and Mr Whitaker highlighted the benefits of integration for people with disability:

> … once they are appreciated for their abilities, they can fill in and play reserves footy or fill in when the club is in need of a player. They can run water, they can help out at the club and they bring more people into the club as far as supporting their own team. I suppose the last 10 years have pushed that link to local footy clubs.
>
> … That integration, which is part of our name, is so important. Yes, they are playing football, and they are a member of the club, but they are socialising. You should see their faces light up when the senior footballers come down and help out with training. They will be the most loyal volunteers you will ever have. If you want them there at 9 o'clock on a Saturday morning, every Saturday morning, to do the scoreboard, they will not miss; they will be there every time.[134]

In its submission to the Inquiry, Disability Sport and Recreation also supported integration. It provided the example of a football development program run by the Northcote City Football Club:

> The 7-a-side football development program, run by Northcote City FC (NCFC) in partnership with Disability Sport & Recreation is a good example of advancing social inclusion and participation through sport and recreation. 7-a-side football is a modified version of soccer, designed for participants with cerebral palsy, acquired brain injury or those who have experienced stroke. NCFC is the only football club in Victoria offering 7-a-side football. Although a specialist disability program, it is fully integrated into the club's structure, providing people with disability access to regular games, specialised coaching, club uniforms, invitations to club social events, including the end of year NCFC presentation night. The entire NCFC community supports the program, organising fundraisers and exhibition games for participants. The 7-a-side football development program at NCFC demonstrates the impact that a positive attitude by coaches and administrators can have. The coaches are respectful to each individual's level of ability, working one on one with players, assisting with their skill development. They demonstrate high levels of patience and understanding of coaching people with disability, creating an inclusive environment. Family members and friends of participants are encouraged to attend the program, forming a support network. Each season, coaches organise a game

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[132] Department of Transport, Planning and Local Infrastructure, *Access for all abilities.* Accessed on 15 August 2014 from http://www.dpcd.vic.gov.au/sport/inclusive-sport/Access-For-All-Abilities.

[133] *Submission S065*, REAL Inc (Rights, Employment, Accommodation, Leisure), p.3.

[134] *Transcript of Evidence*, Football Integration Development Association (FIDA), Melbourne, 26 May 2014, p.4.

between participants and their families and friends. The program could be used as a model for social inclusion in all sporting codes.[135]

In its Submission to the Inquiry, Riding for Disabled Association of Victoria Inc (RDAV) also highlighted its focus on achieving inclusion and participation of people with disability in mainstream organisations. It explained that there continue to be attitudinal barriers including 'fear of the consequences and risk based on lack of knowledge about various disabilities and lack of skills around using adaptive equipment and coaching techniques to accommodate the functional limitations of the disability. Sometimes this fear of the consequences is manifest by excessive demands and restrictions placed on the rider.'[136] RDAV highlighted a number of examples that illustrate underlying attitudes towards disability that still need to be addressed:

> After an open competition, where a young RDA registered rider won, a parent was heard complaining 'how come that nuffy beat my daughter'.[137]

RDAV identified several mainstream equestrian clubs that provide 'best practice' in inclusion, noting that these clubs are characterised by:

- a values set that acknowledges diversity, respect

- relationships of trust with the riders, their families and key individuals who have championed the inclusion of individuals with disability

- preparedness to seek information and utilise the expertise available in relation to adaptive equipment, rule variations to take account of the impact of the disability and coaching.[138]

The *State disability plan 2013–16* acknowledges the importance of inclusion of people with disability in sport and physical recreation, and makes an undertaking to 'build the capacity of the sport and recreation sector to develop pathways for people with disability to participate in sporting and physical activities.'[139]

The Committee considers that increasing partnerships between mainstream and disability specific sporting and recreational organisations is an important part of increasing participation of people with disability in sport and recreation.

Finding 6.5

People with disability participate in a variety of sports, yet in substantially lower rates than other people in the community despite the valuable health benefits.

6.5.2. Arts, culture and creativity

Participation in and access to the arts creates opportunities for all people to enjoy cultural activities in the community as audience members and as participants. It can help people to develop skills and explore their creativity as well as to develop relationships with people who share their interests. Arts and culture can

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[135] *Submission S055*, Disability Sport & Recreation, pp.6–7.
[136] *Submission S066*, Riding for Disabled Association of Victoria Inc (RDAV), p.2.
[137] *Submission S066*, Riding for Disabled Association of Victoria Inc (RDAV), p.2.
[138] *Submission S066*, Riding for Disabled Association of Victoria Inc (RDAV), p.2.
[139] Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014*, p.20.

also play a significant role in raising awareness and challenging stereotypes about people with disability through communication of the lived experience of disability (discussed further in Chapter 8). Disability Media Australia produces television content with and about people with disability. It told the Inquiry that:

> We know that having people with disability on television every week, showing them and sharing their intelligence and their stories makes a significant contribution to breaking down ignorance around disability and fostering social inclusion. It is one of the most efficient ways to create wholesale change in social attitudes, and it is an opportunity that has not been maximised.[140]

In 2008, the Office for Disability in partnership with Arts Victoria and Disability Services Division undertook the 'Picture This' research project to examine ways to increase the participation of people with disability in the arts as artists and as audience members. A literature review conducted in 2008 as part of the project identified a number of barriers to attendance at arts events and arts venues by people with disability. Table 6.8 outlines these barriers.

Table 6.8: Supports and adjustments that foster inclusion in the arts in Victoria

Barrier	Description
Financial	• cost of admission and capacity to pay
Physical	• transport and parking difficulties
	• lack of disabled access features in arts venues, both physical (for example wheelchair access, hearing loop technology)
	• interpretive (for example subtitles and Auslan interpreters for the Deaf and hearing impaired)
Low levels of arts awareness	• lack of information about accessible arts venues and accessible activities in arts marketing materials
Inadequate training of arts personnel	• low levels of disability awareness and training among staff at arts venues
Attitudinal	• negative views held by arts personnel and society in general about people with disability

Source: Office for Disability, Department of Planning and Community Development (2010) *Picture this: Literature review and analysis, September 2008. Increasing the cultural participation of people with a disability in Victoria.* Melbourne, DPCD, p.3.

The review identified that these barriers can be disincentives for arts practitioners with disability seeking to pursue a career in the arts.[141] The 2009 *Picture this community consultation report* identified a need for change in four key areas.

• Community awareness and attitudinal change—audience development strategies to break down 'patronising attitudes about the quality of art created

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140 *Transcript of Evidence*, Disability Media Australia, Melbourne, 24 March 2014, p.4.
141 Office for Disability, Department of Planning and Community Development (2010) *Picture this: Literature review and analysis, September 2008. Increasing the cultural participation of people with a disability in Victoria.* Melbourne, DPCD, p.2.

       by people with disability', disability awareness training for arts organisations.

- Policy, legislation and compliance—requirements to improve physical access.

- Employment and education—professional and leadership development of artists with disability and improving employment prospects.

- Capacity building and sustainability—strengthening community building through local government, changing the role of arts and disability peak bodies to focus on capacity building, professional development strategies and advocacy, data collection, financial support and reliable and accessible space and time for art making, presentation and performance.[142]

The *State disability plan 2013–16* acknowledges the importance of inclusion of people with disability in arts and culture, and makes an undertaking to 'provide tailored industry resources and training to build the capacity of the arts and cultural sector to be more inclusive of people with disability.'[143]

Nationally, in 2009 the Cultural Ministers Council developed the *National arts and disability strategy 2010–2020*. The Council was a forum of Commonwealth, state and territory ministers responsible for the arts and culture in Australia which operated up until 30 June 2011. The Strategy set out a vision for improving access and participation in artistic and cultural activities for people with disability across Australia. It provided a framework for planning and action in the areas of access and participation, arts and cultural practice, audience development and strategic development. An Implementation Report released in 2011 identified that a range of initiatives had been undertaken in Victoria.[144]

Evidence to the Inquiry reflected that the acceptance of disability media, art and culture in mainstream media is limited.[145] Disability Media Australia explained that the mainstream media is gradually starting to take an interest in disability. However, it noted that:

> … the national conversation about disability is still too often about the tragic victims and inspirational heroes and not often enough about ordinary, everyday experiences of living life with disability.[146]

The Committee heard about the ADAPT Program, a recent collaboration between Arts Victoria, Arts Access Victoria and the Department of Human Services (DHS) to deliver training and resources to mainstream organisations to build their capacity for development of inclusive arts practice.[147]

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142   Office for Disability, Department of Planning and Community Development (2010) *Picture this: Community consultation report and analysis, September 2008. Increasing the cultural participation of people with a disability in Victoria*. Melbourne, DPCD, pp.3–5.

143   Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014*, p.20.

144   The National Arts and Disability Strategy Working Group *The national arts and disability strategy jurisdiction implementation report*. Meeting of Cultural Ministers, p.21. Accessed on 26 May 2014 from http://mcm.arts.gov.au/working-groups/nads.

145   *Submission S111*, Melbourne City Mission, p.29.

146   *Transcript of Evidence,* Disability Media Australia, p.4.

147   Arts Victoria *ADAPT - The Arts Disability Action Plan Training Project*. Arts Victoria. Accessed on 27 May 2014 from

The Committee considers that there is scope through this program and other initiatives to increase the participation of people with disability in mainstream arts avenues.

Finding 6.6
People with disability participate in arts and cultural activities, but experience barriers that prevent their full participation due to physical inaccessibility, negative attitudes and lack of information about accessibility.

6.6. Civic participation and leadership roles

Civic participation is an important right for all Victorians. The United Nations (UN) Convention on the Rights of Persons with Disabilities (UN Convention) acknowledges the right of people with disability to participate in political and public life on an equal basis with others.[148] The importance of civic participation was emphasised by Carers Victoria in its submission to the Inquiry:

> Citizenship involves participation in civil society and often involves interaction with institutions. Examples include voting, legal access, upholding of rights. Citizenship requires empowerment and a 'voice'. Again, citizenship relies upon material needs being met (social inclusion), but social inclusion (narrowly interpreted) may not be sufficient to ensure citizenship.[149]

In Victoria, there has been an increasing emphasis on involving people with disability in developing policy, services and opportunities for participation. This includes leadership opportunities for people with disability through avenues such as disability advisory committees, self-advocacy organisations and peer support groups. For example, as outlined in Chapter 2, the Victorian Disability Advisory Council (VDAC) was established under the *Disability Act 2006* (Vic) (Disability Act) to provide advice to the Victorian Government on polices and strategies to increase the participation of people with disability in the Victorian community. The majority of the 14 three-year membership positions on VDAC are held by people with disability. Such avenues for leadership are discussed in the context of awareness raising initiatives in Chapter 8.

The Committee identified a continuing need for people with disability to have their voice heard and taken into account in political decisions. For example, the Darebin Disability Advisory Committee told the Inquiry that many people with disability are not aware of their rights or do not understand them. It considered that self-advocacy was a crucial avenue to empowering people with disability 'to be more active participants in their own life and more active citizens in their community.'[150]

The *State disability plan 2013–16* contains a range of strategies and actions to enable better representation of people with disability in human rights and civic issues that affect them. These are outlined in Table 6.9.

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http://www.arts.vic.gov.au/Research_and_Resources/Resources/ADAPT_-_The_Arts_Disability_Action_Plan_Training_Project.

[148] United Nations enable *Article 29 – Participation in political and public life.* Accessed on 15 August 2014 from http://www.un.org/disabilities/default.asp?id=289.

[149] *Submission S087*, Carers Victoria, p.4.

[150] *Submission S041*, Darebin Disability Advisory Committee, pp.10–11.

Table 6.9: *State disability plan 2013–16*—**strategies and implementation actions to enable better protection for human rights and greater participation in the community, 2013–14**

Strategies and implementation actions
Strategy: Better enable people with disability, families and carers to exercise their rights
• Collaborate with the Victorian Electoral Commission and relevant agencies to develop an approach that will increase access to voting centres in priority electorates.
Strategy: Increase the voice and representation of people with disability
• Encourage the representation of people with disability on boards and committees.
• Enable the views of people with disability, families and carers to be considered by the Victorian Government through the advice given by the Victorian Disability Advisory Council.

Source: Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014.* Melbourne, DHS.

6.6.1. Self-advocacy groups

The Committee heard about the important role of self-advocacy groups in empowering people with disability to stand up for their rights, influence decisions that affect them, and educate people, organisations and government about their place in the community. In its submission, the VEOHRC explained that:

> Social inclusion and consumer control by people with disability relies on active and engaged advocacy and self-advocacy bodies.[151]

Inquiry participants identified the importance of self-advocacy groups which are 'led by and for people with disability, recognising them as the experts on their own lives and promoting inclusion and justice.'[152]

The Committee considered that diversity amongst self-advocacy groups was important as different issues arise for different population groups. For example, young people with disability and disability groups can benefit from advocacy about their different and specific issues. For example, the Youth Affairs Council of Victoria and Youth Disability Advocacy Service outlined some of the specific issues for young people with disability:

> Some of the most significant transitions in relation to learning, working, engaging and having a voice occur during a person's adolescent and young adult years. These include finishing school, moving into higher forms of education, entering the workforce, becoming involved in sexual relationships, taking part in new cultural and recreational activities, and becoming eligible to vote. Secondly, young people are disproportionately vulnerable to certain problems, such as low income, difficulty in entering the housing market, poor mental health and struggles for independence and identity.[153]

The Victorian Advocacy League for Individuals with Disability (VALID) strongly recommended the value of self-advocacy for people with intellectual

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[151] *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.16.
[152] *Submission S021*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, p.6.
[153] *Submission S021*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, p.4.

disability, stating that there is a role for peer groups and self-advocacy groups that can:

> … act as 'resource bases' from which people with disability can gain confidence and build the skills necessary to influence decisions, stand up for their rights and interact positively with others in the community. They also act as 'launching pads' from which people with disability can collectively influence community attitudes, break down barriers and 'launch' themselves with confidence into community activities and relationships.[154]

As discussed in Chapter 2, while recognising the importance of advocacy by non-government organisations (including community groups that facilitate self-advocacy of people with disability), in its 2011 report on disability care and support, the Productivity Commission identified that support for this role should be provided by the state and territory governments.[155] Accordingly, there is a continuing significant role for the Victorian Government in supporting advocacy efforts and ensuring a strong voice of people with disability.

6.6.2.   Broader representation

As with other forms of participation, the Committee identified that opportunities for civic participation and leadership for people with disability is often through specialised rather than mainstream roles. Vision Australia identified that people with blindness or low vision are able to vote through accessible means, such as telephone and electronic voting systems. It also stated that people with vision impairment have run for political office in federal and state government.[156]

However, it must be recognised that, apart from disability-specific organisations and roles, there appears to be a lack of proportionate representation of people with disability in mainstream committees of management, boards and elected office. For example, Deaf Victoria explained to the Inquiry that:

> In civil areas, a number of Deaf and hard of hearing people are involved in disability politics from a grassroots level, however not in mainstream politics due to lack of accessibility. Given access, there is likely to be an increase in participation. An increase of participation of Deaf, hard of hearing, and other people with disability in politics is essential to achieving social inclusion, as to lead the way to demonstrate inclusiveness.[157]

Whitehorse City Council expressed a similar view about the low levels of civil participation by people with disability in society:

> Civic participation has morphed into community participation failing to acknowledge people with disability as voters, members of boards and committees, active participants in a host of local activities and events.[158]

Deaf Victoria, for example, explained some of the physical barriers for people with disability wishing to undertake community leadership roles:

> In areas of social community and civic activities, there is very rarely any forethought into planning for access needs. For example, if a Deaf person wants to sit on a board of directors for a community organisation or sporting organisations, it is very unlikely the organisation will pay for access requirements, such as an interpreter or notetaker, to aid their participation.[159]

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[154]   *Submission S059*, VALID (Victorian Advocacy League for Individuals with Disability Inc), p.10.
[155]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.525.
[156]   *Submission S112*, Vision Australia, p.7.
[157]   *Submission S007*, Deaf Victoria Inc, p.2.
[158]   *Submission S097*, Whitehorse City Council, p.6.
[159]   *Submission S007*, Deaf Victoria Inc, p.2.

While not an Australian example, Deaf Victoria provided the Inquiry with an overview of the barriers experienced by a Deaf female member of parliament (MP) in New Zealand:

> One example internationally is the case of the Deaf member of parliament in New Zealand: MP Mojo Mather's had to fight New Zealand parliament to pay for the interpreting costs for her participation in order for her to do her job. She eventually won, but the fact that she had to fight for it does not demonstrate a very socially inclusive environment. This may go some way to explaining why there is rarely a person with disability participating in state or federal politics.[160]

However, attitudinal barriers arguably play an even greater role. In her evidence to the Inquiry, Professor Christine Bigby, the Research Program Leader and Deputy Chair of the Academic Board at La Trobe University, identified that research undertaken by a PhD student about participation on advisory groups and boards found that 'the most important thing is the attitude of other members of the board rather than individual support.'[161]

The Committee acknowledges that some people do not wish to disclose or draw attention to their disability, particularly in mainstream leadership roles. This is particularly the case for people with mental illness.

The Committee determined that greater attention is needed to raise the profile of people with disability and their capability to undertake leadership positions across all areas of society. A positive example is a UK Government initiative undertaken in 2011 to provide extra support to help people with disability to stand as members of parliament, councillors or other elected officials. Following a community consultation, the UK government announced its commitment to a number of steps, including funding for training and development and establishing an 'access to elected office' fund to support disability-related costs.[162] This initiative is outlined in Box 6.11. The Committee considers that this initiative could provide a model for the Victorian Government in promoting the representation of people in elected office.

Box 6.11: UK Government—access to elected office for disabled people strategy

The UK Government conducted consultations in 2011 and worked closely with community organisations and other stakeholders to determine what extra support is needed to help people with disability to stand as members of parliament, councillors or other elected officials. This resulted in the *Access to elected office for disabled people strategy:*

- provided training and mentoring through the Local Government Association's *Be a councillor* campaign[163]

- provided paid internships through a Parliamentary placement scheme[164]

- provided online guidance for political parties on their legal obligations towards disabled members and candidates[165]

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[160]   *Submission S007*, Deaf Victoria Inc, p.2.

[161]   *Transcript of Evidence*, Professor Christine Bigby, La Trobe University, Melbourne, 20 March 2014, p.6.

[162]   Local Government Association (UK) *Being a councillor and disability.* Accessed on 15 August 2014 from http://www.beacouncillor.org.uk/couldibe/disability.htm.

[163]   Local Government Association (UK) *Being a councillor and disability.* From http://www.beacouncillor.org.uk.

[164]   Department for Culture, Media & Sport, Government Equalities Office (UK) (4 September 2013) *Internships making politics more accessible for disabled people.* GOV.UK. Accessed on 15 August 2014 from https://www.gov.uk/government/news/internships-making-politics-more-accessible-for-disabled-people.

Box 6.11: UK Government—access to elected office for disabled people strategy

- published online booklet promoting the experiences of disabled people in political life[166]

- changed the law so that personal costs can be exempted from candidates' expenses limits at English and Welsh local elections, meaning that disability related costs are no longer counted towards candidates' spending limits at those elections.

- established the Access to Elected Office for Disabled People Fund to help candidates with disability related costs of standing for election. The aim of the fund is tackle barriers including; transport, paying for sign language interpreters and paying for extra travel and accommodation for support workers.[167]

Disability Employment Australia suggested that the Victorian Government could consider introducing a job shadowing program as has been implemented in Ireland.[168] The initiative is called the Job Shadow Day, and involves people with disability spending a day with a member of the Irish Parliament or another high-profile person.[169] Disability Employment Australia identified that shadowing a member of parliament or another high-profile person can provide a person with disability with an opportunity to:

- gain insight and knowledge about how systems work, how democracies work and how major organisations work

- build a sense of self-value through associating with people of significance and real social value and role in society.

Following the success of the Job Shadow Day in Ireland, the initiative will be introduced in other parts of Europe in 2015.

Finding 6.7

While people with disability are increasingly participating in advocacy and leadership roles within the disability community, there remain very few people with disability in political, elected and other civic roles in the broader community, such as committees of management and board positions.

Recommendation 6.6

That the Victorian Government develop a strategy on access to elected office for people with disability.

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[165] Government Equalities Office (UK) (2012) *Access to elected office for disabled people strategy. Compliance with the Equality Act 2010 guidance for political parties.* London, GOV.UK. Accessed on 15 August 2014 from https://www.gov.uk/government/publications/access-to-elected-office-for-disabled-people-strategy-compliance-with-the-equality-act-2010-guidance-for-political-parties.

[166] Department for Culture, Media & Sport, Government Equalities Office (UK) (2014) *Political life: Disabled people's stories.* Accessed on 15 August 2014 from https://www.gov.uk/government/publications/political-life-disabled-peoples-stories.

[167] Access to Elected Office Fund (UK) *Welcome to the access to elected office for disabled people fund.* Accessed on 15 August 2014 from http://www.access-to-elected-office-fund.org.uk/.

[168] *Transcript of Evidence,* Disability Employment Australia, p.4; Irish Association of Supported Employment *About job shadow day.* Accessed on 1 September 2014 from http://www.iase.ie/pages/job_shadow/job_shadow.html.

[169] *Transcript of Evidence,* Disability Employment Australia, p.4.

Chapter 7
Accessible and enabling environments

AT A GLANCE

Background

Seamless access to information, the built environment and transport networks contributes to social inclusion by ensuring that people can live, work and move around the community as they want and need to. Over the past two decades the Victorian Government has continued to make efforts to improve accessibility in the community, including:

- the physical infrastructure of the public transport system

- accessibility of public spaces and new buildings

- providing information in accessible formats.

Key findings

- People with disability continue to:

  ♦ Report that they have challenges moving through the community on public transport, with key issues relating to whole of journey travel, customer service staff attitudes in the public transport system and the accessibility of information relating to travel. **(Finding 7.1)**

  ♦ Experience challenges in accessing the built environment, particularly in older buildings where staged change needs to occur. **(Finding 7.2)**

  ♦ Experience challenges accessing information relevant to their daily lives and engagement with the community. **(Finding 7.3)**

- Advances in technology have contributed to increased physical independence, functional capacity and social interactions of people with disability, but technology can also create unintended barriers for the participation of people with disability. **(Finding 7.4)**

Recommendations

That the Victorian Government:

- Establish measurable outcomes and targets in future State Disability Plans and implementation plans that relate to improved accessibility for people with disability in the built environment and public spaces, accessible information, and whole of journey travel. Tender requirements should give consideration to the priority of the needs of people with disability. **(Recommendation 7.1)**

- Identify a long-term strategy for improving the accessibility of pre-existing buildings, such as schools, and public spaces in the community. **(Recommendation 7.2)**

- Explore the evolving role of technology in the lives of people with disability and how it enables their social inclusion to identify ways to intersect technology with current support and accessibility initiatives. **(Recommendation 7.3)**

Seamless access to the physical environment, transport and information ensures that people can live, work and move around. Without it, most people would be unable to function properly in society. Unfortunately, however, this is a reality for many people with disability.

