Report to Congress on Borderline Personality Disorder

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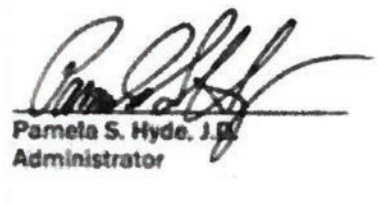

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I. Executive Summary

In response to the U.S. House of Representatives' Committee on Appropriations request in House Report 111-220,[1] the Substance Abuse and Mental Health Services Administration (SAMHSA) is pleased to present this overview of borderline personality disorder (BPD) and our recommendations for expanding early detection, evidence-based treatment, and family education to promote resilience and recovery for individuals diagnosed with BPD.

On page 141 of its report on the Fiscal Year (FY) 2010 appropriation for the Department of Health and Human Services,[1] the Committee on Appropriations of the House of Representatives stated the following:

> *The Committee encourages SAMHSA to convene a panel of experts to make recommendations for expanding early detection, evidence-based treatment, and family education to promote resiliency and recovery for borderline personality disorder (BPD). The Committee again requests that SAMHSA submit a report to the Committee on Appropriations of the House of Representatives and Senate detailing SAMHSA's plans to expand its programs for BPD by April 1, 2010.[1] (HR 111-120, p 141)*

In response, SAMHSA conducted an extensive literature review and gathered input from selected leading experts in the field of BPD research, treatment, and services; consumers and family members; and national organizations that reached out to SAMHSA expressing interest in contributing to SAMHSA's response.[i] SAMHSA conducted a series of substantive calls with subject matter experts in the field including leaders of the National Alliance on Mental Illness and the National Educational Alliance for Borderline Personality Disorder, consumer representatives and mental health professionals. This series of calls served as a "virtual" expert panel and achieved the goal of conducting an expert panel more cost-effectively. Our research was guided by the key areas cited in the Committee's request: early detection, evidence-based treatment, and family education. The result is the following discussion of a highly complex and often misunderstood mental health diagnosis.

Recent data indicate that an estimated 18 million Americans will develop borderline personality disorder (BPD) in their lifetimes,[i,22] with symptoms commonly emerging during early adolescence and adulthood. BPD symptoms can be severe, debilitating, and isolating, and individuals with the disorder are subject to discrimination and bias. Family and other personal relationships, employment, and overall functioning can be adversely affected. With such a large proportion of the population directly affected by a diagnosis of BPD or sharing their lives with someone who has the disorder, it is imperative to both individual and public health to provide awareness of and services for this complex illness.

[i] The National Alliance on Mental Illness (NAMI) and the National Education Association for BPD (NEA-BPD) requested an opportunity to provide input into this report, and representatives of both organizations were interviewed.

Early detection and intervention are critical to ameliorating the negative impacts of this disorder. The 2009 Institute of Medicine (IOM) report *Preventing Mental, Emotional, and Behavioral Disorders Among Young People: Progress and Possibilities*, commissioned by SAMHSA's Center for Mental Health Services,[3] provides concrete evidence that many mental, emotional, and behavioral disorders in young people are, in fact, preventable. For example, school-based violence prevention programs and social and emotional learning programs may reduce problem behaviors and improve academic outcomes. Preventing mental disorders and promoting mental health are key tenets of SAMHSA policy and of a public health approach to health care.

In addition to early detection and intervention, SAMHSA supports the development, dissemination, and widespread use of empirically based treatment approaches. There are a number of evidence-based treatments for BPD that have been evaluated in randomized controlled trials, but more research is needed and the field requires better access to and understanding of these techniques. It is imperative that behavioral health professionals have the tools and knowledge to support consumers with all mental and substance use disorders, including co-occurring disorders, and the resources to make appropriate referrals.

Illnesses such as BPD occur in a larger context than just the individual with the diagnosis. Spouses, partners, parents, children, friends, neighbors, and co-workers of people with BPD can also benefit from services. To effectively treat the disorder, we must also provide education and tools for consumers and their personal support networks. Family psychoeducation is crucial to fostering an environment of recovery that will enable consumers to achieve and sustain their treatment goals. We are committed to providing individuals with BPD, their families, and the communities in which they live with a full range of prevention, promotion, and treatment services. Our ultimate goal is healthy individuals, healthy communities, and a healthy Nation.

II. Introduction and Overview

Recent data indicate that an estimated 18 million Americans will develop borderline personality disorder (BPD) in their lifetimes.[2] With such a large proportion of the population directly affected by a diagnosis of BPD or sharing their lives with someone who has the disorder, it is imperative to both individual and public health to provide awareness of and services for this complex illness.

BPD symptoms can be severe, debilitating, and isolating, and individuals with this disorder suffer discrimination and bias.

However, despite its severity and burden, BPD has a surprisingly good long-term prognosis with a high rate of recovery. Awareness, education, and access to treatment and services are critical to ensuring that individuals with BPD and their families have the tools and support consumers need to achieve recovery.