The Committee acknowledges that a lot of work has been undertaken in Victoria to improve access for people with disability. However, there is a need for continuing focus on this area. Environmental factors continue to limit the choices and participation of people with disability. In July 2012, writer and disability advocate Ms Stella Young explained her experience:

> By far the most disabling thing in my life is the physical environment. It dictates what I can and can't do every day.[1]

These limitations have consequences for social inclusion and further improvements are needed to make transport, buildings and outdoor spaces more accessible. Access to technology and information are equally important to the daily lives of people with disability and while they enable social inclusion, many people with disability continue to report that barriers exist to accessing technology and information.

7.1. Accessibility

The Committee received considerable evidence about the lack of accessibility to various essential features of everyday life, many of which are considered to be the 'linchpin in creating social inclusion.'[3] Many of these barriers are a consequence of past governments, planners and developers not considering universal access needs in the design stage of the provision of goods and services. In the last 10 years, there has been significant progress made to improve accessibility, however, there is still a long way to go to achieve this.

Accessibility—*in common language, the ability to reach, understand, or approach something or someone. In laws and standards on accessibility, it refers to what the law requires for compliance.*[2]

The Executive Director of Women with Disabilities (WDV), Ms Keran Howe, told the Inquiry that 'we know that people with disability are deeply and systematically excluded from the most basic access to the community.'[4] She went on to provide an example from her own life experience:

> If I draw on my experiences as a person with disability, I currently choose my doctor, dentist, accountant, where I shop for my clothes, what cafes I go to, what entertainment I choose and where I buy my lunch all based on not what the quality of the service is or what I like about it but whether or not I can get into the building. That is just an example from a person with physical disability. All of us with our diverse and different impairments find those sorts of characteristic exclusions based on our disabilities or our impairments.[5]

The Research Program Leader and Deputy Chair of the Academic Board at La Trobe University, Professor Christine Bigby furthered this point regarding

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1   S. Young (2 July 2012) *We're not here for your inspiration.* Ramp Up. Accessed on 27 May 2014 from http://www.abc.net.au/rampup/articles/2012/07/02/3537035.htm.
2   World Health Organization (2011) *World report on disability.* Geneva, WHO, p.170.
3   *Submission S126*, Victorian Council of Social Service (VCOSS), p.13.
4   *Transcript of Evidence*, Women with Disabilities Victoria, Melbourne, 6 March 2014, p.2.
5   *Transcript of Evidence,* Women with Disabilities Victoria, p.2.

developments in accessibility for people with physical disability in the context of accessible environments. She emphasised the need to think about accessibility more broadly for people with all forms of disability:

> The ideas of inclusive communities are ones that primarily enable accessibility of physical and sensory ways to public places, to community groups, to shops and to businesses. Much of the focus in recent years in public policy has been on accessibility and social inclusion of people with physical and sensory disabilities. That is what people always revert to when they are thinking about social inclusion: they think about trams, transport, all those things, being physically accessible. There has been much less attention given to people with cognitive disabilities and people with communication difficulties, and the types of access and inclusion that they need, and the way in which public places and mainstream services need to adapt and change in order to be responsive to that group of people—particularly I am thinking around the health system, the transport system and the criminal justice system.[6]

Ms Valerie Johnstone told the Inquiry about the challenges that she must overcome daily in order to move through the community and engage in her regular activities:

> My vision impairment—optic atrophy, impacts on my daily living such as use of public transport, use of voice software when using the computer and other equipment. The lack of visual cues requires a great deal of time, concentration, memory and a willingness to find other ways to get things done.[7]

A case study provided by the Public Transport Ombudsman set out in Box 7.1 illustrates the specific needs of a person with autism in the transport system.

Box 7.1: Case study—disability, diversity and public transport

Chris got off his train and made his way to the exit. He was wearing his headphones and wasn't aware that Authorised Officers were trying to get his attention so they could check his ticket.

By the time Chris realised he needed to show his ticket, five Authorised Officers had surrounded him. He showed his ticket but it took some time for the Authorised Officers to move on.

Chris has autism and found the interaction really confronting. He ended up needing hospital treatment because the incident bought on an anxiety attack.

Source: *Transcript of Evidence,* Public Transport Ombudsman Victoria, Melbourne, 24 March 2014, pp.3–4.

In regard to the transport system, Section 7.2.5 discusses the need for culture change in the provision of transport services to address accessibility issues for people with cognitive disability or communication difficulties.

7.1.1.   Disability action plans and accessibility

The *State disability plan 2013–16* and disability action plans in public entities, particularly local government, have a focus on accessibility and have contributed to a gradual change in the area of accessibility. Ongoing commitments exist in the *State disability plan 2013–16* and new areas for improving accessibility are continually identified.

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[6]   *Transcript of Evidence*, Professor Christine Bigby, La Trobe University, Melbourne, 20 March 2014, p.2.
[7]   *Submission S018*, Ms Valerie Johnstone, p.1.

As outlined in Chapter 2, the *Disability Act 2006* (Vic) requires all public sector bodies to have a disability action plan.[8] The plans are documents that organisations prepare and use in order to reduce and remove barriers experienced by people with disability. Amongst other requirements, the Disability Act stipulates that one specific purpose of disability action plans is to 'reduce barriers to people with disability accessing goods, services and facilities.'[9] All Victorian local governments have a disability action plan, which has contributed to increased focus on accessibility by local councils.[10] Examples of the way in which local government disability action plans aim to address accessibility include:

- improving access and enhancing liveability of local environments

- increasing engagement in council planning processes through disability advisory committees

- providing accessible transport options.

Although many Inquiry participants praised the work of local governments on improving the accessibility of local environments, some identified that there are no mechanisms in place to ensure effective implementation of disability action plans. The effectiveness of disability action plans is discussed in Chapter 2 and the Committee recommends that the Auditor-General undertake an audit of the suitability, effectiveness and implementation, and the monitoring and improvement of disability action plans by local government (Recommendation 2.3)

The Municipal Association of Victoria (MAV) commented that councils identify significant challenges associated with improving accessibility in local areas. It explained that limited financial resources and multiple competing priorities hamper momentum on achieving accessibility, particularly in the case of smaller rural councils. The MAV went on to outline the planning and building system constraints:

> The planning and building systems and their associated regulatory arrangements create barriers to being able to ensure all key aspects influencing the urban design of local physical infrastructure work together to achieve better access and inclusion in local precincts. For example some councils report difficulty with requiring access and inclusion to be addressed by builders/developers in their master planning of sites; others commented on constraints on their ability to influence the orientation and interface between a building and surrounding areas in a manner consistent with good access principles. Other councils raised issues of retirement villages being built without due consideration of access and inclusion issues and council having little capacity to require improvements.[11]

The role of local government in the context of social inclusion and disability is discussed in more detail in Chapter 2.

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[8] *Disability Act 2006* (Vic) s.38.
[9] *Disability Act 2006* (Vic) s.38.
[10] Municipal Association of Victoria *Disability*. MAV. Accessed on 1 August 2014 from http://www.mav.asn.au/policy-services/social-community/disability/Pages/default.aspx.
[11] Municipal Association of Victoria *Disability*. From http://www.mav.asn.au.

7.2.   Transport

For all people in the community, social inclusion is enhanced by the ease with which they can get from place to place—including travelling to work, to school or to social activities. People with disability can be restricted in their ability to move around the community when public transport is inaccessible and unreliable. Difficulties in navigating transport systems and completing a journey from one place to another due to inaccessibility are major barriers for the social inclusion of people with disability. Travellers Aid Australia emphasised this point:

> Transport plays a key role in terms of social inclusion to enable people to make choices about how they spend their time; that could be catching up with friends and family, it could be travelling or holiday leisure and it could also be for volunteering, employment and education.[12]

The Committee acknowledges that in Victoria improvements have been made to the infrastructure of transport systems and networks to increase accessibility. Yet attitudes of customer service staff and others who provide transport services continue to impact on accessibility.

According to the Victorian Equal Opportunity and Human Rights Commission (VEOHRC), in 2012–13 there were 223 complaints by people with disability regarding access to goods and services (including access to transport). In its submission, the VEOHRC also highlighted to the Inquiry the findings from its 2013 report titled *Who's on board? Public transport for people with disabilities in Victoria*, which comprised a survey the VEOHRC conducted in May 2013 of transport users with disability. The following findings reflect ongoing challenges in accessing public transport and taxi services:

- the majority of respondents thought that public transport had not improved over the past year

- barriers to access exist on all forms of public transport and taxi services—including large gaps between trams and superstop platforms and taxi driver awareness and attitudes to the diverse requirements of people with disability (use of assistance dogs or safety harnesses)

- many respondents reported experiencing long waiting times for taxi services

- improvements to access are welcome but may be limited by other infrastructure or the service that exists around them—such as accessible trains with inaccessible train platforms or transport staff that forget or refuse to deploy the portable ramp.[13]

Consideration should also be given to the importance of infrastructure maintenance. For example, the availability of working lifts at train stations is critical for people with disability, and may mean that a person with disability is at risk of being stranded on inaccessible train platforms. The Committee considered that effective maintenance of lifts at suburban train stations is also a critical accessibility and safety issue for people with disability.

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[12]   *Transcript of Evidence*, Travellers Aid Australia, Melbourne, 24 March 2014, p.3.
[13]   Victorian Equal Opportunity and Human Rights Commission (2013) *Who's on board? Public transport for people with disabilities in Victoria*. Carlton, VEOHRC, p.19; *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.11.

Evidence to the Inquiry suggests that barriers to accessing public transport may be greater than suggested by complaints figures because people are reluctant to submit formal complaints. The Public Transport Ombudsman, Ms Janine Young, informed the Inquiry that:

> Sixty per cent of agencies stated that their members would probably not contact my office because they were reluctant due to fear or lack of trust in authority, communication impairment, lack of awareness of the existence of my office or complaint processes or systems that were too difficult.[14]

The Committee heard that in order to ensure fully accessible transport, the way that accessibility is interpreted needs to extend beyond allowing for boarding and disembarking public transport by people with mobility aids. The Public Transport Ombudsman suggested a definition of accessible public transport which takes into account the diversity of needs that people with disability can have:

> Accessible public transport provides the ability for all commuters to reach their destination unhindered, independently or aided when required and on a timely basis, regardless of how many modes of travel are utilised. A public transport journey should involve multimodal, integrated, consistent and effective communication, respectful customer service, regardless of the commuter's circumstances, and the focus should be on accessibility not disability. To do that I guess goes beyond … trains, trams, buses and the ticketing system myki. You also need to look at taxis. You also need to look at footpaths, roads and whether people can cross the road to get to a bus stop or train station … it starts at someone's home and ends at the destination to which they are going and the return journey.[15]

The *State disability plan 2013–16* outlines a range of actions that recognise the importance of transport to people with disability and the need to ensure connected and responsive transport services are provided. The Department of Transport, Planning and Local Infrastructure committed to developing a plan for accessible transport and recently released the *Accessible public transport action plan 2013–17*. This Action Plan outlines its strategy for delivering accessible bus, train, tram and taxi services throughout Victoria. It will report on the implementation of the Action Plan.

The Committee is of the view that improvements should consider the needs of people with disability when determining priorities for new infrastructure such as accessible tram stops. The *Accessible public transport action plan 2013–17* has a focus on active consultation and community engagement through regular meetings with the Public Transport Access Committee (PTAC). The PTAC is a ministerial advisory committee on accessibility issues for older people and people with disability, and other users and stakeholders. In its evidence, the VEOHRC endorsed this approach:

> In particular, we support the Public Transport Action Plan's commitment to regular consultation with people with disability around key barriers they face, including: tram and bus boarding, accessible toilets at railway stations and bus access.[16]

The Public Transport Ombudsman also observed that public transport operators have improved their collaborative efforts in the development of accessibility policies and plans, and are starting to consult with the Ombudsman earlier in the process.[17]

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14 *Transcript of Evidence*, Public Transport Ombudsman Victoria, Melbourne, 24 March 2014, p.2.
15 *Transcript of Evidence,* Public Transport Ombudsman Victoria, p.2.
16 *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.12.
17 *Transcript of Evidence,* Public Transport Ombudsman Victoria, p.3.

7-8

Table 7.1 outlines the range of strategies and implementation actions in the *State disability plan 2013–16* that relate to transport systems and ease of access.

Table 7.1: *State disability plan 2013–16*—strategies and implementation actions to improve transport options, 2013–14

Strategies and implementation actions
Strategy: Make it easier to use a range of forms of transport
• Ensure public transport planning better aligns and connects public transport modes.
• Finalise the detailed operational arrangements of the Australian Disability Parking Scheme in consultation with a range of stakeholders.
• Implement the government's response to the Taxi Industry Inquiry.
Strategy: Make public transport more accessible
• Develop the *Accessible public transport in Victoria action plan 2013–2017* (the Action Plan). The Action Plan embeds an access approach to public transport. The key priorities in the Action Plan will set the direction over the six year period of the Action Plan. In its initial stage, the actions listed below will be achieved.
• Improve access to existing buildings and facilities at priority metro and regional railway stations.
• Continue upgrading bus stops across Victoria in accordance with the Disability Standards for Accessible Public Transport to improve access to the bus network.
• Continue to replace non-accessible buses with new low floor buses.
• Introduce E-class low floor trams and increase the number of level access stops on Route 96.
• Look at innovative ways to improving accessibility and independent travel for users at stations e.g. raised ramps trial at Box Hill, Flinders Street and Newport metropolitan rail.
• Incorporate principles of universal design and *Disability Discrimination Act 1992* (Commonwealth) compliance in all new public transport infrastructure, rolling stock and facilities.
• Consult with a range of stakeholders, including people with disability, older Victorians and people with mobility restrictions, as part of the development of public transport infrastructure and rolling stock.

Source: Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014*. Melbourne, DHS.

7.2.1. Vehicles and infrastructure—progress on accessibility

Accessible public transport has been on the national agenda for over a decade. In 2002, the Australian Government released national *Disability standards for accessible public transport* (2002) (Transport Standards).

In May 2014, the Australian Department of Infrastructure and Regional Development released a draft report of the *Review of the disability standards for accessible public transport 2002*. The Review identified the following general

areas of concern that need to be addressed to improve the effectiveness of the Transport Standards in removing discrimination against people with disability:

- lack of a national framework for reporting on compliance with the Transport Standards

- constraints on people with disability to undertake whole journeys

- lack of consistency in the provision of public transport information to people with disability

- lack of understanding by public transport staff of the difficulties faced by people with disability.[18]

Victoria has made progress in taking steps to increase accessibility of the public transport system and to comply with the national Transport Standards. Table 7.2 outlines progress and ongoing areas for improvement relating to public transport accessibility in Victoria. These were identified in the *Review of the disability standards for accessible public transport 2002*.

Table 7.2: National review of public transport accessibility — progress in Victoria

Type	Progress	Concerns identified
Trains	Metro: A total of 98 per cent of the suburban fleet of 204 carriages were accessible. Mobility-aid boarding is only available at the front carriage. Regional: A total of 92 per cent of the 62 trains were accessible. Mobility-aid boarding is available at any carriage. Some of the older carriages are not compliant for manoeuvring areas and allocated spaces.	Providing access only at the front carriage of a train, particularly during peak travel times, is considered unsatisfactory. Waiting in a designated space at the platform and having to inform the driver of the need for a ramp continues to distress people with disability. Raised platforms have been adopted at several metropolitan locations as an interim measure. The raised platforms, which take account of train door height and fill the horizontal gap between the platform and train by using a combination of solid rubber and rubber bristles, remove the need for direct assistance.
Rail infrastructure	Metro: Access to railway stations is around 55 per cent of the 208 metropolitan railway stations on 15 train lines. Regional: Access to railway stations is 55 per cent of the 87 regional railway stations on 8 train lines.	In situations where lifts are the only means of access to and from railway stations, if they are out of service the stations become inaccessible to people with disability. The lack of availability of 24-hour accessible toilets for people with disability. Correct placement of tactile ground surface was seen as

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[18]   Department of Infrastructure and Regional Development (2014) *Review of the disability standards for accessible public transport 2002. Draft report*. Canberra, Commonwealth of Australia, p.72.

Type	Progress	Concerns identified
		critical to ensuring visually impaired or blind passengers could successfully navigate rail infrastructure and access conveyances.
Buses	Metro: The Bus Replacement Program has resulted in 1,421 low-floor buses and had achieved 75 per cent compliance with the Transport Standards. All low-floor buses have manual ramps fitted that can be deployed by the driver. These buses meet requirements for priority seating, allocated spaces and manoeuvring. Regional: Approximately 49 per cent of the 554 buses that operate in regional towns and rural areas of Victoria are accessible and meet compliance requirements. The Bus Replacement Program will increase the number of low-floor accessible buses in regional areas over time. For regional coach services operated by V-Line, 56 per cent of the total fleet of 103 coaches are accessible and meet the requirements of the Transport Standards. The biggest accessibility challenge for passengers of coach services is the constraints on their ability to use mobility aids on these services.	Intermittent availability of low-floor accessible buses. Inability of people with mobility aids to board buses and coaches. Problems experienced by the vision impaired and blind in flagging down buses in motion. Lack of driver understanding of the needs of people with disability. Allocated space on accessible buses being used by bicycle owners and passengers without disability.
Bus infrastructure	Metro: Access to bus infrastructure is around 52 per cent of the 17,961 bus stops. Regional: Access to bus infrastructure is around 52 per cent of the 6,136 stops.	Progress falls short of the 2012 compliance milestone. However, there have been 10,000 upgrades to bus stops including the installation of tactile ground surface indicators, access paths and surface upgrades.
Trams	100 low-floor accessible trams are in operation in Melbourne's tram fleet of 487 cars.	The 2012 compliance targets have not been met and compliance is currently around 23 per cent.

Type	Progress	Concerns identified
		Because older, high-floor trams cannot be retrofitted and made accessible, and trams have a replacement cycle of 30 years, Victoria is likely to have difficulty meeting the 2017 milestones. A tram replacement program is in place with 50 low-floor trams on order.
Tram infrastructure	In 2012, 65 per cent of the 1,770 tram infrastructure in Melbourne met the accessibility requirements of Transport Standards overall. However, only 21 per cent of tram stops are platform and easy-access stops that can be considered to be fully accessible for people who have a mobility aid that requires a ramp or assisted access. Victoria has continued to build level-access tram stops up to the current total of 364. Other low-floor tram routes are receiving power upgrades and accessibility improvements.	The majority of tram stops do not have a raised kerb, and where they do, the horizontal gap is still exceeding the allowable distance of 40 mm under the Transport Standards. While bridging plates are now available on some versions of the new low-floor trams, they need to be available on all new tram roll-outs, as well as signage indicating that the service is available and how it is activated. Irrespective of new infrastructure improvements to the tram network, without a consistent roll-out of bridging plates the accessibility of trams will still not have improved.

Source: Adapted from the Australian Department of Infrastructure and Regional Development (2014) *Review of the disability standards for accessible public transport 2002. Draft report.* Canberra, Commonwealth of Australia.

Inquiry participants recommended a need for 'integrated action' to enable people with disability to get where they need to go when they need to. There has been considerable planning and consideration of innovative transport solutions. However, the Committee heard there has not been the same level of action, particularly action that is integrated across all aspects of public transport.[19]

The VEOHRC supported the commitment in the *Accessible public transport action plan 2013–17* to improved data collection and reporting against the plan, including a commitment to annual public reporting over the life of the plan.[20]

7.2.2. Whole of journey infrastructure

For some people with disability, an accessible journey requires more than the ability to get on and off transport. Inquiry participants emphasised that there is a need for a 'whole-of-journey' approach to improving the transport infrastructure.[21] Although Victorian Government transport policy is increasingly

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19   *Transcript of Evidence,* Travellers Aid Australia, p.4. See also *Submission S075*, Mr Tony Clark, pp.2–4.
20   *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.12.
21   *Submission S126*, Victorian Council of Social Service (VCOSS), p.13.

recognising this need, the Committee heard that there is still little evidence of integrated action to achieve this.

The Deputy Chair of the Victorian Aids and Equipment Action Alliance, Mr Peter Willcocks, pointed out that accessible tram stops may assist some people in wheelchairs, but this only represents a small proportion of people with disability gaining increased access to transport.[22] Mr Willcocks gave examples of people with vision impairment or those who cannot walk long distances as people for whom accessible public transport stops alone would be of no benefit. He explained that it is difficult for people with mobility issues to attend a major events because trams and buses cannot comfortably fit more than one wheeled vehicle at a time (including a bicycle or pram).[23]

Travellers Aid Australia explained that for some people the absence of accessible toilet facilities 'is the deciding factor as to whether they will travel or not.'[24] Travellers Aid provides personal care and support to people with disability who use rail transportation. It currently operates two metropolitan locations (Flinders Street and Southern Cross railway stations) and two pilot locations in regional Victoria (Wangaratta and Wodonga). The service provides 'practical things like helping people go to the bathroom, helping people with toileting and offering communication assistance and meal assistance.'[25] Initiatives to improve access to toilet facilities are discussed in Section 7.3.

The Committee acknowledges that the Victorian Government's *Accessible public transport action plan 2013–17* incorporates a whole-of-journey approach and the importance of accessible information to all passengers. The Plan recognises that a compliance approach to accessibility 'does not necessarily lead to greater access for people with disability or mobility restriction.'[26] It states that:

> … while compliance remains an important measure of performance, the focus has changed over the past couple of years to improving the overall accessibility of public transport, including connectivity between modes.[27]

The 2014 *Review of the disability standards for accessible public transport 2002* endorsed the approach detailed by the Victorian Government submission to a whole-of-journey approach and the need for the Action Plan to be accompanied by an implementation plan. The review suggested that Victoria's approach could be a possible model for other jurisdictions:

> Incorporating a whole-of-journey approach into action plans … is one way of ensuring that this planning is consciously addressed … This broader approach also provides a greater focus on better integrated and coordinated public transport services. Victoria also advised that action plans should be accompanied by an implementation plan that outlines how priorities and outcomes from the action plan will be delivered and funded. This review sees the approach detailed by Victoria as a possible model for other jurisdictions.[28]

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[22] *Transcript of Evidence*, Victorian Aids and Equipment Action Alliance, Melbourne, 20 March 2014, pp.8–9.

[23] *Transcript of Evidence,* Victorian Aids and Equipment Action Alliance, p.8.

[24] *Transcript of Evidence,* Travellers Aid Australia, p.4.

[25] *Transcript of Evidence,* Travellers Aid Australia, p.3.

[26] Department of Transport, Planning and Local Infrastructure (2013) *Accessible public transport in Victoria. Action plan 2013–2017.* Melbourne, DTPLI, p.4.

[27] Department of Transport, Planning and Local Infrastructure (2013) *Accessible public transport in Victoria. Action plan 2013–2017*, p.4.

[28] Department of Infrastructure and Regional Development (2014) *Review of the disability standards for accessible public transport 2002. Draft report*, p.129.

The VEOHRC also told the Inquiry that it supported the Victorian Government's commitment to a whole-of-journey approach:

> The Commission believes that there must be greater emphasis on improving whole-of-journey accessibility outcomes for passengers with disability.[29]

The Committee identified that a whole-of-journey approach should enable the development of new public transport infrastructure to better address the needs of people with disability. For example, the development of accessible tram stops at major transport nodes is likely to have a greater impact on the ability of people with disability to navigate the public transport system as a whole to reach their destinations.

7.2.3.   Rural and regional travel

A number of Inquiry participants identified that there are inadequate transport options in rural and regional Victoria. Transport was identified as being inaccessible and infrequent. Concerns were also raised about poor timetabling and out-of-date vehicles and infrastructure.[30] In its submission, Mansfield Shire Council informed the Inquiry that:

> Lack of adequate accessible transport (and often just any transport – Mansfield is ranked one of the lowest of local government areas in Victoria for percentage of population close to public transport) has been identified as a particular challenge limiting the capacity to achieve participation by people with disability in activities and employment.[31]

Similarly, Cardinia Shire Council highlighted concerns of regional areas with respect to the availability and accessibility of public transport, the high reliance on cars, and the consequent disadvantage of groups who are not able to drive:

> There are limited public transport options within Cardinia Shire. There are many townships where there is no public transport available. In other parts of the Shire there are bus services but frequency levels are insufficient to meet the needs of local residents. For residents with limited mobility this situation is further compounded by the limited provision of low floor buses and maxi taxis in the Shire.
>
> Without access to public transport, people with disability are unable to access the necessary employment, services, education and recreational facilities that otherwise enhance their social inclusion. Car ownership levels in Cardinia Shire are understandably high with the majority of households required to own and maintain multiple vehicles because of limited public transport options … anecdotal reports from the Shire's rural townships indicate that transport [for] disadvantaged groups, such as the elderly or people on disability pensions who do not have the financial capacity to own a car or who do not drive are further excluded from attending activities, programs and services.[32]

Flexibility of travel is also limited for people with disability. For example, in her submission, Ms Leanne Robson, a service manager in a disability service, explained that customers accessing V/Line bus services on a wheelchair are required to book the service 24 hours in advance so that internal seats can be removed to accommodate them.[33]

According to V/Line's *Accessibility guide*, customers are no longer required to provide 24 hours advance notice of their planned travel on a V/Line coach

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[29]   *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.12.

[30]   *Submission S083*, Wellington (Local Government Area) Community, p.2.

[31]   *Submission S057*, Mansfield Shire Council, p.2. See also *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.4; *Submission S053*, Municipal Association of Victoria, p.8.

[32]   *Submission S085*, Cardinia Shire Council, p.3.

[33]   *Submission S022*, Ms Leanne Robson, Yooralla Service Manager, pp.1–2. See also *Submission S032*, Mrs Trudy Golding, pp.1–2, 5–6.

service.[34] However, the Guide suggests that a single wheelchair space has been allocated for each coach, which may still restrict travel if more than one person with a wheelchair accesses the service.

7.2.4.   Taxis

The Committee considers that initiatives recommended by the Taxi Services Commission established by the Victorian Government in 2012 hold considerable promise in improving taxi services for people with disability. The implementation of these initiatives in metropolitan and regional areas of Victoria should be prioritised in order to ensure that taxis are a viable transport alternative for people with disability.

Inquiry participants emphasised the importance of accessible taxis for people with disability as a complementary service to public transport. Some people with disability rely daily on taxis in order to go to work, school or appointments, and many use taxis to attend activities and to connect to other public transport options.[35]

The 2012 Taxi Industry Inquiry chaired by Professor Allan Fels made a number of recommendations with respect to people with disability, such as improved driver training and changes to regulations to allow more accessible and purpose-built taxis.[36]

In 2013, the VEOHRC reached similar conclusions to the Taxi Industry Inquiry. In its Report *Who's on board?*, the VEOHRC highlighted its survey findings of transport users with disability. Survey respondents identified a number of ongoing accessibility issues relating to taxi services, including:

- taxi drivers who refuse to accept a fare because of a person's disability, such as their use of a mobility device or guide dog

- insufficient awareness and knowledge among taxi drivers about safety, including how to install safety harnesses for mobility devices

- long waits for taxi services.[37]

Inquiry participants also reported these experiences. For example, in its submission, Vision Australia told the Inquiry that many taxi drivers do not accept dog guides in their vehicles 'due to a lack of awareness of the role assistance dogs play in the lives of people who are blind or have low vision.'[38] Guide Dogs Victoria also identified instances in which people with guide dogs are refused taxi services:

> Regrettably, too many instances of guide dog handlers being refused entry or service still occur. These challenges to the rights of the person who is blind or vision impaired are unacceptable and continued awareness of legal, social and moral obligations is necessary.[39]

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[34]   V/Line (2013) *Accessibility guide.* V/Line. Accessed on 28 August 2014 from http://www.vline.com.au/pdf/publications/Accessibility_Guide_draft.pdf.

[35]   See for example, *Submission S115*, Victorian Equal Opportunity and Human Rights Commission. Appendix 2; *Submission S001*, Mrs Brenda Rawlins, p.1.

[36]   Taxi Services Commission (2012) *Final report: Customers first. Taxi industry Inquiry,* Melbourne, Taxi Services Commission.

[37]   Victorian Equal Opportunity and Human Rights Commission (2013) *Who's on board? Public transport for people with disabilities in Victoria.*

[38]   *Submission S112*, Vision Australia, p.6.

[39]   *Submission S062*, Guide Dogs Victoria, p.8.

Similarly, UnitingCare Community Options told the Inquiry that difficulties with securing accessible taxi services were highlighted by its participants and workers:

> … major difficulties [were] encountered in securing a taxi booking during peak times. This meant that in many instances a participant would miss out on being able to attend their place of work, education or community program because of insufficient taxi operators. In addition, these have to be pre-planned significantly in advance, so any change of plans or spontaneous opportunities are unable to be accessed.[40]

The need to regularly use a taxi service makes travel too expensive for some people with disability, despite the availability of the Multi Purpose Taxi Program subsidy. Brimbank City Council, for example, told the Inquiry that the Multi Purpose Taxi Program 'is capped well below what an individual requires.'[41]

In May 2013, the Victorian Government responded to the recommendations made by the Taxi Inquiry. It acknowledged that people with disability 'comprise a considerable proportion of taxi customers but continue to experience unacceptable levels of service quality, availability and accessibility.'[42] The Victorian Government committed to implementing a number of reforms including:

- improved training for drivers to assist people with disability

- changes in regulations to allow more accessible and purpose-built taxis

- development of a new Central Booking Service in metropolitan areas to reduce wait times and provide more accurate booking information.[43]

In its submission, the VEOHRC acknowledged that significant work is currently underway to implement the recommendations of the Taxi Industry Inquiry. It told the Inquiry it is currently in the process of working with the Taxi Services Commission in order to:

- address the unacceptably long wait times for wheelchair accessible taxis, as well as poor service standards

- develop options for a new Central Booking Service as a means of ensuring that Wheelchair Accessible Taxis are available for people with disability as a priority

- ensure that the Taxi Services Commission meets its positive duty under the *Equal Opportunity Act* (Vic) by ensuring that it can adequately monitor drivers that discriminate against people with disability by refusing to accept jobs

- ensure that the eligibility criteria for the Multi Purpose Taxi Program provides adequate subsidised taxi fares for Victorians with severe and permanent disability who also experience financial hardship.[44]

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40   *Submission S070*, UnitingCare Community Options, p.6.
41   *Submission S086*, Brimbank City Council, p.8.
42   Victorian Government (2013) *Government response: Taxi industry Inquiry and final recommendations* Melbourne, Victorian Government, p.5.
43   Victorian Government (2013) *Government response: Taxi industry Inquiry and final recommendations* p.5.
44   *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.12.

Responsiveness to people with disability is one of the elements of the Knowledge Test developed by the Taxi Services Commission, which came into effect on 30 June 2014. All taxi and hire car drivers in Victoria are required to pass this test in order to gain accreditation, which is designed to ensure that 'taxi and hire car drivers have high levels of local geographical expertise, disability awareness and general customer service skills.'[45]

7.2.5. Information, communication, attitudes and customer service

The Public Transport Ombudsman identified that there is a need for culture change and an improvement in service provision in public transport to meet the travel needs of people with disability. The Ombudsman told the Inquiry that in the past, the industry focus was on compliance, infrastructure and government funding. She explained that there has not been the same degree of focus on service provision.[46] The Ombudsman also advised that since her appointment in 2010, public transport operators have been increasingly more proactive in their approach to improving service and communication.[47]

The 2014 national *Review of the disability standards for accessible public transport 2002* also identified improvements in accessibility of information, including in Victoria. The Review observed that transport operators have improved print and online transport information such as:

- better timetable information

- more accessible network maps

- large-print versions of published information on request

- enhanced electronic tools to help people plan their trip

- more customer service officers at major city tram stops and train station interchanges

- provision of information and advice during peak hours

- progressive installation of display screens at tram stops with timetable information.[48]

Public Transport Victoria has improved its public transport website and mobile applications to take into account accessibility requirements. These platforms are designed to allow commuters planning their journey to set a number of accessibility preferences such as their need for wheelchair accessible services, accessible stops and minimal walking. Other requirements, however, such as the availability of accessible amenities cannot be identified using the current technology. There is an ongoing need to ensure these technologies are updated to reflect improvements to the accessibility of the public transport system.

Despite these improvements, the national review identified ongoing gaps in information. It found that many train stations, some trains and most trams and

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[45]   Taxi Services Commission *Knowledge test.* Accessed on 26 August 2014 from
          http://www.taxi.vic.gov.au/drivers/the-knowledge.
[46]   *Transcript of Evidence,* Public Transport Ombudsman Victoria, p.2.
[47]   *Transcript of Evidence,* Public Transport Ombudsman Victoria, p.3.
[48]   Department of Infrastructure and Regional Development (2014) *Review of the disability standards for accessible public transport 2002. Draft report*, p.66.

buses do not have visual information to accompany audio announcements, or staff available to provide direct information assistance to people who are deaf or hard of hearing. In addition, it identified a need to improve the accessibility of government and transport operator websites and printed information in a range of formats.

The *State disability plan 2013–16* acknowledges the importance of accessible information on transport, and makes an undertaking to ensure all transport websites are Level AA compliant with the Web Content Accessibility Guidelines. Accessibility of information is discussed more generally in Section 7.4, including the actions set out in the *State disability plan 2013–16* outlined in Table 7.4.

In addition to information accessibility, the Committee heard there is a need for improved attitudes in the provision of customer service. For example, research by Travellers Aid Australia shows that people with disability can be quite forgiving in cases of disruptions, infrastructure breakdown and traffic faults. However, failures in communication and 'being stranded' were poorly received by people with disability.[49]

In 2013, the Public Transport Ombudsman's report *Closing the accessibility gap* provided practical suggestions about how public transport experiences for people with disability could be improved with a focus on customer service standards and information provision.[50] The report recommended:

- industry wide training for staff on disability and effective and respectful communication with people with disability

- improvements to complaint resolution

- provision of accessible information about boarding public transport

- improving public announcements in consultation with people with disability

- accessible updated guide for myki

- accessible design into public transport infrastructure.[51]

Furthermore, in her evidence to the Inquiry, the Ombudsman suggested that public transport operators can play a stronger role in improving attitudes towards people with disability more generally. She expressed the view that:

> … the operator staff need to role model positive behaviours. Therefore commuters may be driven to positive, inclusive behaviour rather than poor behaviour based on what they see. Operator staff also have a proactive role in identifying poor behaviour by some commuters towards others and stopping it. There are authorised officers and other people that could take that role.[52]

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[49]   *Transcript of Evidence,* Travellers Aid Australia, p.4.

[50]   Public Transport Ombudsman Victoria (2013) *Closing the accessibility gap. How the accessibility of public transport can be improved through innovation to customer service standards and information provisions* Melbourne, PTO, p.20.

[51]   Public Transport Ombudsman Victoria (2013) *Closing the accessibility gap. How the accessibility of public transport can be improved through innovation to customer service standards and information provisions* pp.8–9.

[52]   *Transcript of Evidence,* Public Transport Ombudsman Victoria, p.3.

Finding 7.1

People with disability continue to report that they have challenges moving through the community on public transport, with key issues relating to whole of journey travel, customer service staff attitudes in the public transport system and the accessibility of information relating to travel.

Recommendation 7.1

That the Victorian Government establish measurable outcomes and targets in future State Disability Plans and implementation plans that relate to improved accessibility for people with disability in the built environment and public spaces, accessible information, and whole of journey travel. Tender requirements should give consideration to the priority of the needs of people with disability.

7.3. Buildings and outdoor spaces

Inequitable access to the built environment is a significant barrier to the full inclusion of people with disability. In particular, it prevents people from accessing work environments and from participating in social and recreational activities due to their inability to access places such as cafes, cinemas, libraries, sporting and swimming facilities. This inaccessibility not only works against people with disability living independently in the community but it also reinforces the invisibility of people with disability in broader society, often reducing their quality of life:

> It is hard for people without disability to imagine the difficulties many people with disability encounter as they move around the community. Organising to meet a group of friends for dinner only to discover the restaurant is inaccessible. Being unable to attend a child's end-of-year ballet concert because the venue has no access. Not being able to go to the movies because there are no screens with technology to assist people with a hearing impairment. Playgrounds that contain accessible equipment but that are routinely locked and can only be accessed with a key.[53]

Of the 223 complaints received by the VEOHRC regarding access to goods and services, 8.5 per cent (19) related to accessing premises and one complaint related to accessing a club. In evidence to the Inquiry, the VEOHRC also drew attention to the importance of people with disability having access to private and dignified toilet facilities in public places, and advised that standard accessible toilets do not always meet the needs of people with disability.[54] As noted earlier, evidence to the Inquiry suggests that the number of people who have these experiences may be greater than suggested by the level of complaints, as people with disability may be reluctant to 'speak up.'[55]

Inquiry participants identified the ability to independently access buildings and outdoor spaces as a key factor in empowerment and social inclusion. For example, in her submission Ms Raelene West explained that:

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[53]   National People with Disabilities and Carer Council (2009) *Shut out: The experience of people with disabilities and their families in Australia*. Canberra, Commonwealth of Australia, p.43.
[54]   *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.13.
[55]   *Transcript of Evidence*, Disability Services Commissioner, Melbourne, 3 March 2014, p.3; *Transcript of Evidence, * Public Transport Ombudsman Victoria, p.2.

> … having a fully accessible built environment provides full social inclusion, choice and empowerment for people with disability. Where individuals with mobility impairments are given the capacity to move freely and with choice through the built environment, their capacity for social inclusion is increased.[56]

The Association for Children with Disability told the Inquiry that responsibility for accessible buildings and public spaces is broad, highlighting that:

> Business and construction industries play a significant role in shaping our community. Architects, planners and developers need to ensure that the design of public buildings and spaces addresses access issues.[57]

Buildings in specific industries are subject to standards that require adjustments to ensure access for people with disability. For example, with respect to education settings, the Department of Education and Early Childhood Development (DEECD) explained to the Inquiry that:

> … under the Disability Standards for Education 2005 the department is required to make the necessary adjustments to allow every student, child and young person in school to access and participate. So while it does not go to the larger part of your question, we do have the accessible school buildings program, and we have a requirement that where individual students at schools require facility modification or infrastructure, that is undertaken. That could be anything from building ramps to hearing loops to Soundfield systems. So we do meet our requirements. It is not directly in reply to the bigger question that you mean, but I think it is important to state that we do take it seriously.[58]

Issues associated with access to education are discussed in greater detail in Chapter 6.

Since 1 May 2011, it is a requirement that new premises meet basic standards of access under the *Disability (access to premises-buildings) standards 2010* (Access Standards). The Access Standards introduce some new access requirements and improve existing requirements, including:

- entrances and doorways to buildings

- space and accessibility requirements for lifts, accessible toilets, passageways, doorways and common areas

- signage of accessible facilities

- hearing augmentation for PA systems

- accessible spaces in cinema and theatres

- accessible units in hotels and motels

- accessibility requirements for certain public swimming pools.

Table 7.3 outlines the current Victorian Government commitments under the *State disability plan 2013–16* to implement the national accessibility standards and improved accessibility of public spaces and community facilities.

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[56] *Submission S010*, Ms Raelene West, p.3.
[57] *Submission S122*, Association for Children with a Disability, p.7.
[58] *Transcript of Evidence*, Department of Education and Early Childhood Development, Melbourne, 3 March 2014, p.7.

Table 7.3: *State disability plan 2013–16*—strategies and implementation actions to improve access to buildings, 2013–14

Strategies and implementation actions
Strategy: Increase the application of accessible design standards in the built environment
• Support implementation of the *Disability (access to premises-building) standards 2010* (Commonwealth)
• Provide a planning and building web portal that includes information and guidelines on design for the built environment
• Improve community awareness of the benefits of universal design principles
Strategy: Make community facilities and public spaces more accessible and safer
• Promote universal design principles in the funding of all community facilities in particular for sport and recreation
• Increase the accessibility of facilities owned by not-for-profit culturally and linguistically diverse community organisations, by providing infrastructure funding. This may include the installation of lifts, disabled toilet facilities or disability ramps
• Continue to promote urban design training for built environment professionals that provide a better understanding of the urban design approaches that support accessibility and safety in the public realm

Source: Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014.* Melbourne, DHS.

The Inquiry was informed of several initiatives at the local level to improve access to buildings. An example is the *Good access is good business* Program, which has been adopted by a number of local governments across Victoria. Box 7.2 outlines the details of this program, which supports local businesses to meet the legal and community expectations that all people should have fair access to goods, services and opportunities.[59]

Box 7.2: Supporting business initiative—*Good access is good business*
A number of local governments have developed *Good access is good business* guides.
These guides appeal to 'good business sense' by outlining the benefits of enhanced access for local businesses, including:
• reaching potential customers
• meeting legal responsibilities.
The guides explain four ways in which access can be improved for all customers, and include tips and suggestions for businesses to make:
• it easy for people to find you by advertising your advantages, making the entrance easy to see and avoiding obstructions
• it easy for people to get in by providing level access, better doors and doorways, and clear sight lines

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[59] Enterprise Melbourne *Good access is good business.* City of Melbourne. Accessed on 6 June 2014 from https://www.melbourne.vic.gov.au/ENTERPRISEMELBOURNE/BUSINESSSUPPORT/Pages/Access.aspx.

Box 7.2: Supporting business initiative—*Good access is good business*

- it easy for people to get around, including people who are blind or have vision impairments, for people who may have difficulty hearing, for people with mobility impairments (including provision of accessible toilets).

- the most of customer service by ensuring respect (suggestions about focusing on the person, giving assistance, asking questions), good communication (suggestions about approaches that can be helpful for communicating with people who may have a learning difficulty, intellectual disability or brain injury, for those with a hearing impairment and those with vision impairments) and finding alternative ways to provide customer service (including telephone or online delivery, home visiting services).

Source: Adapted from Moreland City Council, *Good access is good business. A guide for small business and retailers.* Accessed on 10 July 2014 from http://www.moreland.vic.gov.au; Marrickville Council (NSW) and the Human Rights and Equal Opportunity Commission (2004) *Missed Business? How to attract more customers by providing better access to your business: A guide for small business.* Accessed 25 July 2014 from http://www.marrickville.nsw.gov.au.

Despite these improvements at the local level, Inquiry participants observed that many buildings remain inaccessible for people with disability. MetroAccess South Division commented that inaccessible buildings include:

- older shops and venues in shopping strips

- council buildings such as Neighbourhood Houses and Community Centres

- private buildings where insufficient funding options are available for owners and landlords who want to improve access

- heritage buildings, where heritage considerations often override access concerns when design and upgrades are being developed

- infrastructure in public spaces, such as playgrounds, beaches and sporting facilities.[60]

The World Health Organization (WHO) supports a staged approach to achieving accessibility, stating that 'often, accessibility is more easily achieved incrementally.'[61] The Committee acknowledges that while there remains much to do, it is critical to prioritise adjustments to the built environment that will make the biggest difference to people with disability within a reasonable timeframe. In order to achieve this, it is important for people with disability 'from various walks of life' to be involved in developing a prioritised program.[62] The Manager of Social Policy at the MAV, Ms Clare Hargreaves explained that:

> It really is unrealistic to say that every heritage building is going to be able to make the adjustments required, or it is going to take so long that it is not going to be in the lifetime of the people who need assistance. Somehow the prioritisation in the community has to occur as sort of a joint effort about what is most important to people and, as you say, being done in a respectful way that is going to be dignified for them.[63]

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[60] *Submission S131*, MetroAccess South Division: Bayside Peninsula & Southern Melbourne, p.8.
[61] World Health Organization (2011) *World report on disability*, p.169.
[62] *Transcript of Evidence*, Municipal Association of Victoria, Melbourne, 17 March 2014, p.5.
[63] *Transcript of Evidence,* Municipal Association of Victoria, p.5.