To help Americans understand this disorder and ensure that it receives the attention it deserves, the House Committee on Appropriations requested that the Substance Abuse and Mental Health Services Administration (SAMHSA), U.S. Department of Health and Human Services, submit a report containing recommendations for expanding early detection, evidence-based treatment, and family education to promote resiliency and recovery for BPD.

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This report is intended to provide a brief overview of BPD and how it affects consumers, their families, and their communities. We provided an Executive Summary in Section I. In this introduction (Section II), we highlight what follows in the balance of the report. Section III contains the key findings of our exploration of BPD that directly address the core areas in the Committee's request. In Section IV, we describe how SAMHSA provides services and supports for individuals with BPD and their families through its existing range of formula and discretionary grant programs. These programs are not aimed at any particular diagnosis-specific population but rather address prevention, treatment, and services for a wide range of mental illnesses and addictive disorders.

Finally, in Section V, we delve into BPD in more detail, discussing its symptoms, development, and prognosis; diagnostic challenges and treatment approaches; and the encouraging evidence of recovery. We also explore the perspectives of mental health consumers living with a diagnosis of BPD and their family members. We offer a brief conclusion of our findings in Section VI. At the end of this document we provide not only a list of cited references, but also a bibliography on BPD containing seminal works dating to the origin of the diagnosis as well as key publications from the last decade.

[ii] The National Alliance on Mental Illness (NAMI) and the National Education Association for BPD (NEA-BPD) requested an opportunity to provide input into this report, and representatives of both organizations were interviewed.

III. Key Findings

Early Detection and Early Intervention

As recognized throughout the research literature, BPD is affected by heritable as well as environmental factors. Although a diagnosis of BPD is seldom made in children and adolescents, research overwhelmingly demonstrates that BPD symptoms and risk factors can be observed in even very young children. Self-injuring behaviors that are so often present in persons with BPD can emerge as young as ages 10-12 years. To avoid years of disability and impairment, a focus on early detection of BPD is essential. Many of the consumers and family members we interviewed lamented the years lost due to the absence of early detection and intervention or to multiple misdiagnoses.

Awareness and education must include both the public and the professional community—clinicians who diagnose and provide treatment for BPD must be equipped with knowledge and training on evidence-based and promising practices and resources to support their clients with BPD. Effective tools, treatments, and approaches to service delivery exist, yet are not widely disseminated or used. Information dissemination should be a cornerstone of any plan to improve outcomes for this illness.[iii]

Although the illness does have a surprisingly good prognosis in the long term, such symptoms as self-injury and suicidality are extremely dangerous—individuals diagnosed with BPD have a suicide rate approximately 50 times that of the general population. In addition, individuals diagnosed with BPD are extremely high users of emergency departments and crisis resources, representing a significant public health cost.[4] Symptoms of BPD can also interfere with individuals' ability to contribute fully to their community, enjoy meaningful and secure relationships, and have optimum health throughout their life.

A recent report by the Institute of Medicine, commissioned by SAMHSA's Center for Mental Health Services, provides concrete evidence that many mental, emotional, and behavioral disorders in young people are, in fact, preventable.[3] The report's authors noted that interventions that strengthen families, individuals, schools, and other community organizations and structures have been shown to reduce mental, emotional, and behavioral disorder and related problems. School-based violence prevention programs and social and emotional learning programs may reduce

[iii] P. Hoffman, Ph.D., J. Gunderson, M.D., B. Palmer, B. Elliott, J. Hall, T. Woodward, and J. Payne representing the National Education Alliance for Borderline Personality Disorder, personal communication, January 6, 2010.

problem behaviors and improve academic outcomes. In addition, the IOM found evidence that improving family functioning and positive parenting serves as a mediator of positive outcomes and can moderate poverty-related risks. Preventing mental disorders and promoting mental health are key tenets of SAMHSA policy and the essence of a public health approach to health care.

Evidence-based Treatment

Individual and group psychotherapy, skills training, family psychoeducation, pharmacotherapy, and peer support are among the empirically based interventions for BPD. Research has also identified many effective approaches to addressing the consequences of trauma and implementing trauma-informed services, which is particularly relevant to this diagnosis because of the high prevalence of trauma in the lives of individuals with BPD. Section V of this report provides a discussion in greater depth of effective interventions for BPD including specific types of psychotherapeutic, pharmacologic/somatic, and family psychoeducational approaches.

In the last two decades, there has been an increase in the number of relevant evidence-based practices, but there is still a need for additional research to support best practices in the field. There are multiple symptoms and manifestations of this disorder, and the field needs a better understanding of which interventions are most effective for specific symptoms and groups of symptoms and the proper training to apply this knowledge in clinical settings.

The treatment and service delivery approaches already shown to be effective for BPD must be made more accessible, both to individual clinicians and to inpatient and outpatient facilities that may serve individuals with BPD in a crisis situation. The discrimination and bias surrounding BPD pervade the mental health clinical community as much as it does the general population—and fear or reluctance to treat an individual with BPD may stem from feelings of helplessness on the part of the provider when faced with this complex illness. Primary and behavioral health care professionals, from pediatricians and school counselors to psychologists and psychiatrists, need to have ready access to effective techniques for managing this complex diagnosis or the awareness and ability to make referrals when and where appropriate.