Many Inquiry participants spoke of the positive effect of the Changing Places initiative, which provides toileting facilities for people with disability who need additional assistance and equipment not available in disabled toilets.[64] Originating in the United Kingdom (UK), this initiative recognises that standard accessible toilets do not always meet the needs of people with disability.

In Victoria, Maroondah City Council has trialled the Changing Places initiative. The toilet facilities provide 'a height-adjustable adult sized changing bench, a tracking hoist system, enough space and a safe and clean environment'.[65] VEOHRC noted that there is a role for the Victorian Government to expand the availability of such facilities to other councils:

> There is a clear role for the Victorian Government to facilitate the rollout of these facilities in key public places, including major transport hubs and public places, in public buildings, and to ensure the use of mobile Changing Places as a contracted deliverable for major events, including key sporting events, arts festivals and other public events.[66]

The Changing Places Information Kit provides examples that demonstrate the importance of appropriate toileting facilities and its effect on social inclusion. One of these examples is outlined in Box 7.3.

Box 7.3: Changing Places

It's fantastic when I can go out with my friends but doing that is complicated because we all have different needs. Without Changing Places my day becomes restricted to being close to home so I can have my personal care needs met. This really limits where I can go.

I am also a passionate self-advocate and I want you to know how important Changing Places are to me, not only for myself and my friends but also for tens of thousands of other children and adults with disability. Some people are 'changed' on the floor of a disabled toilet, I don't want this so I have to go home to have my personal care needs met. What a waste of my time when I could have the same convenience and spontaneity as you if there were Changing Places. We need Changing Places with an adjustable height change table and hoist. You and I deserve the same right to dignity, hygiene and safety. This would happen if there were Changing Places available.

Living at home with mum, dad, my brothers and sister is great but I really like to get out and enjoy life. I do pretty much the same as my brothers and sister, but I have better taste in music. One of the major differences is I know they don't plan their days out around the only toilet they can use in the city.

Having Changing Places all over Australia would be great. They would give me the freedom to live a life with more choices about what I can do, where I can go and when I can do it – we really do need Changing Places to go places.

Source: Association for Children with a Disability (2013) *Changing Places transforming lives information kit.* Armadale, ACD, p.9.

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[64] See, for example *Submission S027*, Mitchell Shire Council Access and Inclusion Advisory Committee, p.1; *Submission S031*, Spina Bifida Foundation Victoria, pp.4–5; *Submission S045*, National Disability Services Victoria, p.11; *Submission S037*, Whittlesea Disability Network, p.4; *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.14; *Transcript of Evidence*, Association for Children with a Disability, Melbourne, 17 March 2014, p.5.

[65] Association for Children with a Disability (2013) *Changing places transforming lives information kit.* Armadale, ACD, p.6.

[66] *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.14.

Finding 7.2

People with disability continue to experience challenges in accessing the built environment, particularly in older buildings where staged change needs to occur.

Recommendation 7.2

That the Victorian Government identify a long-term strategy for improving the accessibility of pre-existing buildings, such as schools, and public spaces in the community.

7.4.   Access to information

In the same way that inaccessibility to the built environment can limit the ability of people with disability to participate in community life, so too does inaccessible information, particularly for people with an intellectual or a sensory disability. In its 2009 consultation report titled *Shut out*, the National People with Disabilities and Carer Council explained that 'information is essential to meaningful participation in a range of activities, as well as essential to understanding and exercising basic rights.'[67]

Enabling access to information and ensuring effective communication of information is critical in increasing social inclusion for people with disability. Ablelink identified that communication of information affects a broad range of areas in the lives of people with disability:

• socialisation

• communication

• environmental information

• managing personal affairs.[68]

The Committee received extensive evidence about the constraints in accessing information experienced by people with sensory impairments, such as those who are blind or vision impaired, and those who are deaf or hard of hearing. For many people with disability it is difficult to access information that meets their specific needs. For example, Blind Citizens Australia stated in its submission:

> There are varying levels of blindness and vision impairment with no such thing as a 'one size' fits all approach in terms of providing accessible information to people who are blind or vision impaired. People who are blind or vision impaired may require a range of different formats to be made available including large print, Braille, audio and electronically to ensure that they do not fall through the gaps as a result of not having access to information that is crucial to their participation in society. Inaccessible information printed on pharmaceutical packaging and phone numbers that appear on-screen during television advertisements, but are not verbalized, are examples of the restrictions that this can impose upon someone who is blind or vision impaired.[69]

Deafblind Victorians also identified that lack of information is very isolating for people with deafblindness.[70] The Committee considers that this applies equally

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[67]   National People with Disabilities and Carer Council (2009) *Shut out: The experience of people with disabilities and their families in Australia*, p.44.

[68]   *Submission S033*, Ablelink, p.4.

[69]   *Submission S082*, Blind Citizens Australia, p.2.

[70]   *Submission S113*, Deafblind Victorians, p.1.

to people living with other forms of disability who do not have information in a format they can access:

> Having access to information in appropriate formats is vital to ensure social inclusion. Without access to information, people who are deafblind are unaware of many of the basics in life: what's going on in the news, what services we might be entitled to, our rights, access to arts, leisure and cultural events and opportunities that the rest of the community are aware of and can participate in.[71]

The Committee heard that many people with disability have difficulty with access to information, leading to barriers in accessing goods and services, navigating the environment and poor health and social inclusion outcomes.[72] MetroAccess South Division, for example, told the Inquiry:

> People with disability have difficulty navigating 'the system' including information about services and supports available. Who provides what and how to apply can be very time consuming and difficult, especially for those who can't advocate for themselves. Many people with disability find it difficult to access the right support. Often the most disadvantaged people are the ones who miss out the most, especially if there is low literacy and/or disability across generations. Transitioning between services (Children to Adult) from age 16 into adulthood is a particularly challenging time. Information is not always available in accessible formats such as Easy English, audio and word formats, especially for local services and events.[73]

The format of published information is a key issue for people with a vision impairment. In order to maximise opportunities in education, employment and recreation, people with a vision impairment require published information in Braille, audio and plain text formats. However, Vision Australia told the Inquiry that 'less than 5 per cent of all published material is released in an accessible format in Australia due to copyright restrictions.'[74]

The *State disability plan 2013–16* outlines a range of actions to improve access to government information, including information relevant to transport, buildings and places. Table 7.4 outlines the strategy and its intended actions.

Table 7.4: *State disability plan 2013–16*—strategies and implementation actions to make government information more accessible, 2013–14

Strategies and implementation actions
Strategy: Provide accessible information about government services
• Ensure all transport websites are Level AA compliant with the Web Content Accessibility Guidelines
• Provide accessible justice and consumer related information for people with disability
• Provide policies, standards and guidelines to assist all government departments and agencies to make their websites more accessible to people with disability
• Undertake an accessibility audit of the Department of Sustainability and Environment website with Vision Australia
• Review the accessibility statement on the Department of Sustainability and Environment website

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[71] *Submission S113*, Deafblind Victorians, p.1.
[72] *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.14.
[73] *Submission S131*, MetroAccess South Division: Bayside Peninsula & Southern Melbourne, p.5.
[74] *Submission S112*, Vision Australia, p.5.

Strategies and implementation actions

- Review the current government communication requirements and develop a tool kit for Victorian Government Departments to assist in making their communication more accessible to people with disability

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Source: Department of Human Services (2012) *Victorian state disability plan 2013–2016. Implementation plan 2013 and 2014.* Melbourne, DHS.

Finding 7.3

People with disability continue to experience challenges accessing information relevant to their daily lives and engagement with the community.

7.5.   Technology and accessibility

Many Inquiry participants emphasised that changing technology is an important enabler for people with disability. They spoke about the benefits of increasing access by people with disability to emerging technologies. In her submission, Ms Raelene West stated that:

> Innovation and emerging technologies can provide increased physical independence and functional capacity that can improve quality of life and reduce formal support requirements needed with some daily tasks of people with impairment. They can provide pathways to improved social inclusion, increase physical mobility and provide critical advances in means and forms of communication.[75]

The Committee heard that technology has become more accessible and mobile, which enables people to carry it everywhere they go. Inquiry participants explained that advances in technology have given many people with disability greater autonomy, communication options and opportunities to engage with others. Ablelink explained the way in which mobile devices have become an 'essential item' for people with disability:

> … they provide the opportunity to travel safely, to have face to face communication when no interpreter is available and provide an unlimited amount of real time information about what is happening around them, including the weather, storm, heat or fire alerts, public transport time tables and notifications, news events, including disasters. With the range of devices now available it is possible to customise the right device to suit the disability and many are choosing tablets and smart phones as their preferred device. It is also worth noting that Apps are the preferred medium to access social media rather than the internet as they tend to be more accessible. The millions of users of apps have been very innovative in driving design that is 'accessible for all'.[76]

Section 5.2.3 of Chapter 5 discusses the facilitative communication aids in greater depth and how technology has improved the experience of many people with disability.

For people in rural and regional areas, technology provides a way to overcome some of the limitations of distance. Mr Ian Parsons of the Centre for Rural and Regional Law and Justice made this point in his presentation to the Inquiry He also cautioned against over-reliance on technology, which needs to complement rather than replace face-to-face services:

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[75]   *Submission S010*, Ms Raelene West, p.11.
[76]   *Submission S033*, Ablelink, p.3.

> In terms of technology, as in so many areas, it certainly makes communication much more accessible for someone when the person they need to communicate with is not physically nearby. The opportunities made available through things such as videoconferencing, different web-based community legal education services and those sorts of things are fantastic for people who might not otherwise be able to access those services.
>
> The risks involved, though, include an assumption or a tendency to think that it means the need for face-to-face and on-the-ground services is therefore less. It usually is not less, particularly for people with disability. I am thinking mainly of people with a mental impairment — someone with either intellectual disability or perhaps an acquired brain injury — who may find some of that technology just too difficult to navigate. It is not something that arises just in relation to law and justice services; anything that has a technology-based solution to replace a human-based solution is likely to disadvantage some people with disability.[77]

The Committee also heard, however, that accessibility of internet and mobile technologies is variable. Able Australia, for example, noted that while the availability of mobile and tablet technology has afforded a degree of independence for Deafblind Victorians, this is only half the battle. It told the Inquiry that 'much of the online content remains inaccessible to Deafblind users due to design flaws.'[78] Although government information is subject to the World Wide Web Consortium's Web Content Accessibility Guidelines 2.0, there does not appear to be any requirements for businesses to make internet resources accessible to people with disability.[79]

The current *Victorian Government ICT strategy 2014–15* released in February 2013 states that one of the actions to be completed by March 2015 is to 'review existing accessibility guidance for outward-facing and internal-to-government systems to ensure ICT [information and communication technology] systems take into account contemporary accessibility practice and legal obligations.'[80]

The Committee also identified that costs of technology and navigating connectivity and access can be prohibitive for people with disability. Ablelink explained the barriers for people with deafblindness:

> Ongoing connectivity costs can be prohibitive for many and there is a low level of understanding amongst the entire community around the contracts and costs incurred. Bill shock is common with a general lack of understanding around contracts. Information and support for service plans is largely conducted 'over the phone' or in busy disability unfriendly retail shops and people with disability are at great disadvantage in accessing these services. Information on the internet is their only access and this is complex, confusing and difficult to understand. There are 'affordable' plans for people on low incomes but these ONLY include voice calls. Many people with deafblindness rely on video, not only for their communication but also as an information source, via YouTube. One proposed solution could include subsidised generous data plans for the deaf and Deafblind communities, in line with the subsidies voice plans offered to the wider community.[81]

Some Inquiry participants cautioned about over-reliance on information technology. The Victorian Council of Social Service (VCOSS), for example

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77 *Transcript of Evidence*, Centre for Rural Regional Law and Justice, Deakin University, Melbourne, 6 March 2014, p.6.

78 *Submission S054*, Able Australia, p.8.

79 The Victorian Government states that its website conforms to this standard and to the Victorian Government's Accessibility Standard. See Victorian Government *Accessibility statement.* Accessed on 7 June 2014 from http://www.vic.gov.au/accessibility.html.

80 Victorian Information and Communication Technology Advisory Committee (2014) *Victorian Government ICT strategy 2014 to 2015*. Melbourne, Victorian Government, p.16.

81 *Submission S033*, Ablelink, p.3.

suggested that such over-reliance can mean that information provided in a clear, simple and appropriate format can be difficult to find:

> The proliferation of internet technologies, including internet-connected phones and tablets, has quickly transformed the way people receive information. Some people with disability have been at the forefront of these changes, with new technologies, including social media, enabling them to make connections, share and receive information that was previously difficult to do—a key benefit from a social inclusion perspective. At the same time, other people with disability have been unable to benefit from these technologies, because they:
>
> - are living on low-incomes and been unable to afford them
>
> - have limited knowledge and skills in the technologies and face difficulty in acquiring them
>
> - cannot use the technologies because they require them to be adapted
>
> - have not been able to receive information in the correct format for use.[82]

Similarly, Whitehorse City Council told the Inquiry that 'reliance on the internet as the sole communication portal can be limiting as not all people with disability and/or their families have the skills and resources to access the internet'. It further explained that:

> Information needs to be available in accessible formats and with both hard copy and electronic version. Information needs to be presented in ways that are relevant and respectful to community groups.[83]

A number of Inquiry participants also cautioned that emerging technologies can in some cases have a detrimental effect on access for people with disability. For example, Blind Citizens Australia explained how the increasing use of touch screen technology by businesses poses challenges for people with vision impairment:

> The increasing prevalence in the use of touch screen systems both in public facilities and on home appliances also presents a significant barrier to the full social inclusion of people who are blind or vision impaired. The use of such technologies is due to increase in the next 20 years, making this barrier far more problematic. This is demonstrated in the growing increase in the use of self-service systems in airports, supermarkets and other public facilities, along with the subsequent decline in the availability of customer service staff. Unless equipped with speech output to allow a person who is blind or vision impaired to be able to navigate the screen independently, these systems are completely inaccessible and serve to disempower many people by forcing them to rely on sighted assistance.[84]

The Committee determined that improving access to and familiarity with emerging technologies for people with disability is critical. The Committee considers it vital as part of this process to consult with disability groups and industry professionals to ensure that content is fully accessible. In addition, the Victorian Government could play a greater role in raising awareness in the community more broadly about internet accessibility guidelines.

Finding 7.4

Advances in technology have contributed to increased physical independence, functional capacity and social interactions of people with disability, but technology can also create unintended barriers for the participation of people with disability.

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[82]   *Submission S126*, Victorian Council of Social Service (VCOSS), p.14.
[83]   *Submission S097*, Whitehorse City Council, p.10.
[84]   *Submission S082*, Blind Citizens Australia, p.3.

Recommendation 7.3   7-29

That the Victorian Government explore the evolving role of technology in the lives of people with disability and how it enables their social inclusion to identify ways to intersect technology with current support and accessibility initiatives.

Chapter 8

Changing attitudes and behaviour towards people with disability

AT A GLANCE

Background

Although society's understanding of disability and how it treats people with disability has improved over time, pervasive attitudes about disability continue to undermine true social inclusion.

Key findings

- People with disability identify the attitudes of others as one of the most significant barriers to social inclusion. **(Finding 8.1)**

- Attitudes towards people with disability include fear, ignorance and being regarded as inferior or as objects of pity. These attitudes are often expressed as low expectations, discrimination, bullying, hostility and avoidance. **(Finding 8.2)**

- Evidence has shown initiatives that go beyond changing attitudes to target the way people treat and interact with people with disability can be effective in increasing social inclusion for people with disability. **(Finding 8.3)**

- Changing society's attitudes towards people with disability can be achieved at a reasonably low cost using a multi-pronged approach that includes:

  - a focus on positive personal experiences and interactions with people with disability

  - broad-based approaches and approaches that target specific audiences

  - encouraging initiatives that aim to change the way people treat and interact with people with disability. **(Finding 8.4)**

Recommendations

That the Victorian Government:

- Initiate a review through the Council of Australian Governments in order to streamline and clarify the interaction of state and Commonwealth avenues for lodging complaints about discriminatory treatment of people with disability. **(Recommendation 8.1)**

- Incorporate a strategy into its future State Disability Plan in 2016 to change attitudes towards people with disability and how they are treated in the general community that aims to:

  - encourage interactions and positive personal experiences between people with disability and members in the community

  - change broad community attitudes, prevent children and young people from developing negative attitudes, and target specific audiences to change negative attitudes

  - promote initiatives that aim to change the way people treat and interact with people with disability. **(Recommendation 8.2)**

- Establish an inclusion innovation hub to promote the development of innovative approaches to changing attitudes towards and interaction with people with disability. **(Recommendation 8.3)**

Despite significant changes to disability approaches over the past few decades, the outcomes for people with disability highlighted throughout this report indicate that there remains a long way to go to make social inclusion an ordinary part of life. In order to achieve this, there needs to be a significant shift in attitudes towards disability and how these attitudes manifest in the way people interact with and treat people with disability.

The Inquiry heard that attitudes towards people with disability can affect social inclusion in all areas of their life, including their social connections, their access to places and their involvement in employment, education and other activities.

In the words of Robyn, a mother of a person with disability who was consulted by the Summer Foundation for this Inquiry:

> The broader community still keeps people with disability at a distance unless it is somebody they're related to, or know well. Society considers people with disability to be lesser beings. We need to change society's perception of PWD [people with disability]. We need to value people as human beings. It is easier said than done. People need to change the way they think feel and react to people with disability.[1]

As explained in Chapter 2, the National Disability Insurance Scheme (NDIS) will have a limited role in improving awareness and attitudes towards people with disability. In its 2011 report on disability care and support, the Productivity Commission identified that where appropriate the NDIS (through 'Tier 1')[2] would have a general community awareness raising role but would not 'duplicate the campaigns provided elsewhere.'[3] It envisaged the National Disability Insurance Agency (NDIA) would provide information to the government and not-for-profit organisations running such campaigns, and would only directly carry out such programs 'in cases where it had a clear advantage in doing so.'[4]

In addition, the aim of addressing attitudinal barriers is embedded in the *Disability Act 2006* (Vic) through the disability action plans that public sector bodies in Victoria are required to develop. These plans are discussed in Chapter 2.

The Committee considers that the Victorian Government will continue to have an important role in improving attitudes towards disability and how people interact and treat people with disability. Evidence provided to the Inquiry indicates that changes in attitudes and treatment of people with disability can be achieved in a cost effective way.

8.1. Attitudes and interactions—disability and social inclusion

As discussed in Chapter 2, anti-discrimination legislation, awareness of human rights, deinstitutionalisation, and an increasing focus on individualised approaches to disability services, have all contributed to a greater understanding and acceptance of the rights of people with disability to exercise choice and to have control of their life.

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[1]   *Submission S121*, Summer Foundation Ltd, p.6.
[2]   Refer to Chapter 2 for an outline of the NDIS, its tiered approach and the specific nature of the three identified tiers.
[3]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*. Canberra, Commonwealth of Australia, p.161.
[4]   Productivity Commission (2011) *Disability care and support. Volume 1, report no. 54*, p.161.

However, Inquiry participants suggested that 'negative, misguided or patronising' attitudes towards people with disability continue to result in segregation and undermine meaningful social inclusion in all areas of life, including social connections, accessibility, education, employment and other activities that people with disability want to engage in.[5]

> **Attitudes**—*an expression of favour or disfavour towards a person, place, thing, or event.*
>
> *Attitudes and corresponding behaviour are related in complex ways.*

The Committee's review of the Inquiry evidence reflects a range of underlying attitudes that relate to social inclusion of people with disability. Some of the evidence indicates that there has been a shift in attitudes in the broader community about people with disability, as exemplified in the broad community support for the NDIS. However, the evidence also points to underlying attitudes that are less positive or uninformed, including that:

- disability is a problem that needs to be fixed

- disability is a burden on our society

- disability professionals are the best people to engage with people with disability

- organisations, workplaces and places of education are not equipped to include people with disability as a normal part of their activity

- people with disability need to be protected from mainstream education, workplaces and the community

- people with disability are not entitled to express their sexuality or take on social roles such as parenting

- people with disability are extraordinary for navigating basic activities in the community that the broader population takes for granted.[6]

Research evidence reveals a continuing negative impact of attitudes on the social inclusion of people with disability. For example, the *1 in 4 poll on social inclusion* conducted by Scope and Deakin University in 2011 showed that almost 40 per cent of participants considered attitudes to be a barrier to social inclusion.[7] Scope (Vic) told the Inquiry:

> In the survey we asked participants to tell us the barriers to their social inclusion. The biggest single barrier they identified was the attitudes of others.[8]

Similarly, a 2011 literature review conducted by the Social Policy Research Centre for the Australian Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) found that 'negative attitudes, along with

5   *Submission S077*, City of Melbourne Disability Advisory Committee, p.3. See also *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.8; *Submission S078*, Hobsons Bay City Council, p.3.
6   See for example *Transcript of Evidence*, Inclusion Melbourne, Melbourne, 20 March 2014, p.3; *Submission S012*, Office of the Public Advocate, pp.7–8; *Submission S016*, Post Polio Victoria Inc, p.2; *Submission S044*, WISE Employment, p.9; *Submission S070*, UnitingCare Community Options, p.10; *Submission S089*, The Able Movement, p.8; *Transcript of Evidence*, Independence Australia, Melbourne, 17 March 2014, p.6.
7   The *1 in 4 poll on social inclusion* was conducted in 2011 by Scope and Deakin University. The Poll consisted of an online survey of 761 adult participants (over the age of 18) with disability across Australia, including 430 Victorians. *Submission S129*, Scope (Vic) Ltd, pp.5, 14.
8   *Submission S129*, Scope (Vic) Ltd, p.14.

misconceptions and lack of awareness, present barriers to social inclusion in various life domains such as education, employment and community participation.'[9] This is supported by research suggesting that a significant proportion of the community is uncertain about or reluctant to engage with people with disability.[10]

Attitudes influence behaviour in complex ways. A great deal of research has been undertaken on attitudes and how they can be changed, based on the theory that changes in attitudes lead to corresponding changes in behaviour. However, the Committee identified that attitudes and behaviours are interrelated and both need to be influenced in order to improve the way in which people interact with and treat people with disability.

8.1.1.   Prevalence of negative attitudes

The Inquiry found that negative attitudes are experienced in a range of settings. For example, the *1 in 4 poll on attitudes* conducted in 2013 by Scope and Deakin University highlighted how pervasive the experience of negative attitudes is in Victoria. Scope (Vic) told the Inquiry that people with disability experience negative attitudes in many aspects of life, including 'at work, TAFE or university, Centrelink, while receiving disability services, health services and other settings.'[11]

The Committee was cautious about drawing definitive conclusions from the research as there are some limitations in the data. For example education is not included and it is not clear to what extent the figures reflect the frequency with which participants accessed these services. Nevertheless, the results of Scope's research are an indication of how widespread the effect of attitudes is on all types of social inclusion.

The Victorian results provided to the Inquiry are outlined in Table 8.1.

Table 8.1: Experiences of negative attitudes — Scope *1 in 4 poll on attitudes*

Location of negative experience	Percentage of respondents
Accessing Centrelink	87.5
Public transport	64.9
Shops, pubs and restaurants	64.7
Receiving health services	57.1
Workplace	55.7
In the media	55.7
Receiving disability services	47.2

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9   D. Thompson, K. Fisher, C. Purcal et al. (2011) *Community attitudes to people with disability: Scoping project*. Canberra, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, p.vi.

10   ResearchWise (2001) *Understanding community attitudes about disability: Laying foundations for participation through community inclusion*. Melbourne, Department of Human Services, p.5.

11   The *1 in 4 poll on attitudes* was conducted in 2013 by Scope and Deakin University as a follow up to the *1 in 4 poll on social inclusion*. This Poll consisted of an online survey of 530 adult participants (over the age of 18) with disability across Australia, including 207 Victorians. *Submission S129*, Scope (Vic) Ltd, p.16.

Location of negative experience	Percentage of respondents
Dealing with utilities	46.2
Education	43.2

Source: *Submission S129,* Scope (Vic) Ltd, p. 16–17; *Supplementary evidence*, Response to request for information, Scope (Vic) Ltd, 18 July 2014.

In addition to their impact on incidental interactions, attitudes and treatment of people with disability can also affect more meaningful social interactions and connectedness, as discussed in Chapter 4.

In 2009, in its consultation report titled *Shut out*, the National People with Disabilities and Carer Council identified that:

> … very little progress has been made in challenging prevailing myths and stereotypes about people with disability. They still find themselves the subjects of fear and ignorance, regarded as burdens or objects of pity.[12]

These research findings were also reflected strongly in the evidence submitted to the Inquiry. As stated by the Victorian Council of Social Service (VCOSS):

> Too often, people make the presumption, consciously or not, that having a particular impairment somehow renders the entirety of that person less capable in all other dimensions. This results in people being ignored, treated with disrespect or as inferior, and assumed to be incapable of being rational, informed or having a valid opinion.[13]

Past international research has also identified negative community attitudes towards disability, despite focusing mostly on intellectual disability and on attitudes in the United States:

> Studies carried out in the 1990s revealed mostly negative attitudes towards persons with ID [intellectual disability] and behaviours that limited their independence and integration …
>
> More recent studies evaluating attitudes towards persons with ID or other forms of disability describe reactions of suspicion and even hostility to the idea of integrating persons with limitations. The public seems uneasy, uncomfortable and uncertain about how to act in the presence of a person with disability. Individuals also feel fear and pity towards these persons.[14]

While the overwhelming evidence indicates that there is considerable progress to improve community attitudes towards disability, a study conducted in 2013 in Canada identified some promising shifts in public attitudes towards intellectual disability. It found that these shifts are connected to increasing public policy attention on social inclusion. The research study measured attitudes against five factors—(1) discomfort, (2) sensibility or tenderness, (3) knowledge of causes, (4) knowledge of capacity and rights, and (5) interaction. The study found that:

> In contrast to several studies reviewed which indicated negative attitudes towards IDs, the results of the current study showed that public attitudes were generally positive …[15]

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[12] National People with Disabilities and Carer Council (2009) *Shut out: The experience of people with disabilities and their families in Australia*. Canberra, Commonwealth of Australia, p.12.

[13] *Submission S126*, Victorian Council of Social Service (VCOSS), p.19. See also *Submission S062*, Guide Dogs Victoria, p.3.

[14] D. Morin, M. Rivard, A. Crocker et al. (2013) 'Public attitudes towards intellectual disability: A multidimensional perspective'. *Journal of Intellectual Disability Research*, Vol. 57, No. 3 (279–92), p.281.

[15] D. Morin, M. Rivard, A. Crocker et al. (2013) *Public attitudes towards intellectual disability: A multidimensional perspective*, p.288.

The research study also determined that there were particular areas that could be targeted where less positive attitudes were identified:

> Despite the public's relatively positive attitudes, some aspects stand out as potential additional targets for education on the discomfort factor. In line with previous research, feeling embarrassed in the presence of individuals with ID emerges as a significantly more negative attitude.[16]

As discussed in earlier chapters, negative attitudes hamper the participation of people with disability in activities. In order to gain education or employment or to engage in other activities of their choosing, people with disability often have to overcome:

- low expectations

- concerns about their perceived disruptive influence

- greater exposure to bullying

- overly protective attitudes of parents, teachers and services.

These sorts of barriers often lead to an increased likelihood of segregation, reduced prospects in life, and limited opportunities for social inclusion.

Negative attitudes can also prevent people with disability accessing services in the community. The Public Transport Ombudsman, for example, identified that although most of the 'thousands of personal interactions' between transport operator staff and consumers are positive and respectful, when interactions do not go well, this can have 'long term and unforeseen consequences' for people with disability. In evidence to the Inquiry, the Ombudsman explained:

> A throwaway line, a comment uttered in frustration, or a reluctance or refusal to help can lead to people losing confidence when travelling. This can lead to people not using public transport at all; a decision with financial impacts through using private transport and/or one that can disconnect people from the things that are most important in their lives.[17]

Examples of inappropriate staff behaviour reported to the Ombudsman include verbal abuse, inappropriate language, failure to adjust communication approaches to take account of disability and providing discriminatory or misleading advice to consumers. The Ombudsman provided the Inquiry with the following examples:

- A concerned commuter contacted the Ombudsman to complain after witnessing an elderly man being yelled at by a bus driver for not hailing the service with his hand, despite being physically unable to do so as he needed to hold onto his walking frame.

- A man who had reconstructive knee surgery and used a walking stick to aid his mobility complained after a bus driver refused to lower a ramp to assist him to board and then called him names after he took extra time to carefully board the bus via the stairs.

- Consumers using mobility aids were advised they could not be 'loaded' onto a train service due to overcrowding, a term they found offensive.

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[16] D. Morin, M. Rivard, A. Crocker et al. (2013) *Public attitudes towards intellectual disability: A multidimensional perspective*, p.289.

[17] *Submission S023*, Public Transport Ombudsman Victoria. Appendix 1, p.20.

- A bus driver advised a young man with epilepsy that he could not use a bus service in future without being accompanied by a carer as it was not safe.[18]

These examples reflect the evidence about the continuing need to address attitudes of transport service operators. Whittlesea Disability Network, for example, identified that their members report 'frequent instances of people with disability being ignored and not picked up at bus stops.'[19] UnitingCare Community Options also identified transport operators failing to pick up people with disability, citing risk-related rules and regulations.[20]

Customer service is identified as a key priority in the Victorian Department of Transport's *Accessible public transport in Victoria action plan 2013–17*, based on the premise that 'people with disability and those with mobility restrictions can expect to receive an equivalent level and quality of customer service, information and support from public transport service providers.'[21]

The importance of improving customer service attitudes for better access to transport services is discussed further in Section 7.2 of Chapter 7.

Finding 8.1

People with disability identify the attitudes of others as one of the most significant barriers to social inclusion.

8.1.2.   Low expectations

The Inquiry heard that there is a general lack of belief within the community regarding the capacity of people with disability to contribute and participate. As a consequence, many people in Victoria have low expectations of what people with disability can achieve. The Committee found that low expectations can prevent people from being socially included and can discourage them from participating to their full capacity in ways they want to participate.

In 2013, Scope's *1 in 4 poll on attitudes* found that between 60 and 70 per cent of Victorians with disability identified that they commonly experience the following attitudes:

- people making assumptions about their intelligence (69.2 per cent)

- being treated as incapable of making their own decisions (68.8 per cent)

- not being listened to or being ignored (65.4 per cent)

- being treated more as a child than an adult (62.1 per cent)

- people wrongly assuming they are dependent on someone or need to be cared for (59.9 per cent).[22]

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18 *Submission S023*, Public Transport Ombudsman Victoria. Appendix 1, pp.20–21.
19 *Submission S037*, Whittlesea Disability Network, p.2.
20 *Submission S070*, UnitingCare Community Options, p.8.
21 Department of Transport, Planning and Local Infrastructure (2013) *Accessible public transport in Victoria. Action plan 2013–2017*. Melbourne, DTPLI.
22 *Submission S129*, Scope (Vic) Ltd, p.16; *Supplementary evidence*, Response to request for information, Scope (Vic) Ltd, 18 July 2014.

The Summer Foundation also provided examples to the Inquiry of similar low expectations. Its submission included the following quotes from people with disability who were consulted for its submission:

> People are unaware what your abilities are, your mental capacity and your ability to problem solve and who you are. Not just your physical ability. (Vicki)

> People assume that she is in a chair that we can't understand mentally what they are saying to us or they yell and talk slowly to you, like you are stupid. (Anj)[23]

In its submission, Inclusion Melbourne highlighted the existence of a 'culture of low expectations' and its consequences for the social inclusion of people with disability:

> A culture of low expectations commences early in our society—formed by people with disability, their families and the wider community. Segregated education appears to prepare students for segregated working environments. It also sends the message to the wider community and other students that students with disability are different and need to be educated separately—what we see often becoming the 'tyranny of low expectations.'

> Our view is that low expectations lead to segregation, which leads to permanent and intractable poverty.[24]

In addition, as outlined in Chapter 3, the Inquiry found that low expectations in the community regarding the capabilities of people with disability can affect the aspirations of people with disability themselves. For example, in its evidence, the Association for Children with a Disability (ACD) explained:

> Children will mirror the level of expectation that others place on them. Many families who seek assistance from ACD, relay stories of their constant fight to counter these reduced expectations, demonstrated by other children, other parents and professionals—in their early years, during school and into adulthood. A set of values that manifest themselves in attitudes which focus on what a person cannot do rather that want they can, is the greatest challenge to achieving acceptable levels of social inclusion.[25]

8.1.3. Discrimination

The Inquiry heard that many people with disability face discrimination that prevents them from being socially included. Discrimination can take the form of denying a person access to a job, organisation or an activity based on stereotypes about disability (such as a perception that the person may spend too much time attending medical appointments).[26] Discrimination can also be less obvious, such as imposing conditions that by default exclude people with disability because they are unable to meet those conditions (for example, requiring employees to use a standard computer without reasonable modifications may be discriminatory towards an employee with a vision impairment).[27]

Inquiry evidence suggests that despite discrimination legislation operating in Victoria and nationally, people with disability continue to experience discrimination. In this context, Associate Professor Paul Ramcharan from RMIT University told the Inquiry:

> We have strong complaints procedures, we have strong representation through the Disability Services Commissioner, we have VEOHRC [the Victorian Equal Opportunity and Human Rights Commission] and we have the Australian Human Rights Commission;

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[23] *Submission S121*, Summer Foundation Ltd, p.6.
[24] *Submission S056*, Inclusion Melbourne, p.1. See also *Submission S114*, Dental Health Services Victoria, p.5.
[25] *Submission S122*, Association for Children with a Disability, p.3.
[26] *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.4.
[27] *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.4.

however, underneath that, 99.9 per cent of the things that happen to people go on. Many of them are infringements and people do not feel empowered enough to do anything about them.[28]

The Committee heard that people with disability are often discriminated against and excluded from activities, despite their ability or capacity to engage in such activities. VCOSS, for example, told the Inquiry about the way in which discriminatory attitudes affect the treatment of people with disability:

> Too often, people make the presumption, consciously or not, that having a particular impairment somehow renders the entirety of that person less capable in all other dimensions. This results in people being ignored, treated with disrespect or as inferior, and assumed to be incapable of being rational, informed or having a valid opinion.[30]

Discrimination is addressed in both Commonwealth and Victorian legislation which both provide an avenue for people with disability to lodge complaints about discriminatory treatment — to the Australian Human Rights Commission and the Victorian Equal Opportunity and Human Rights Commission (VEOHRC), respectively. Both direct and indirect discrimination are subject to the operation of the Victorian and Commonwealth legislation. There is considerable overlap between Commonwealth and Victorian anti-discrimination law, although it is not possible to make a complaint under both.[31]

> **Discrimination**—*can be direct or indirect.*
>
> *Direct discrimination is treating or proposing to treat a person with an attribute unfavourably because of that attribute.*
>
> *Indirect discrimination can happen when a requirement, condition or practice is imposed or proposed that is not reasonable and has or is likely to have the effect of disadvantaging a person with an attribute.*[29]

Federally, the *Disability Discrimination Act 1992* (Cth) (DD Act) applies to discrimination against people with disability in employment, education, access to premises, provision of goods, services and facilities, accommodation, buying land, activities of clubs and associations and sport and administration of Australian Government laws and programs. The DD Act contains an obligation on the part of employers, contract workers, commission agents and partnerships to make reasonable adjustments for a person's disability. The DD Act also prohibits disability harassment and makes it unlawful to discriminate against someone because they have a carer, use an assistance animal or have a disability aid.[32]

The *Fair Work Act 2009* (Cth) also incorporates measures to address discrimination against people with disability. It makes it unlawful for an employer to take adverse action against a person who is a current, former or prospective employee because of a physical or mental disability.

In the context of education, in 2005 the Australian Government introduced the *Disability standards for education 2005* (Disability Standards). The Disability Standards provide guidelines for schools about their legislative obligations. They

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[28] *Transcript of Evidence*, Associate Professor Paul Ramcharan, Centre for Applied Social Research, RMIT University, Melbourne, 3 March 2014, p.4.

[29] *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, p.4.

[30] *Submission S126*, Victorian Council of Social Service (VCOSS), p.19.

[31] Fitzroy Legal Service *Chapter 17 Discrimination: Introduction. The Law Handbook.* Accessed on 7 July 2014 from http://www.lawhandbook.org.au/handbook/ch17s01s01.php.

[32] *Disability Discrimination Act 1992* (Cth) ss.7, 8.

also outline reasonable steps schools should undertake to ensure that students with disability are provided with opportunities to realise their full potential.[33]

In Victoria, the *Equal Opportunity Act 2010* (Vic) (EO Act) provides protections from discrimination for people with disability in the areas of education, employment, sport or the provision of goods and services and accommodation. The EO Act imposes a duty on employers, educational authorities and goods and services providers to make reasonable adjustments to accommodate people with disability so that a person with disability can safely and productively:

- perform the genuine and reasonable requirements of employment

- participate in an education program

- access a service, or derive a substantial benefit from a service.[34]

In addition, the EO Act requires employers, educators and services to take reasonable proportionate measures to prevent discrimination. For example, in the case of employment, the VEOHRC explained the duty imposed by the EO Act on employers specifically:

> An employer or principal will be liable for unlawful discrimination unless it can show that the organisation has taken reasonable precautions to prevent the employee or agent unlawfully discriminating.[35]

Despite these protections, the Committee heard that people with disability continue to experience discrimination. This is largely due to the need to change community attitudes, as described elsewhere in this chapter. Nevertheless, there are some clear limitations within the legislative protections currently available:

- Both Commonwealth and Victorian legislation allow exemptions to the disability legislation in certain circumstances. For example, in Victoria, discrimination in education and employment on the grounds of impairment is permissible where necessary facilities cannot be reasonably provided. In addition, schools can bypass the Disability Standards if it would cause them 'unjustifiable hardship.'[36]

- Current legislative protections rely on people with disability making a complaint, and many experiences of discrimination are likely to go unreported. For example, the Disability Services Commissioner, Mr Laurie Harkin, told the Inquiry that 'lots of parents of children with disability in the education system are afraid to complain because they have the fear that their children will be excluded from the education system.'[37]

- There are instances of systemic discrimination which are difficult to address through legislation. For example, research conducted by Australian Institute of Family Studies (AIFS) shows that the outcomes for people with intellectual disability in child protection cases can be influenced by discriminatory practices such as inappropriate use of assessment tools, an over reliance on IQ testing (instead of directly assessing parenting

[33] Fitzroy Legal Service *Section 6.3 Education law: Discrimination.* The Law Handbook. Accessed on 7 July 2014 from http://www.lawhandbook.org.au/handbook/ch06s03s05.php.

[34] *Equal Opportunity Act 2010* (Vic) ss.40, 45.

[35] *Submission S115*, Victorian Equal Opportunity and Human Rights Commission, pp.4–5.

[36] Fitzroy Legal Service *Section 6.3 Education law: Discrimination.* From http://www.lawhandbook.org.au.

[37] *Transcript of Evidence*, Disability Services Commissioner, Melbourne, 3 March 2014, p.5.

skills/knowledge) and an emphasis on the parents' intellectual disability as the reason for any difficulty in parenting.[38]

> **Recommendation 8.1**
>
> That the Victorian Government initiate a review through the Council of Australian Governments in order to streamline and clarify the interaction of state and Commonwealth avenues for lodging complaints about discriminatory treatment of people with disability.

8.1.4.   Bullying, hostility and abuse

Scope's *1 in 4 poll on attitudes* identified that levels of hostility towards people with disability are a concern for people with disability in Victoria. Scope defined these types of attitudes or behaviours as 'the tendency to express feelings of antipathy and hatred towards people with disability.'[39] Table 8.2 outlines the types of hostile attitudes or behaviours the research found was experienced by people with disability.

Table 8.2: Experiences of hostile attitudes — Scope *1 in 4 poll on attitudes*

Experience of hostile attitudes	Percentage of respondents (Victoria)
People acting in violent ways towards them	32
People bullying them	47.8
Not being welcomed in public places	51.2
People using unkind words towards them	61.3

Source: *Submission S129,* Scope (Vic) Ltd, p.17.

The Inquiry heard that disability can make people more vulnerable to violence and bullying which in turn has implications for their social inclusion. Women with Disabilities Victoria (WDV), for example, told the Inquiry that evidence shows women with disability are at higher risk of violence. The organisation explained that causes for this increased risk include negative attitudes as well as other factors specific to disability. Experiences of violence often contribute to further social exclusion:

> … perpetrators can choose to exert additional types of control over women with disability, for example, withholding aids, withdrawing supports, restricting movement, or mis-administration of medicines. In comparison to women without disabilities, women with disability experience violence at a higher rate, for longer periods, from more perpetrators, and in more severe episodes.[40]

One of the key considerations for parents in choosing schooling for children with disability is a concern about bullying in mainstream educational settings. However, the Inquiry heard that 'a lot' of bullying also occurs in specialist

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38   Australian Family & Disability Studies Research Collaboration *In practice: Assessment.* Parents with intellectual disability. Accessed on 15 July 2014 from http://sydney.edu.au/health-sciences/afdsrc/parents/in_practice/assess.shtml. Referred to in A. Lamont & L. Bromfield (2009) *Parental intellectual disability and child protection: Key issues.* Melbourne, National Child Protection Clearinghouse, Australian Institute of Family Studies, pp.9–10.
39   *Submission S129*, Scope (Vic) Ltd, pp.16–17.
40   *Submission S051*, Women with Disabilities Victoria, p.12.

settings.[41] Ms Ariane Garner-Williams, a member of the Steering Committee for the Youth Disability Advisory Service, told the Inquiry that although some children may not always be aware they are the target of bullying (for example if they have a hearing or vision impairment), this sort of behaviour has a profound effect on the whole school:

> Actually, there is a lot of ongoing bullying that goes on. A lot of the students do not realise that they are actually being bullied, such as when aids are banging on tables to get the attention of deaf people because they can feel the vibration or yelling and calling them names, because they cannot hear them—and all of that sort of stuff. Just because they cannot hear them, does not mean the people around them cannot hear them, because we are not allowed to say anything about how that student is being treated. That student is not getting the respect they deserve.
>
> I think this is a really big thing to do with social inclusion, because if they are not getting the respect, then they are not going to grow up thinking they are able to do things, and that is one of the greatest injustices of this education system. I think there should be better training for aids with more money put towards it, tighter restrictions on what aids can and cannot do—putting in place rules around that …[42]

8.1.5.   Not knowing how to behave

How people interact with people with disability has been identified as a significant barrier to social inclusion. The Committee heard people in the community often feel awkward or embarrassed about not knowing how to behave and consequently avoid situations when they might have to interact with people with disability.

In its *1 in 4 poll on attitudes*, Scope identified that 71.2 per cent of study participants identified that people did not know how to behave around them. In turn, this awkwardness and discomfort can lead to social exclusion when people in the community choose to avoid such interactions.[43]

In their evidence to the Inquiry, Karingal expressed its view that social exclusion is often caused by lack of skills and confidence in interaction rather than 'bad intent':

> We believe that social exclusion often occurs not because of bad intent but because people do not have the basic tools to make them feel equipped and confident to interact well with people with disability. Fears, myths and stereotypes underpinning attitudes continue to be the biggest barrier overall for social inclusion.[44]

Professor Christine Bigby, the Research Program Leader and Deputy Chair of the Academic Board at La Trobe University, also observed that confusion and uncertainty can lead to avoidance behaviour:

> We identified a number of barriers — why that avoidance was happening and why people were not connecting with people in those public places. We found that people going out in groups with staff creates a sort of barrier around people in the community, which means that community members do not make that individual connection. We found that community members had a high degree of confusion and uncertainty about how they should behave, particularly in relation to people with very high support needs.[45]

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[41]   *Transcript of Evidence*, Youth Affairs Council of Victoria & Youth Disability Advocacy Service, Melbourne, 20 March 2014, p.3.

[42]   *Transcript of Evidence,* Youth Affairs Council of Victoria & Youth Disability Advocacy Service, pp.3–4.

[43]   *Submission S129*, Scope (Vic) Ltd, p.16.

[44]   *Transcript of Evidence*, Karingal, Melbourne, 26 May 2014, p.3.

[45]   *Transcript of Evidence*, Professor Christine Bigby, La Trobe University, Melbourne, 20 March 2014, p.4.

Professor Bigby told the Inquiry that research indicates that people in the community generally have a lack of confidence about how to behave, a fear of non-standard behaviours and a fear of being engaged in a conversation or an interaction that they would not quite know how to handle because it was 'not quite the norm'.[46]

Scope's *1 in 4 poll on attitudes* indicated that these attitudes can be influenced by a lack of knowledge and understanding of disability. For example, 87 per cent of people with disability identified a lack of knowledge and understanding of their disability and 75 per cent identified that others lacked belief in the extent of their disability.[47]

A 2001 ResearchWise study commissioned by the Department of Human Services (DHS) resulted in a report titled *Understanding community attitudes about disability: Laying the foundations for participation through community inclusion.* The study identified three groups of attitudes, each representing about a third of the community:

- active avoiders—those who respond to people with disability with uncertainty and fear

- pro inclusion—those who are knowledgeable and supportive

- passive avoiders—those who fail to engage or to see any major problem.[48]

The ResearchWise Report also stated that there is a 'continuum of willingness' to engage with a person with disability. Figure 8.1 illustrates the stages in this continuum. The study found that 'those very familiar with each form of disability are much more confident in their dealing with people with disability in general, highlighting the importance of increasing opportunities for regular contact.'[49]

Figure 8.1: Continuum of willingness to engage with a person with disability

Continuum of Willingness

1. **Total avoidance**
2. **Discomfort /hesitancy/ vacillation** (minimal 'polite' contact may be attempted)
3. **Limited interaction** (often forced by context – e.g. presence of a person with a disability in the workplace, or professional role e.g. in customer service)
4. **Routine interaction and inclusion**

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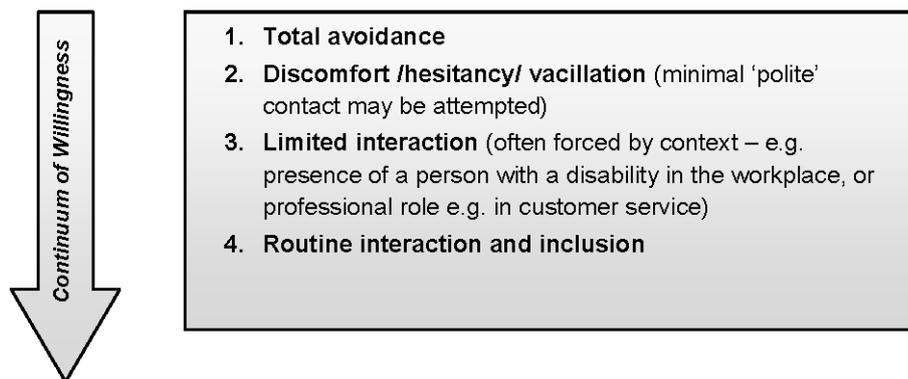
[46]   *Transcript of Evidence,* Professor Christine Bigby, p.4.
[47]   *Submission S129*, Scope (Vic) Ltd, p.16; *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.6.
[48]   ResearchWise (2001) *Understanding community attitudes about disability: Laying foundations for participation through community inclusion*, p.5.
[49]   ResearchWise (2001) *Understanding community attitudes about disability: Laying foundations for participation through community inclusion*, p.8.

Source: Adapted from ResearchWise (2001) *Understanding community attitudes about disability: Laying the foundations for participation through community inclusion*. Melbourne, Department of Human Services, p.8.

Scope's *1 in 4 poll on attitudes* also found that avoidance behaviour is common. The Poll identified that a significant number of people with disability experience avoidance or rejection by others. This is outlined in Table 8.3.

Table 8.3: Experiences of avoidance — *Scope 1 in 4 poll on attitudes*

Experience of avoidance	Percentage of respondents (Victoria)
People not being willing to spend time with them or talk with them (69.2 per cent in other States)	58.1
People rejecting or avoiding them	58.5
People not listening to them or ignoring them	65.4

Source: *Submission S129,* Scope (Vic) Ltd, p.16.

The Committee determined that there is a relationship between 'knowing what to do' and levels of familiarity with people with disability. In her evidence, Ms Garner-Williams highlighted her experience:

> I think that one thing was that more people with disability had been through the certificate course [in screen and media], so the guy who was actually working with me knew more about how to help people with disability and had actually ordered specific equipment to help me. He organised a special camera with a remote, so one of my other classmates and I could operate it ourselves, be part of the class ourselves, and not have so many physical difficulties.[50]

Finding 8.2

Attitudes towards people with disability include fear, ignorance and being regarded as inferior or as objects of pity. These attitudes are often expressed as low expectations, discrimination, bullying, hostility and avoidance.

8.2. Changing attitudes and behaviour

Changing society's attitudes towards disability requires a multi-pronged approach that is evidence-based and results in people with disability feeling that they are included, valued and respected. Research about attitudes shows that governments can achieve such change at a reasonably low cost by focusing on personal experiences, targeting specific audiences and addressing ways in which people treat and interact with people with disability.

The 2011 Social Policy Research Centre Review *Community attitudes to people with disability* identified that interventions to change attitudes towards people with disability need to take place at three levels:

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[50]   *Transcript of Evidence,* Youth Affairs Council of Victoria & Youth Disability Advocacy Service, p.5.

- Personal—initiatives directed towards improving community attitudes at the personal level, through awareness campaigns, training and information for individuals, monitoring media portrayals of people with disability and their portrayal and social inclusion.

- Organisational—initiatives directed at sectors relating to people's life domains, in particular education, employment and health.

- Structural—policies that enact, implement and monitor legislation, in particular disability rights legislation.

The review found that 'familiarity with people with disability—that is, knowing them personally as acquaintances, friends and colleagues—seems the most promising way to increase respect and inclusion, especially if exposure is consistent and recent.'[51]

Research supports the need for measures that also focus on changing the way in which people treat and interact with people with disability. In 2007, a review of Victorian disability awareness-raising programs was undertaken by Justine Kleeman and Associate Professor Erin Wilson for Scope (discussed further in subsequent sections of this chapter). This review found that targeted behaviour change is a key factor in the success of programs that seek to influence attitudes.[52] The review recommended that programs need to focus on behaviours and activities that participants can implement in their everyday activities. It also suggested identifying clear action and behaviour that people can adopt in specific contexts:

> At present, disability awareness programs in Victoria appear to focus on what is described in this research as the first and second levels of awareness: making people with disability visible, rather than invisible; and understanding the issues facing people with disability.
>
> Whilst most programs include a focus on general skills development, few appear to focus on building specific skills in specific contexts, and identifying clear action or behavioural plans.[53]

The Committee identified that some important research lessons from behavioural theory have shown that policy can be designed not only to improve attitudes but also to influence behaviours in our society. These are discussed in Section 8.2.4.

8.2.1. What has been done to change attitudes?

A range of initiatives have been undertaken in Australia by various governments and community organisations to change attitudes towards people with disability. These initiatives are varied in their approach and focus. Some are about changing attitudes, some relate to raising general awareness and understanding of disability and others target how people interact with people with disability. Largely, these varied initiatives are referred to as 'awareness raising' measures. The Committee observed that these initiatives broadly fall within three categories, as outlined in Table 8.4.

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[51] D. Thompson, K. Fisher, C. Purcal et al. (2011) *Community attitudes to people with disability: Scoping project*, p.vi.

[52] J. Kleeman & E. Wilson (2007) *Seeing is believing: Changing attitudes to disability. A review of disability awareness programs in Victoria and ways to progress outcome measurement for attitude change.* Melbourne, Scope (Vic), p.34.

[53] *Submission S129*, Scope (Vic) Ltd, p.21.

Table 8.4: Initiatives to change attitudes

Initiative type	Example	Focus
Broad media-based campaigns	*See the person not the disability* campaign	Breaking down stereotypes about disability
	Disability is everyone's business	Challenging attitudes towards disability care, leading up to the introduction of the NDIS
Specific campaigns	Training delivered to specific organisations (generally in the health and disability sector)	Educating people about the issues and experiences of people with disability and developing the skills to address their needs
Community building	Programs to build capacity in communities to include people with disability have been undertaken by local governments through the MetroAccess and RuralAccess programs.	Creating a more inclusive community through positive behaviour change

Source: Compiled by the Family and Community Development Committee.

Inquiry participants generally spoke positively of broad media-based campaigns about disability. Participants recognised the important role that past campaigns have played in 'raising the consciousness' of the community about people with disability. However, it was acknowledged that such media-based campaigns were few and under-funded.[54] Carers Victoria suggested that some awareness campaigns may not 'reach those who are the hardest to reach, who need the help the most.'[55]

Many Inquiry participants spoke positively about community building initiatives. In particular, many initiatives connected with the Building Inclusive Communities Program (formerly the Community Building Program) were considered to be successful in changing attitudes and behaviours in the community.[56] Chapter 2 discusses this Program in depth.

Scope's 2007 review of disability awareness-raising programs identified 13 formal disability awareness programs in Victoria. The vast majority of these were one-off programs delivered to specific schools or organisations. All these programs aimed to raise awareness and educate people about the needs, issues and experiences of people with disability. Half of the programs were focused on developing skills to address the needs and issues of people with disability. A small number of programs also identified specific behaviour change goals, such as encouraging health staff and students to use more appropriate language with

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[54] For example, see *Submission S012*, Office of the Public Advocate, p.24; *Submission S041*, Darebin Disability Advisory Committee, p.6.

[55] *Transcript of Evidence*, Carers Victoria, Melbourne, 3 March 2014, p.9.

[56] For example, see *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.8.

patients with disability and using experience-based learning to promote behaviour change.[57]

The Committee found that, in combination, these programs and initiatives have contributed to significant progress in changing attitudes towards people with disability. However, the Inquiry identified that to achieve further changes in attitudes better targeting of initiatives is required.

8.2.2.   Positive personal interactions

A number of Inquiry participants explained that positive personal interactions with people with disability are important for changing attitudes. For example, the Centre for Developmental Disability Health Victoria (CDDHV) told the Inquiry:

> Positive personal experiences are the most powerful influencer of individual attitudes. Such experiences reduce barriers created by ignorance, prejudice and misunderstanding and build opportunities for authentic social inclusion.[58]

The CDDHV provided a positive example of this approach as part of education programs aimed at health professionals in which a focus on the inclusion of people with disability in teaching was a key component.[59]

Scope's 2007 review of disability awareness-raising programs identified that direct contact between program participants and people with disability was a key ingredient for attitude change.[60] Furthermore, the quality and duration of the contact was influential. The review found that direct contact should include the following features:

- longevity of contact (i.e. a sustained period of time)

- the ability/time to get to know each other

- equal status of people with and without disability

- a focus on the person with disability as connected with and representative of other people with disability

- mutual work on shared goals

- positive shared experiences.[61]

The review also emphasised the importance of programs being designed for ongoing rather than one-off interactions, and going beyond the traditional persuasive format to be 'personally involving and experiential.'[62] It recommended that programs focus on behaviours and activities that participants have control over and can implement in their everyday activities, such as working collaboratively with people with disability in a service, work, or project setting.

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[57]   J. Kleeman & E. Wilson (2007) *Seeing is believing: Changing attitudes to disability. A review of disability awareness programs in Victoria and ways to progress outcome measurement for attitude change*, p.28.

[58]   *Submission S108*, Centre for Developmental Disability Health Victoria, p.2.

[59]   *Submission S108*, Centre for Developmental Disability Health Victoria, p.4.

[60]   J. Kleeman & E. Wilson (2007) *Seeing is believing: Changing attitudes to disability. A review of disability awareness programs in Victoria and ways to progress outcome measurement for attitude change*, pp.28–29.

[61]   J. Kleeman & E. Wilson (2007) *Seeing is believing: Changing attitudes to disability. A review of disability awareness programs in Victoria and ways to progress outcome measurement for attitude change*, p.32.

[62]   *Submission S129*, Scope (Vic) Ltd, p.21.

An important aspect of positive personal interaction is the need to provide environments where such interaction is possible. For example, Professor Bigby explained that:

> Generally people go to places where there are poor conditions for making individual contact and where there is no chance to have that individual social interaction. You get to be known when you go to clubs and societies, when you are in places where there is a chance to interact. That obviously does not happen in general shopping centres and in cafes, which is where most people seem to go.[63]

8.2.3.   Encouraging problem solving

People with disability often need to adjust how they do things in order to pursue activities of their choosing and be socially included. Because of the diversity of people with disability and the range of situations they find themselves in, problem solving can be a key aspect of social inclusion.

In her evidence, Ms Garner-Williams highlighted that people with disability are very good at making adjustments in order to achieve their aims. However, they may need support to achieve these adjustments. She identified that the reaction to this need is varied. Commenting on an experience when she requested flexibility from a member from the institute where she was studying for a diploma, Ms Garner-Williams told the Inquiry:

> … every time I met with him he seemed a bit stunned by what I was asking. He was like, 'I can look into it, but I do not know how we are going to do that.' It was as if problem solving was not his thing.[64]

Ms Garner-Williams went on to explain the importance of training people about how to make adjustments:

> … most of it, I figured out through this process, is training — training people that 'these might be the adjustments you have to make'. You have to bring in room for adjustment. You have to be able to relate to the person themselves. It is not just how you teach a person with disability, it is about how you relate to them.[65]

8.2.4.   Addressing behaviour change

Behavioural theory has been increasingly used to inform policy decisions that seek to influence community behaviour. Changing attitudes alone may not contribute to changes in the way people are treated or how people behave and interact with people with disability. A number of the specific awareness raising programs referred to in Section 8.2.1 recognise the need to address behaviour change. For example, Scope's Young Ambassador Program, analysed in its 2007 review of disability awareness-raising programs, intentionally focused on enacting behaviours through various learning activities that require specific student actions in real life contexts (for example, activities focusing on students working collaboratively with people with disability).[66] The program is outlined in Box 8.1 in Section 8.3.1.

Although legislative and regulatory approaches have an important role to play in changing the way the community treats people with disability (as discussed in

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[63]   *Transcript of Evidence,* Professor Christine Bigby, p.4.
[64]   *Transcript of Evidence,* Youth Affairs Council of Victoria & Youth Disability Advocacy Service, p.5.
[65]   *Transcript of Evidence,* Youth Affairs Council of Victoria & Youth Disability Advocacy Service, p.4.
[66]   J. Kleeman & E. Wilson (2007) *Seeing is believing: Changing attitudes to disability. A review of disability awareness programs in Victoria and ways to progress outcome measurement for attitude change,* p.28.

Section 8.1.3), frameworks such as the MINDSPACE model outlined below suggest that less coercive policy approaches can be powerful in challenging entrenched behaviours.

The MINDSPACE framework is a useful public policy tool that has been developed by the Institute for Government for the United Kingdom (UK) Cabinet Office. The framework identifies behavioural influences on the success of policies that seek to change public attitudes. It is based on a theory that:

> … approaches based on 'changing contexts'—the environment within which we make decisions and respond to cues—have the potential to bring about significant changes in behaviour at relatively low cost. Shaping policy more closely around our inbuilt responses to the world offers a potentially powerful way to improve individual wellbeing and social welfare.[67]

MINDSPACE is an acronym for nine drivers of behaviour that can be considered by policy makers in order to change behaviour. Table 8.5 outlines these drivers and their possible application to designing policy to improve social inclusion of people with disability in Victoria.

Table 8.5: MINDSPACE checklist for drivers of behaviour

Driver	Description	Considerations for policy
Messenger	We are heavily influenced by who communicates information.	Attributes of the person delivering a message are important, including: • their perceived authority (for example, a person with disability delivering the message) • their similarity to the recipient (for example, whether the message is delivered by a peer, a person of similar age or similar economic, social or cultural background).
Incentives	Our responses to incentives are shaped by predictable mental shortcuts such as strongly avoiding losses.	The perception of gains and losses is not equally weighted and value is not necessarily aligned with the magnitude of the gains and losses. For example: • the possibility of losses is more influential than the possibility of gains • people give greater weight to small probabilities (for example, the perceived chance of being audited may be higher than it actually is). There may be positive and negative spill over effects of incentives that need to be clearly understood.
Norms	We are strongly influenced by what others do.	Social norms can be used to target messages, particularly messages that convey norms adopted by the target audience. The use of social networks and the need to reinforce norms should be considered.

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[67] P. Dolan, M. Hallsworth, D. Halpern et al. (2010) *MINDSPACE: Influencing behaviour through public policy.* London, Institute for Government, p.8. Accessed on 19 June 2014 from http://www.instituteforgovernment.org.uk/publications/mindspace.

Driver	Description	Considerations for policy
Defaults	We 'go with the flow' of pre-set options.	Often people go along with behaviours that are the default.
Salience	Our attention is drawn to what is novel and seems relevant to us.	People are more likely to respond to messages that are novel, accessible and simple.
Priming	Our acts are often influenced by sub-conscious cues.	Certain cues can help facilitate acceptance of a message such as words, images and environments.
Affect	Our emotional associations can powerfully shape our actions.	Messages provoking an emotional response can be powerful in changing behaviour.
Commitments	We seek to be consistent with our public promises, and reciprocate acts.	People who publicly pledge to change behaviour are more likely to do so.
Ego	We act in ways that make us feel better about ourselves.	People's desire for a positive self-image can influence behavioural decisions.

Source: Dolan, P., Hallsworth, M., Halpern, D., King, D., & Vlaev, I. (2010) *MINDSPACE: Influencing behaviour through public policy.* London, Institute for Government, Accessed on 19 June 2014 from http://www.instituteforgovernment.org.uk/sites/default/files/publications/MINDSPACE.pdf.

A current example of a disability awareness campaign that illustrates a number of the above elements is the 'End the Awkward' Campaign launched in May 2014 by Scope in the UK. This campaign was prompted by research showing that two thirds of the British public feel uncomfortable talking to disabled people. The research revealed that younger people are more likely to have negative attitudes and display avoidance behaviour because they are unsure of how to communicate with people with disability.[68]

The campaign involves advertisements featuring three humorous socially 'awkward' situations and their resolution, such as greeting a person in a wheelchair, or flirting with a person with a hearing impairment in a bar. These premiered once on national television and currently feature in Scope UK's online

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[68] H. Aiden & A. McCarthy (2014) *Current attitudes towards disabled people.* London, Scope (UK), p.3. Accessed on 20 June 2014 from http://www.scope.org.uk/Scope/media/Images/Publication%20Directory/Current-attitudes-towards-disabled-people.pdf?ext=.pdf.

campaign.[69] The following elements of the MINDSPACE drivers can be observed:

- Messenger—the campaign was targeted at changing the behaviour of younger people – with this in mind, the advertisements featured a young comedian with disability as the central narrator delivering the message.

- Incentives—the incentive presented for changing behaviour is to avoid the risk of an 'awkward' situation, which is in line with the idea that the risk of a negative outcome is more influential than the possibility of a perceived gain.

- Norms—the resolution of the scenarios is presented as natural and normal, reinforcing the desired behavioural norm.

- Salience—the campaign message is simple and the comic delivery is novel.

- Ego—the campaign appeals to people's desire for a positive self-image.

These and other behavioural considerations could be taken into account in designing disability awareness programs and campaigns in Victoria.

Finding 8.3

Evidence has shown initiatives that go beyond changing attitudes to target the way people treat and interact with people with disability can be effective in increasing social inclusion for people with disability.

Recommendation 8.2

That the Victorian Government incorporate a strategy into its future State Disability Plan in 2016 to change attitudes towards people with disability and how they are treated in the general community that aims to:

- encourage interactions and positive personal experiences between people with disability and members in the community

- change broad community attitudes, prevent children and young people from developing negative attitudes, and target specific audiences to change negative attitudes

- promote initiatives that aim to change the way people treat and interact with people with disability.

8.3. Specific and generalised approaches

The Committee acknowledges that there is a need for targeted initiatives and generalised campaigns that aim to change attitudes to people with disability towards and how they are treated in the community. Targeted initiatives are those that are directed at specific audiences with the intention of influencing their attitudes and the way they treat people with disability. Generalised campaigns include broader media campaigns and community leadership programs.

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[69] Scope (UK) *Why is Scope running this campaign?* End the awkward. Accessed on 9 September 2014 from http://www.scope.org.uk/About-Us/awkward/Why-is-Scope-running-this-campaign.

8.3.1. Targeting specific audiences

Targeting initiatives to improve attitudes and treatment of people with disability is important for two reasons:

- to change existing negative attitudes and treatment of people with disability

- to prevent people from forming negative attitudes about people with disability in the first place (this prevention work is often carried out in the context of childhood and education).

Changing people's attitudes and interactions

Many Inquiry participants explained that there is value in targeting attitudes in specific groups such as health and education professionals, service providers, employers and children. Scope's research also identified that there is justification for targeting the attitudes of people over 25 years, with lower levels of education and those with no experience of disability:

> Additionally, there is some evidence to suggest that some groups in community may require a heightened level of focus than others. For example, people over 25 years, people with lower levels of education, and people without previous experience of disability, are all likely to hold more negative views of people with disability (according to research published in the literature).[70]

Participants encouraged the Committee to consider approaches that go 'beyond the traditional focus of disability awareness programs.'[71] A number suggested that different groups in the community may require different approaches. As Scope explained to the Inquiry:

> Attitude and behaviour change is influenced by aspects of the context and of the broader attitudes endorsed within this context. This requires targeted work within the specific contexts in which disability awareness programs are delivered, i.e. schools, universities, workplaces, local government and community groups.[72]

The MINDSPACE framework outlined in Section 8.2.4 encourages an approach to designing programs that considers the attributes of the messenger, the salience of the message and other audience-specific factors.

Scope's 2007 review of Victorian disability awareness-raising programs recommended that specific measures are needed to develop programs that create attitudinal and behavioural change. It encouraged:

> Work to develop the policy and regulatory environment of these contexts to ensure these support the desired attitudes focused on by awareness programs. Ensuring that policies and structural practices 'line up' or are consistent with desired attitudes and behaviours is likely to increase these positive behaviours;
>
> Work to address the barriers to action within specific contexts, identified by participants, to enable participants to enact behaviours (that is, have the skills, opportunities and resources) and be rewarded (rather than disadvantaged) with positive benefits when they do act in this way.[73]

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[70] *Submission S129*, Scope (Vic) Ltd, p.21.
[71] *Submission S129*, Scope (Vic) Ltd, p.30.
[72] *Submission S129*, Scope (Vic) Ltd, p.30.
[73] J. Kleeman & E. Wilson (2007) *Seeing is believing: Changing attitudes to disability. A review of disability awareness programs in Victoria and ways to progress outcome measurement for attitude change*; *Submission S061*, Associate Professor Erin Wilson, School of Health and Social Development, Deakin University p.34; *Submission S129*, Scope (Vic) Ltd, p.30.

In evidence to the Inquiry, Associate Professor Ramcharan provided an example of a successful targeted campaign. He outlined an approach used in a campaign in the UK that targeted police:

> If you look at the UK, for example, they have self-advocacy groups operating—over 1000 locally—in nine regions. Those nine regions are fed into one central self-advocacy group, with representation all the way through. That group had two people who advised the government every week. One example of the way in which this operated was in relation to the police. You might have heard of the campaign on bullying and victimisation in the UK around people with disability. The local groups engaged the local police constabulary, asking, 'what can you do in my community to change things, the way we are treated?'. The nine groups worked at county level, so that they were engaging the police authorities at county level and providing training. Then at government level there was a link between the Department of Health, which housed disability, and the Home Office, which looked after policing. There was cross-government operation on the basis of a circle of issues feeding back from thousands of people with disability and self-advocacy groups right the way up to government — a dialogue model, one in which you get the production of change in society and where government departments come together.[74]

Scope's 2007 review of Victorian disability awareness-raising programs pointed out that targeted programs for changing attitudes is often part of the work undertaken by community development or inclusion workers. However, it noted that this is 'not well identified by organisations as a task of attitude and social change.'[75] It went on to suggest that:

> This work needs to be understood as complementary even necessary to that of disability awareness programs and could be undertaken as an expansion of these programs or by other staff or organisations, so long as the work is linked and co-ordinated.[76]

Many Inquiry participants supported this observation and spoke positively about the success of the RuralAccess and MetroAccess officers in the Building Inclusive Communities Program in changing attitudes and behaviours in the community. For example, Warrnambool City Council explained:

> A range of community awareness strategies has been developed across the RuralAccess and MetroAccess programs in response to these issues. An evaluation of RuralAccess conducted by the DHS in 2005 indicated a significant shift in regional Victoria in relation to disability awareness and more positive community attitudes as a result of some of the initiatives developed by RuralAccess workers and their councils.[77]

Chapter 2 discusses the Building Inclusive Communities Program in greater detail.

Addressing attitudes and interactions from an early age

Research shows that people form attitudes about people with disability at an early age.[78] Because children and young people are more open to ideas and less resistant to change, raising awareness from an early age may help to establish

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74   *Transcript of Evidence,* Associate Professor Paul Ramcharan, p.9.
75   *Submission S129*, Scope (Vic) Ltd, p.30.
76   *Submission S129*, Scope (Vic) Ltd, p.30.
77   *Submission S067*, Warrnambool City Council (South West RuralAccess Program), p.9.
78   P. Gerber (1977) 'Awareness of handicapping conditions and sociometric status in an integrated preschool setting'. *Mental Retardation*, Vol. 15, (24–25); R. Jones & D. Sisk (1970) 'Early perceptions of physical disability: A developmental study'. *Rehabilitation Literature*, Vol. 31, (34–38). Often those attitudes are negative or rejecting. See M. Horne (1985) *Attitudes towards handicapped students: Professional, peer and parent reactions.* Hillsdale, NJ, Lawrence Erlbaum; R. Jones (1984) *Attitudes and attitude change in special education: Theory and practice.* Reston, VA, The Council for Execptional Children; H. Yuker (1988) *Attitudes towards persons with disabilities.* New York, Springer. Cited in P. Favazza & S. Odom (1997) 'Promoting positive attitudes of kindergarten-age children toward people with disabilities'. *Exceptional Children*, Vol. 63, No. 3 (405–18).

positive attitudes towards disability and to promote positive interactions with people with disability in later life.[79]

Scope provided the Committee with a range of material regarding the effectiveness of awareness programs that target young people in educational settings, including primary schools. These programs allow students to spend time with people with disability and have been well received by children and school communities. They seek to achieve:

- an understanding of the key issues that face people with disability

- the benefits of diversity in our society

- successful communication strategies

- empathy development—seeing the person first.[80]

Box 8.1: Example– addressing attitudes in children and young people

Scope Young Ambassadors (SYA) Program

This program is a youth development and applied learning program available to schools throughout Victoria. The program aims to:

- create tolerance, understanding and acceptance of others in the community

- raise awareness and understanding of the lives of people with disability

- enhance communication and leadership skills

- encourage young people into a life-time commitment to volunteering

- promote a sense of civic responsibility in young people.

The SYA Program includes three interactive sessions at school facilitated by trained Scope presenters. Students also have the opportunity to work alongside people with disability at a Scope Business Enterprise.

An important aspect of this program is the time students students spend with people with disability. This life experience enables young people to have their fears, concerns and prejudices about disability challenged in a direct and positive way.

The program brochure provides the following student Perspectives of the SYA Program:

- In the future I will feel more confident communicating with people with disability. I found out that people with disability are just like you and me

- Overall I had a great time working with people with disability at Scope Business Enterprise, it really opened up my eyes and I learnt a lot. It was a great experience I will never forget.

Source: Scope (Undated) *Scope young ambassadors secondary school program.* Scope (Vic) Ltd. Accessed on 24 July 2014 at
http://www.scopevic.org.au/index.php/cms/frontend/resource/id/1034/name/sya.

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79 G. Ladd, J. Price, & C. Hart (1990) 'Preschoolers' behavioral orientations and patterns of peer contact: Predictive of peer status?'. In Asher, S. & Coie, J. (Eds.), *Peer rejection in childhood.* New York, Cambridge University Press; S. Conant & M. Budoff (1982) 'The development of sighted people's understanding of blindness'. *Visual Impairment and Blindness* Vol. 76, No. 3 (86–90). Cited in P. Favazza & S. Odom (1997) *Promoting positive attitudes of kindergarten-age children toward people with disabilities.*

80 *Supplementary evidence*, Response to request for information, Scope (Vic) Ltd, 18 July 2014.

Programs to encourage positive attitudes in children and young people need to take account of the behavioural elements identified in Section 8.2.4, ensuring that these attitudes are learned through experiences and interactions with people with disability and in a way that is salient to them. As mentioned, Scope's Young Ambassadors Program is an example of experiential learning that addresses children's attitudes and interactions with people with disability. The program is outlined in Box 8.1.

8.3.2. The role of the media

The Committee heard that the media can play an important role in changing attitudes towards people with disability. It also heard that increased inclusion of people with disability in the media is important. For example, in its evidence, Disability Media Australia explained:

> We believe that by seeing and hearing people with disability on television and radio audiences gain a greater appreciation of the world from the point of view of people with disability. We know that fear and ignorance feed discrimination and the ongoing exposure of people with disability in our media is a vital and effective tool in breaking down ignorance.[81]

Melbourne City Mission also told the Inquiry that 'the mass media has the potential to effect significant, positive cultural and attitudinal change.'[82] However, the Committee found that, in order to be effective, the delivery of messages through the media need to be informed by behavioural theory, and be sustained and targeted.

Participants informed the Inquiry of a number of past media awareness campaigns aimed at changing community attitudes towards disability. While some Inquiry participants suggested that such awareness campaigns have been beneficial, many acknowledged that more must be done to change attitudes towards people with disability and their social inclusion. For example, Dental Health Services Victoria told the Inquiry that although media awareness campaigns have been 'instrumental in changing attitudes and expectations' of people with disability, the stigma still exists.[83]

Commenting on the effectiveness of media awareness campaigns, Melbourne City Mission expressed the view that the 'Every Australian Counts' campaign had made a significant contribution to 'positioning disability rights as a mainstream community issue.'[84] However, it suggested there is an ongoing need for a campaign to raise community awareness, given the 'persistent attitudinal barriers to social inclusion.'[85] Melbourne City Mission told the Inquiry that the government, the media and entertainment industries have a critical role to play:

> Whilst government has an important role to play, the media and entertainment industries have a critical role in disseminating information to the mass population and have significant influence on community attitudes.

> Historically, people with disability have been 'marginalised within and through' the media and entertainment industries. Lucy Wood's critique, whilst focused on the UK, is, by and large, reflective of local conditions. For example, Wood writes that:

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[81]   *Submission S025*, Disability Media Australia, p.1.
[82]   *Submission S111*, Melbourne City Mission, p.37.
[83]   *Submission S114*, Dental Health Services Victoria, p.5.
[84]   *Submission S111*, Melbourne City Mission, p.28.
[85]   *Submission S111*, Melbourne City Mission, p.29.

- The media still tends to use the medical model of disability

- The focus is on the impairment more than the individual

- Disabled people are under-represented both in terms of employment in the media and portrayal in the media

- Lots of media forms are inaccessible and broadcasting tends to be at inaccessible times

- Mainstream media do not recognise the disabled art, media culture.[86]

The Able Movement endorsed a sustained multi-faceted campaign that celebrates the diversity and ability of people with disability. It supported the achievements of the annual New South Wales (NSW) 'Don't DIS my ABILITY' campaign, which involves a range of events supported by printed and online material and arts, sport and business ambassadors. However, the organisation recommended that a sustained effort is needed. It recommended that Victoria should initiate a program that operates continuously rather than annually and is measured against clear, inclusion focussed, performance indicators.[87]

Mr Kevin Stone, Executive Officer of the Victorian Advocacy League for Individuals with Disability (VALID) told the Inquiry about his family's experiences of social exclusion and the profound influence of mainstream media on community attitudes. This example is outlined in Box 8.2.

Box 8.2: Example—role of the media

… lo and behold, A Country Practice did a thing on the integration of a kid with Down syndrome at a local school and all the bullying and teasing they were experiencing. In the space of the two weeks that show was on the whole town of Cobram turned completely around. It was unbelievable. The show of support was not patronising but genuine concern. They saw that these kids, including my son—Damien was one of them—were real kids.

My first experience of being excluded and feeling it as a dad was one Sunday morning when my son Damien and I were walking back from the local milk bar. It was a beautiful sunny Sunday morning. Damien was walking about 20 paces ahead of me and carrying the milk and bread. Damien had been living with us for about a month. We came into our street, and out in the street was a father playing kick-to-kick with his two sons. Damien, who is as physically fit as anyone, saw the footy—he was singing at the top of his voice—dropped the bread and milk and took off after the footy. The dad saw him coming, grabbed the footy, kicked it over into his front yard and called his sons inside. That was my first experience. I had never seen Damien cry. It hit me because he just shut up, went home and lay on his bed. It was a feeling of, 'bloody hell! This is what we're doing to kids'.

Up until that point I thought it was okay to be a principal of a segregated school. I thought that was what my job in life was. It was at that point that I realised that if the most we can ever do is make a kid feel like that, then we are all failing. But that changed thanks to A Country Practice. It really did, and that is another pointer to the fact that we do not use the mainstream media. We have been asking for 25 years, 'Where is the public education campaign?'

Source: *Transcript of Evidence,* VALID (Victorian Advocacy League for Individuals with Disability Inc), Melbourne, 3 March 2014*,* p.7.

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[86]   *Submission S111*, Melbourne City Mission, p.29.
[87]   *Submission S089*, The Able Movement, p.16.

8.3.3. Leadership and attitude change

The Committee acknowledges the importance of people with disability undertaking leadership roles and the importance of initiatives such as disability advisory councils and ambassador-style roles. There has been a growing recognition that people with disability must be included in policy making and other leadership roles in order to drive changes in attitude and behaviour. Similarly, prominence of people with disability in leadership roles can have a strong influence on stereotypes and assumptions about the extent to which people with disability are able to be included and valued in our society.

There are a number of ways in which people with disability hold leadership roles in Victoria. Some examples include:

- The Victorian Disability Advisory Council (VDAC) was established under the *Disability Act 2006* (Vic) (Disability Act) to provide advice to the Victorian Government on polices and strategies to increase the participation of people with disability in the Victorian community. It also collaborates with other community and government advisory groups. The majority of the 14 three-year membership positions on VDAC are held by people with disability. Chapter 2 discusses the role of VDAC further.

- The majority of local governments have disability advisory committees or networks which are made of members with disability. These committees are consulted on key council decisions and provide feedback on council operations and policies. People with disability are also included on other council committees. According to the Municipal Association of Victoria (MAV), mentoring opportunities are provided to people with disability by some local governments to develop skills and experience in relation to participating on boards and committees and working for council.[88]

- People with disability can hold leadership roles in disability-focused organisations and disability advocacy bodies. However, representation of people with disability at senior leadership levels is relatively low.[89]

- Some opportunities exist for people to act as ambassadors for programs or specific events such as the Special Olympics. The NSW Government uses disability ambassadors as part of its annual 'Don't DIS my ABILITY' day. Geelong City Council Disability Advisory Committee supported a similar initiative, recommending the engagement of inclusion champions by local governments in order to profile people with disability who actively promote inclusion in the community. It suggested the role could include community awareness and inclusion through speaking engagements, photo opportunities and general public appearances.[90]

- The 'Leading, Educating and Advocating for Disability' (LEAD) initiative — as part of the NDIS Barwon trial site, LEAD guides participants through a

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[88] Municipal Association of Victoria (2012) *Local government: Building inclusive communities. A report on 2011–2012 implementation of the Municipal Association of Victoria's strategic framework for disability. Employment and civic participation.* Melbourne, MAV, p.8.

[89] For example, Women with Disabilities Victoria and Arts Access Australia.

[90] NSW Family and Community Services *Ambassadors.* Don't DIS my ABILITY. Accessed on 5 September 2014 from http://www.dontdismyability.com.au/ambassadors; *Submission S116*, Geelong City Council Disability Advisory Committee, p.2.

program to develop communication, advocacy and leadership skills in order to provide public comment about the NDIS. Chapter 2 discusses this further.

Despite these types of initiatives, people with disability remain under-represented in leadership positions. Section 6.6 of Chapter 6 discusses participation and leadership.

Women with Disabilities Victoria (WDV) told the Inquiry about the importance of leadership development programs and their positive outcomes. It provided a range of examples of how women were empowered through their leadership program to, for example:

• approach their local MP about issues of concern

• speak at public forums

• apply for jobs and gain mainstream employment

• establish community groups.[91]

Other examples of leadership development programs include:

• *People with disability leadership scholarship program*—the Department of Justice funds scholarships to promote career development for Victorians with disability in law, criminology, para-legal, psychology, social work and other justice related fields.[92]

• *Leaders for tomorrow program*—this national program operated between 2010 and 2014. It provided up to 12 months of leadership support to 200 people with disability by linking them with appropriate training, support and mentoring to help them develop the skills and confidence to become leaders in business, the community and government.

The Committee considers that one of the strengths of this approach is empowerment of people with disability to drive their own initiatives and create pathways into other leadership opportunities as a result.

Drawing on this approach, there is scope for the Victorian Government to consider the establishment of a program to build leadership capacity among people with disability. This could be done as an extension of VDAC and the disability action planning processes already in place to encompass an inclusion innovation hub that focuses on developing innovative approaches to changing attitudes towards people with disability and positively influencing the treatment of people with disability and how others interact with them.

Social innovation hubs use principles of technology incubators or think-tanks that combine physical spaces with an online community to achieve enterprising social initiatives. An example is the Global Hub Network commonly known as ImpactHub or just as The Hub. The Hub has been described as 'a global community of people from every profession, background and culture working at

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[91] *Transcript of Evidence*, Women with Disabilities Victoria, Melbourne, 6 March 2014, p.4–5
[92] Department of Justice *Disability scholarship program.* Accessed on 21 August 2014 from http://www.justice.vic.gov.au/utility/careers/disability+scholarship+program.

new frontiers to tackle the world's most pressing social, cultural and environmental challenges.'[93]

Building on the existing work of VDAC and disability action planning processes, a social innovation hub that focuses on inclusion of people with disability could bring together people with disability, government departments and agencies, local governments, MetroAccess and RuralAccess officers, advocacy groups, businesses, and other interested parties to develop and implement innovative ideas to transform attitudes towards and treatment of people with disability and to foster real social inclusion. Short term assignments or placements within such a hub could be structured so as to develop confidence and leadership skills, improve the profile of participants and provide pathways into other leadership roles in the government, community or private sector.

Finding 8.4

Changing society's attitudes towards people with disability can be achieved at a reasonably low cost using a multi-pronged approach that includes:

- a focus on positive personal experiences and interactions with people with disability

- broad-based approaches and approaches that target specific audiences

- encouraging initiatives that aim to change the way people treat and interact with people with disability.

Recommendation 8.3

That the Victorian Government establish an inclusion innovation hub to promote the development of innovative approaches to changing attitudes towards and interaction with people with disability.

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[93]   Social Innovation eXchange *Innovation hubs.* Accessed on 28 August 2014 from http://www.socialinnovator.info/connecting-people-ideas-and-resources/innovation-intermediaries/hubs/innovation-hubs.

Adopted by the Family and Community Development Committee

55 St Andrews Place, East Melbourne

1 September 2014

Appendices

Appendix 1—Submission guide

INQUIRY INTO SOCIAL INCLUSION AND VICTORIANS WITH A DISABILITY

SUBMISSION GUIDE

1. WHO CAN MAKE SUBMISSIONS?

All interested parties can make submissions to the Inquiry. The Family and Community Development Committee is seeking submissions from both individuals and organisations in relation to its Terms of Reference for the Inquiry.

The Committee welcomes submissions from people with a disability, their families and carers, and other organisations and individuals with an interest in issues relating to social inclusion and disability.

This Guide is intended to assist organisations and individuals who want to make a written submission and those who the Committee requests to appear at a public hearing.

The questions in this Guide provide an indication of the issues the Committee will be considering as part of this Inquiry, but they are not intended to be exhaustive and it is not necessary to answer all the questions in comments or submissions.

The Committee is seeking a broad range of views regarding the social inclusion of Victorians with a disability to ensure its Inquiry is well informed and forward-looking in its proposed solutions.

2. TERMS OF REFERENCE

The Family and Community Development Committee has been asked by the Legislative Council to inquire into social inclusion and Victorians with a disability. The Committee is asked to:

a) define 'social inclusion' for Victorians with a disability

b) identify the nature and scale of relative inclusion (exclusion) and participation of Victorians with a disability in the economic, social and civil dimensions of society

c) understand the impact of Victorian government services and initiatives aimed at improving inclusion and participation

d) identify examples of good practice on inclusion and participation driven by local government and the community sector

e) assess how the *Disability Act 2006* has impacted on the social inclusion of people with a disability with respect to Victorian government services

f) recommend ways to increase social inclusion, including the roles of and collaboration between local, state and federal governments, the community sector, individuals with a disability and their carers.

3. DEFINITIONS AND TERMINOLOGY

The Committee acknowledges that there are terms and definitions relating to the Terms of Reference that require further clarification.

Disability

A person with a disability requires significant ongoing and/or long-term episodic support. For these people, their disability is attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or an acquired brain injury (ABI)—or some combination of these. Their impairment or brain injury is generally permanent and results in substantially reduced capacity in their self-care and personal management, their mobility and/or their communication.

Like individuals in the broader population, Victorians with a disability are highly diverse people with varying backgrounds, experiences, needs and expectations. The Committee also recognises that people with a disability vary in their capacity to participate in the community and that different approaches are needed to enable the social inclusion of different individuals.

> 3.1 What needs to happen to ensure that people's individual disability and experience are accounted for in efforts to increase their social inclusion?

Social inclusion

A socially inclusive society is generally defined as one where all people feel valued, their differences are respected, and their basic needs are met so they can live in dignity. Social exclusion is the process of being shut out from the social, economic, political and cultural systems which contribute to the integration of a person into the community.

In this Inquiry, the Committee aims to identify ways to increase the social inclusion of people with a disability. In doing this, it seeks to understand what meaningful 'social inclusion' should look like for people with a disability, and how it differs from 'participation'.

3.2 How should 'social inclusion' for Victorians with a disability be defined?

3.3 What is the difference between the concepts of 'social inclusion' and 'participation' in the context of people with a disability?

3.4 What does social inclusion for Victorians with a disability look like now?

4. VICTORIANS WITH A DISABILITY AND SOCIAL INCLUSION

People with a disability contribute to the Victorian community in a multitude of ways through their economic, social and civic participation. Yet the Committee recognises that Victorians with a disability are not always given opportunities that fully promote their inclusion in the community.

Promoting the participation and inclusion of people with disability in social and community life is a guiding principle within the United Nations *Convention on the rights of persons with disabilities*. It is also a key area of policy action within the Council of Australian Governments' (COAG) *National disability strategy 2012-2020*.

Victorians with a disability represent around 18 per cent of Victoria's population. Of Victoria's population of 5.4 million people in 2009, an estimated one million were people with a disability, and 338,200 were people with a profound or severe disability (6 per cent).[1]

Victorians with a disability are likely to leave school earlier than their peers without a disability and are more likely to be unemployed. In 2009, an estimated 48 per cent of Victorians aged 15 to 64 with a disability were employed, compared with 78 per cent of people without a disability.[2] Furthermore, in 2009 the average income of Victorians with a disability was substantially lower than the income of people without a disability ($305 gross per week, compared with $593 gross per week).[3]

A 2012 survey by the Australian Bureau of Statistics (ABS) indicated that that while most Australians with a disability had participated in at least one activity away from their home in the last 12 months, rates of participation in some of these activities were lower among those with a profound or severe core activity limitation.[4]

Participation in social, community and civic activities also decreased with age. More than half of people aged 65 years and over with a profound or severe core activity limitation had not participated in any of the social or cultural activities described in the survey (compared with one third of all people with a disability in that age group).[5]

4.1 What are the barriers to meaningful social inclusion for Victorians with a disability?

4.2 In what ways do Victorians with a disability participate in the economic, social and civil dimensions of society?

4.3 What do you see as the emerging issues for Victorians with a disability over the next 20 years and how might these influence their social inclusion?

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[1] Australian Bureau of Statistics (2011) *Disability, ageing and carers, Australia: state tables for Victoria: All persons, disability status by age and sex 2009, Table 1*, Cat no. 4430.0, ABS, Canberra.

[2] ABS (2010), 'Persons aged 15–64 years, selected characteristics, by level of highest educational attainment', table 8, Survey of education, training and experience 2009: Victorian tables, cat. no. 6278.0.55, ABS, Canberra. ABS (2011), 'Persons aged 15–64, living in households, disability status by sex and labour force status 2009', table 12, Disability, ageing and carers, Australia: state tables for Victoria, cat. no. 4430.0, ABS, Canberra.

[3] ABS (2011), 'Persons aged 15 and over, living in households, household income quintiles and median gross personal income by age, carer status and disability status 2009', table 11, Disability, ageing and carers, Australia: state tables for Victoria, cat. no. 4430.0, ABS, Canberra.

[4] Core activity limitation refers to limitation in the core activities of self-care, mobility and/or communication.

[5] ABS (2012), *Disability, ageing and carers, Australia: Summary of findings 2012*. Cat no. 4430.0, ABS, Canberra.

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4.4 How effective have awareness campaigns been in improving social inclusion for people with a disability in Victoria?

4.5 How can social inclusion and the participation of people in the community be effectively measured?

4.6 What tools can be used to determine if there have been improvements or changes in the levels of social inclusion for people with a disability over time?

5. *DISABILITY ACT 2006* (VIC)

The introduction of the *Disability Act 2006* (Vic) was intended as a new legislative scheme for people with a disability that aimed to reaffirm and strengthen their rights and responsibilities. It was based on the recognition that achieving this objective requires support across the government sector and within the community.

The Disability Act included a specific focus on advancing the inclusion and participation of Victorians with a disability in the community and enabling them to achieve their individual aspirations. It also sought to maximise their choice and independence.

The legislation required Victoria to establish a state disability plan. It also stipulated that all public services in Victoria have a disability action plan. This included government departments, local government authorities (LGAs), statutory authorities and statutory corporations.

The Victorian Disability Advisory Council was established under the Act. The Council has a community liaison and awareness building role and provides advice to the Minister for Community Services on issues that affect people with a disability across all government services. It also monitors the implementation of strategies for promoting inclusion and participation in the community of persons with a disability and for removing barriers to inclusion and participation.

Reforming the disability service system was a key objective of the Disability Act. It aimed to change the way people access disability services by allowing for a simpler and more consistent system for all people with a disability. This involved moving away from a service-centred approach towards one where supports are provided on the basis of individual needs. It implied that provision should be built around person-centred planning approaches.

The Disability Act also created Victoria's first Disability Services Commissioner, whose role is to work with people with a disability and disability service providers to resolve complaints.

5.1 To what extent have the inclusion and participation of Victorians with a disability been advanced following the introduction of the *Disability Act 2006* (Vic)?

5.2 What impact has the *Disability Act 2006* (Vic) had on the social inclusion of people with a disability with respect to Victorian government services?

6. VICTORIAN SERVICES FOR PEOPLE WITH A DISABILITY

The Victorian Government funds a broad range of services and initiatives for people with a disability that have the potential to increase their social inclusion in the community. Local governments also provide services and programs aimed at improving social inclusion and participation of people with a disability.

The Inquiry is seeking to understand how these services and initiatives increase the social inclusion of people with a disability.

There is a range of support options and accessibility initiatives that aim to increase social inclusion in the community. In the provision of support to people with a disability, there is a strong focus on individualised and self-directed support, often through Individual Support Packages designed to meet the specific needs of each person receiving support.

Broadly, services and initiatives include but are not limited to:

- help living at home (through home and community outreach support)

- a range of supports to be independent in the community

- support for children with a disability in Victorian schools

- assistance for young people to seek employment

- supported accommodation for people with high support needs

- aids and equipment supports

- support for carers and families

- public transport accessibility initiatives.

While funded by the Victorian Government, a large percentage of services are provided by community service organisations.

Local government also has a key role in advancing the social inclusion of people with a disability. LGAs are required to have a disability action plan. They are also involved in the Victorian Government's community building program. This program aims to build inclusive communities for people with a disability through community partnerships facilitated by RuralAccess, MetroAccess and deafaccess officers based in local communities. The role of these workers is to support communities to develop new ways of including people with a disability in local community life.

6.1 How effective are services and initiatives designed to enhance the social inclusion of Victorians with a disability?

6.2 What other sectors and sections of the community should have a greater role in improving the social inclusion of Victorians with a disability?

6.3 Are there examples of good practice in advancing social inclusion and participation driven by local government and the community sector?

7. ROLE OF GOVERNMENTS AND COLLABORATION

In 2010, through COAG, Australian state and territory governments endorsed the *National disability strategy 2010-2020*. The strategy built on existing initiatives across states and territories to provide a national agenda with a focus on enabling people with a disability to participate as equal citizens in society. The Australian Local Government Association also assisted in the development of the strategy.

In 2013, the Australian Government introduced a National Disability Insurance Scheme (NDIS). The introduction of the insurance scheme was in recognition of shortcomings and inequities in the current disability service system. The scheme is designed to provide lifelong support for eligible people who have a severe and profound disability and will lead to significant changes to the provision of supports for people with a disability.

To assist it to prepare for the NDIS, in 2013 the Victorian Government revised the state disability plan and released the *Victorian state disability plan 2013-2016*. The plan describes how the *National disability strategy* will be put into practice in Victoria. It also commits to developing a contemporary approach through disability system reform that aims to give meaningful choice and control to people with a disability.

The Committee recognises that these new initiatives at the state and national level will lead to transition in the role of governments. These changes will potentially have consequences for the social inclusion of people with a disability.

The Committee's Terms of Reference ask it to consider the roles of local, state and federal governments, the community sector, Victorians with a disability and carers of Victorians with a disability. The Committee has also been asked to inquire into ways to increase social inclusion through collaboration across governments, the community sector and these individuals.

7.1 What needs to happen in the implementation of the National Disability Insurance Scheme to improve the social inclusion of Victorians with a disability into the future?

7.2 What should be the role of governments and the community sector in increasing social inclusion for Victorians with a disability?

7.3 In what way could collaboration between government departments, organisations, services and the community sector be improved to enhance social inclusion for people with a disability?

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8. LOOKING TO THE FUTURE

The Committee's Terms of Reference with respect to this Inquiry are broad. While the above is a guide to some issues the Committee would be interested in hearing about, individuals and groups are encouraged to contribute views and ideas about how social inclusion and participation of people with a disability can be improved in Victorians now and into the future.

8.1 What needs to happen to improve the social inclusion of Victorians with a disability into the future?

9. SUBMISSIONS

The Committee welcomes written submissions addressing one, multiple or all Terms of Reference of the Inquiry.

Submissions close on **28 February 2014**.

Guidance regarding submissions can be found at:
www.parliament.vic.gov.au/committees/submissions.html

Submissions can be provided in either hard copy or electronically.

Hard copy submissions should be sent to:

The Executive Officer
Family and Community Development Committee
Parliament House
Spring Street
EAST MELBOURNE VIC 3002

Electronic submissions can be sent via the eSubmission form on the Committee website or by email to FCDC@parliament.vic.gov.au.

The Committee draws your attention that **all submissions are public documents unless confidentiality is requested**.

Please contact the Committee if confidentiality is sought, as this has bearing on how evidence can be used in the report to Parliament. The Committee also has the option to consider requests to with withhold a submitter's name at their request.

10. MAKING A WRITTEN SUBMISSION

Who can make a submission?

Any person or organisation can make a submission to a Committee. Individuals, community groups, private organisations, representatives of government departments and agencies and anyone else interested in an inquiry currently before the Committee are encouraged to make a submission.

Terms of Reference

Before preparing your submission, it is important that you read the Inquiry's Terms of Reference, as your submission must be relevant to the Committee's Inquiry. If you do not have a copy of the Terms of Reference, please contact the Committee's office.

Preparing a submission

Your submission may address all or part of the Terms of Reference. You do not have to comment on every aspect of the Terms of Reference, nor are you confined to just one aspect.

The Terms of Reference are intended to cover a wide range of issues relating to disability and social inclusion.

Your submission can contain factual information, opinion or both. You may want to draw the attention of the Committee to something relevant to the Inquiry. You may choose to emphasise solutions to the matter or issue before the committee. This is entirely your choice.

Your submission will be welcomed by the Committee provided it is relevant, not frivolous or offensive in nature, and addresses the terms of reference.

Submission format

There is no specific method for organising or presenting a submission. Your contribution can take the form of a letter, a short summary paper or a longer research document. You can include relevant data in appendices or incorporate them in the body of the text. It is important that the structure, argument and conclusions of your submission are clear.

Hard copy or electronic submissions

You can send your submission in hard copy, or electronically. If you send it in hard copy, a typed document on A4 paper is preferred. If this is not possible, a handwritten submission is acceptable.

Electronic submission

You can provide your submission electronically, by email, on CD/DVD or by eSubmission (see the Committee website). If you have any questions about the suitability of your file format/size, please contact the Committee office.

Verification of your details

Please sign the submission. Sign on behalf of yourself, or on behalf of the organisation you are representing. If you are representing an organisation, please indicate your position in the organisation. If relevant, specify at what level the submission has been authorised: branch, executive, president, sub-committee, executive committee, national body, etc. If you are sending your submission electronically, please provide your name, and relevant contact details (such as address or phone number).

Supplementary material

You may wish to support your submission with other forms of material, such as a video, photographs or objects. Please contact the staff of the Committee if you plan to do this, so that appropriate arrangements can be made. This may involve material in your possession being loaned or donated to the Committee. Any material borrowed by the Committee will be returned on completion of the Inquiry.

Tone of submissions

Submissions form part of the Committee's proceedings, and help inform it about matters relevant to its inquiries. Most submissions are made public by the Committee, and can be published on its website. Submissions should be relevant, not contain offensive language or remarks, and should not be vexatious. A Committee can choose not to accept a submission if it feels the content breaches any of these guidelines.

The Committee may return any evidence that it considers irrelevant to its proceedings, offensive or possibly defamatory.

Parliamentary Privilege

A submission to a Committee becomes a Committee document once it formally decides to accept it as a submission. A Committee may decide not to accept a submission as evidence if it is not relevant to the Terms of Reference, or is offensive.

Once the Committee has authorised the release of a submission, any subsequent publication of it by the Committee is protected by parliamentary privilege. This means that what you say in your submission cannot be used in court against you.

Parliamentary privilege only extends to submissions that are published by the Committee. If a submission is published in another form or for another purpose, that publication will not be protected by parliamentary privilege. This means that you should not reproduce the submission in another format or context. You can, however, refer others to your submission on the Committee's website, or advise them to contact the Committee directly.

It is against parliamentary rules for anyone to try to stop you from making a submission by threats or intimidation. It is also a breach of these rules for anyone to harass you or discriminate against you because you have made a submission, and Parliament can take action against this behaviour.

Confidentiality

If you wish to have your submission kept confidential, please say so clearly at the top of the submission or in a covering note, explaining why you want it to be kept confidential. If you want part of the submission to be confidential, please put that part on a separate page. The Committee will respect requests for confidentiality. If you have concerns about confidentiality, please discuss these with the Committee's Executive Officer before you make a submission.

Public hearings

The Committee will determine its public hearing schedule and approach individuals and organisations to request them appear at a hearing to give verbal evidence. For more information about appearing at a public hearing, see the Parliament of Victoria's Guide to *Giving Evidence at a Public Hearing to a Parliamentary Committee* (available on its website).

Appendix 2—List of submissions

Submission No.	Name of Submitter
1	Mrs Brenda Rawlins
2	Mr Graeme Wilson
3	Ms Elisheva Picker
4	Mrs Ingrid Hindell
5	Mr Kevin Boyce
6	Mrs Maureen McLeish
7	Deaf Victoria Inc
8	Mrs Delia Fisher
9	Uniting Church Synod of Victoria and Tasmania
10	Ms Raelene West
10A	Supplementary submission
11	Victorian Aids and Equipment Action Alliance
12	Office of the Public Advocate
13	Centre for Rural Regional Law and Justice, Deakin University
14	St Vincent de Paul Society
15	Lifestyle in Supported Accommodation (LISA) Inc
16	Post Polio Victoria Inc
17	City of Stonnington
18	Ms Valerie Johnstone
19	Ethnic Communities' Council of Victoria Inc (ECCV)
20	Marriott Support Services
21	Youth Affairs Council of Victoria (YACV) & Youth Disability Advocacy Service (YDAS)
22	Ms Leanne Robson, Yooralla Service Manager
23	Public Transport Ombudsman Victoria (PTO)
24	Regional Sport Victoria (RSA)
25	Disability Media Australia
26	Down Syndrome Victoria

Submission No.	Name of Submitter
27	Mitchell Shire Council Access & Inclusion Advisory Committee
28	STAR Victoria Inc
29	Aspect Victoria (Autism Spectrum Australia)
30	Belonging Matters
31	Spina Bifida Foundation Victoria
32	Mrs Trudy Golding
33	Ablelink
34	Geelong Parent Network
35	Mr & Mrs Joe & Rosa Miot
36	Mansfield Support Group for Children with Special Needs
37	Whittlesea Disability Network
38	Disability Justice Advocacy Inc
39	Mr & Mrs Jim & Carol Price
40	Early Childhood Intervention Australia (Victorian Chapter)
41	Darebin Disability Advisory Committee (DDAC)
42	SkillsPlus and BRACE
43	Cerebral Palsy Support Network
44	WISE Employment
45	National Disability Services (NDS) Victoria
46	MICH Inc (Manningham Inclusive Community Housing)
47	St Laurence Community Services Inc
48	City of Boroondara
49	Victorian Disability Services Commissioner
50	Australian Community Support Organisation (ACSO)
51	Women with Disabilities Victoria
52	Moonee Valley City Council
53	Municipal Association of Victoria (MAV)
54	Able Australia
55	Disability Sport & Recreation
56	Inclusion Melbourne

Submission No.	Name of Submitter
57	Mansfield Shire Council
58	Ms Elizabeth Gillespie
59	VALID Inc (Victorian Advocacy League for Individuals with Disability)
60	COTA Victoria
61	Associate Professor Erin Wilson, School of Health and Social Development, Deakin University
62	Guide Dogs Victoria
63	Extended Families Australia
64	Manningham City Council
65	REAL Inc (Rights, Employment, Accommodation, Leisure)
66	Riding for Disabled Association of Victoria Inc (RDACV)
67	Warrnambool City Council (South West RuralAccess Program)
68	Monash Health
69	Victorian Coalition of ABI Service Providers Inc (VCASP)
70	UnitingCare Community Options
71	Women's Health West
72	Youngcare
73	Maroondah City Council
74	Confidential
75	Mr Tony Clark
76	Mildura Rural City Council
77	City of Melbourne Disability Advisory Committee
78	Hobsons Bay City Council
79	North East Primary Care Partnership (NEPCP)
80	Melba Support Services Inc
81	Mr Bret Fishley
82	Blind Citizens Australia
83	Wellington (Local Government Area) Community
84	Golden City Support Services
85	Cardinia Shire Council
86	Brimbank City Council

Submission No.	Name of Submitter
87	Carers Victoria
88	Vicdeaf (Victorian Deaf Society)
89	The Able Movement
90	Ms Shaunagh Stevens
91	Ms Wai L. Cheung
92	Ms Michele Denham
93	Dr Christine Baxter
94	Dr Fiona Reidy
95	Netball Victoria
96	Knox Disability Advisory Committee
97	Whitehorse City Council
98	Inability Possability
99	South Coast Primary Care Partnership
100	Communication Rights Australia & Disability Discrimination Legal Service Inc (DDLS)
101	Occupational Therapy Australia (OTA)
102	Noah's Ark
103	Maribyrnong City Council
104	annecto – the people network
105	MacKillop Family Services
106	Frankston City Council
107	Australian Bureau of Statistics (ABS)
108	Centre for Developmental Disability Health Victoria
109	Life Without Barriers
110	Catholic Social Services Victoria
111	Melbourne City Mission
112	Vision Australia
113	Deafblind Victorians
114	Dental Health Services Victoria
115	Victorian Equal Opportunity and Human Rights Commission (VEOHRC)
116	Geelong City Council Disability Advisory Committee

Submission No.	Name of Submitter
117	Psychiatric Disability Services of Victoria (VICSERV)
118	Yarra City Council
119	Council to Homeless Persons (CHP)
120	Monash City Council
121	Summer Foundation Ltd
122	Association for Children with a Disability
123	Northern Support Service's My Place-KeyRing Program
124	Independent Disability Services
125	Mr Matthew Potocnik
126	Victorian Council of Social Service (VCOSS)
127	Australian and New Zealand Assistance Dogs Inc (ANZAD)
128	Mrs Mary Nolan AM
129	Scope (Vic) Ltd
130	Health and Community Service Union (HACSU)
131	MetroAccess South Division: Bayside Peninsula & Southern Melbourne
132	Mornington Peninsula Shire
133	Just Learning

Appendix 3—Public hearings

The Committee held the following Public Hearings:

Date	Venue
3 March 2014	Melbourne
6 March 2014	Melbourne
17 March 2014	Melbourne
20 March 2014	Melbourne
24 March 2014	Melbourne
31 March 2014	Melbourne
5 May 2014	Melbourne
26 May 2014	Melbourne

3 March 2014, Melbourne

Department of Human Services	
Ms Gill Callister	Secretary
Ms Katy Haire	Deputy Secretary, Community and Executive Services Group
Mr Arthur Rogers	Deputy Secretary, Service Design and Implementation group, and Director of Housing
Department of Education and Early Childhood Development	
Mr Simon Kent	Deputy Secretary, Strategy and Review Group
Mr Mark Tainsh	Director, Disability and Inclusion
Ms Carol Kelly	Executive Director, Student Inclusion and Engagement Division
Ms Pippa Procter	Director, Early Childhood Programs and Partnerships
RMIT University	
Associate Professor Paul Ramcharan	Centre for Applied Social Research
Disability Services Commissioner	
Mr Laurie Harkin AM	Commissioner
Ms Lynne Coulson Barr	Deputy Commissioner
Ms Tamara Reinisch	Principal Officer
National Disability Services	
Mr James O'Brien	State Manager, Victoria
Victorian Advocacy League for Individuals with Disability Inc (VALID)	
Mr Kevin Stone	Executive Officer
Ms Heather Forsyth	Self-Advocate Leader
Carers Victoria	
Ms Caroline Mulcahy	Chief Executive Officer
Mr Ben Ilsley	Acting Policy Manager

6 March 2014, Melbourne

Centre for Developmental Disability Health Victoria

Dr Jane Tracy	Director
Dr Rachael McDonald	Deputy Director

Centre for Rural Regional Law and Justice, Deakin University

Mr Ian Parsons	Research Fellow

Women with Disabilities Victoria

Ms Keran Howe	Executive Director
Ms Jen Hargrave	Policy Officer, Violence Against Women with Disabilities
Ms Jane Oldfield	Partnership and Leadership Development Officer

Action on Disability within Ethnic Communities Inc

Mr Keith Hitchen	Executive Director

Office of the Public Advocate

Dr John Chesterman	Manager, Policy and Education

17 March 2014, Melbourne

Australian Bureau of Statistics

Ms Judy Henson	Victorian Regional Director
Ms Michelle Marquardt	Acting Assistant Statistician, Health and Disability Branch

Association for Children with a Disability

Ms Elizabeth McGarry	Chief Executive Officer

AMAZE

Ms Beryl Raufer	Acting Chief Executive Officer
Mr Murray Dawson-Smith	Consultant and Former Chief Executive Officer

Municipal Association of Victoria

Ms Clare Hargreaves	Manager, Social Policy
Ms Jan Black	Policy Adviser

Vicdeaf

Ms Christine Mathieson	Chief Executive Officer
Mr Brent Phillips	Manager, Communication and Community Relations (interpreted by Ms Cheryl Sandilands, Auslan interpreter)

Independence Australia	
Ms Marcia Baron	General Manager, Community Solutions, People and Quality
Dr Andrew Sinclair	Team Leader, Psychology and Counselling Services
Ms Raelea Stewart	Strategy and Service Design
Summer Foundation	
Mr Tom Worsnop	Executive Manager
Ms Carolyn Finis	Program Manager
Mr Bil Hurley	Ambassador

20 March 2014, Melbourne

Disability Sport and Recreation	
Mr Rob Anderson	Chief Executive Officer
Disability Employment Australia	
Mr Craig Harrison	Chief Executive Officer
Northern Support Services	
Ms Gail Younie	Chief Executive Officer
Ms Geraldine Fowler	KeyRing Manager
La Trobe University	
Professor Christine Bigby	Research Program Leader, Deputy Chair Academic Board
Youth Affairs Council of Victoria and Youth Disability Advocacy Service	
Ms Georgie Ferrari	Chief Executive Officer, Youth Affairs Council of Victoria
Dr Jessie Mitchell	Manager, Policy and Projects, Youth Affairs Council of Victoria
Ms Ariane Garner-Williams	Member, Steering Committee, Youth Disability Advocacy Service
Aids and Equipment Action Alliance	
Ms Natasha Layton	Chair
Mr Peter Willcocks	Deputy Chair
Mr Carl Thompson	Project Worker
Inclusion Melbourne	
Mr Daniel Leighton	Chief Executive Officer
Mr Nathan Despott	Policy Officer

Solve Disability Solutions Inc	
Ms Fiona Still	Chief Executive Officer

24 March 2014, Melbourne

Public Transport Ombudsman Victoria	
Ms Janine Young	Ombudsman
Travellers Aid Australia	
Ms Jodie Willmer	Chief Executive Officer
Disability Media Australia	
Ms Sarah Barton	Chief Executive Officer
Ms Sue Taylor	Travelling Chair Volunteer

31 March 2014, Melbourne

Vision Australia	
Mr Jacob Clifton	Manager, Government Relations and Policy
Ms Amy Feldman	Policy and Research Officer
Noah's Ark	
Ms Val Johnson	Senior Manager, Services and Acting Chief Executive Officer
Ms Debbie King	Senior Manager, Innovation and Development

5 May 2014, Melbourne

STAR Victoria	
Mrs Esther Harris	Executive Officer
Ms Emmy Elbaum	Board Member
Dr Philip Graves	Board Member
Golden City Support Services	
Mr Ian McLean	Chief Executive Officer
SANE Australia	
Mr Jack Heath	Chief Executive Officer

26 May 2014, Melbourne

Melba Support Services	
Mr Glenn Foard	Chief Executive Officer
Ms Sarina Bunnett	Outcomes Development Coordinator
Ms Sally Nicol	Manager, Community Connections
Ms Rhiannon Lewis-Lansdell	Advisory Group Representative
Mr Michael Sellwood	Advisory Group Member
Karingal	
Ms Ingrid Waters	Service Development Manager, Disability
Ms Annette Gill	Policy and Development Manager
Ballarat Specialist School	
Mr John Burt	Principal
Football Integration Development Association (FIDA)	
Mr Peter Ryan	President
Mr Logan Whitaker	Football Administration Manager

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