For referrals to be effective, there must be ample and appropriate mental health services in place and available to consumers and family members, preferably in community-based settings. Unfortunately, data from one of the major community psychiatric epidemiology studies, the National Comorbidity Study Replication, show only 41 percent of people with mental disorders (generically) receive

treatment in a year.[5] This finding was corroborated by the consumers, family members, and providers we spoke with in developing this report.[iv] SAMHSA's National Survey on Drug Use and Health (NSDUH) also found that in 2006, approximately 20 percent of the 23.8 million adults who received treatment for a mental health problem in the past 12 months reported an unmet need (e.g., service provision was delayed, services were insufficient[6]). Also of note is a high level of co-occurring substance use disorders in those with a mental health diagnosis, including BPD. For services to be truly effective individuals must receive treatment that encompasses the full spectrum of behavioral health concerns, but NSDUH found that only a small proportion of people with both mental illness and a substance use disorder received treatment for both conditions.[7]

Family Education

The heavy personal and social costs of BPD are not limited to those who have been diagnosed with the disorder. Children, spouses, siblings, and parents all are affected by the illness in someone they know and love. Unstable emotions, anger, and high rates of suicide—all characteristics of BPD—can be extremely stressful and burdensome for family members. Family members of individuals with a diagnosis of BPD report very high levels of depression, grief, isolation, and hopelessness associated with their loved one's illness and may be at risk for developing their own psychiatric problems.[8-11,v] Family psychoeducation to increase family members' understanding of BPD not only helps them develop appropriate ways to deal with stress and maintain bonds with their loved ones, it also correlates strongly with improved outcomes for the individual with a diagnosis of BPD. Family psychoeducation is an evidence-based practice and should be considered a mainstay of any recovery-focused treatment approach.

Family members are often the first to reach out to find mental health services, especially in circumstances where the consumer may be in crisis or otherwise unable to seek professional support themselves. Families need access to reliable and up-to-date information on the most effective treatment and services for people diagnosed with BPD and resources where they can find appropriate mental health services. Cultural competence is critical to effective services and outcomes, and must encompass families and individuals from diverse backgrounds. Culture,

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[iv] P. Hoffman, Ph.D., J. Gunderson, M.D., B. Palmer, B. Elliott, J. Hall, T. Woodward, and J. Payne representing the National Education Alliance for Borderline Personality Disorder, personal communication, January 6, 2010.

[v] P. Hoffman, Ph.D., J. Gunderson, M.D., B. Palmer, B. Elliott, J. Hall, T. Woodward, and J. Payne representing the National Education Alliance for Borderline Personality Disorder, personal communication, January 6, 2010.

race/ethnicity, native language, sexual orientation, and other factors should all play a part in culturally competent services.

IV. SAMHSA Programs and Policies and Borderline Personality Disorder

SAMHSA's programs and policies strongly support the goals and strategies articulated by the Committee on Appropriations in calling for "expanding early detection, evidence-based treatment, and family education to promote resiliency and recovery for borderline personality disorder." These goals and strategies are at the heart of SAMHSA's mission to reduce the impact of substance abuse and mental illness, such as borderline personality disorder, on America's communities. SAMHSA and its stakeholders have demonstrated that *prevention works, treatment is effective, and people recover from mental and substance use disorders*. Behavioral health is an important component of service systems and community-wide strategies that improve health status and control health care and other costs to society. Continued improvement in the delivery and financing of prevention, treatment, and recovery support services provides a cost-effective opportunity to advance and protect the Nation's health.

The primary means by which SAMHSA influences behavioral health policy and practice in the U.S. is through competitive or formula grant programs to States, localities, or community-based programs. These mechanisms include the Substance Abuse Prevention and Treatment Block Grant, the Community Mental Health Services Block Grant, the Projects for Assistance in Transition from Homelessness formula grant, competitive grants for the Children's Mental Health Services Program, Programs of Regional and National Significance, and others. For the most part, SAMHSA's programs are designed to address the behavioral health problems of broad demographic groups, such as children or older adults, or particular social problems with significant behavioral health involvement, such as suicide, co-occurring mental and substance use disorders, homelessness, HIV/AIDS, and criminal or juvenile justice.

SAMHSA's approach to provide funding and other resources to States, communities, and providers allows local needs and priorities to govern resource allocation. This approach means that the majority of SAMHSA's programs are not targeted to specific mental or substance use diagnoses (e.g., schizophrenia, bipolar disorder, depression, or BPD), but rather allow for treatment and services to consumers and families with a range of diagnoses and service needs.

All SAMHSA programs rely on cross-cutting principles such as increasing the use of evidence-based treatment practices; reducing discrimination, bias, and other barriers to services; and responding more effectively to trauma and violence, including physical and sexual abuse. Core guiding principles

for SAMHSA programs include key roles for consumers and families, a focus on resilience and recovery, expanding screening and early intervention, and increasing treatment availability.

SAMHSA programs that provide prevention, treatment and recovery support services are designed for and used to support people with and at risk for mental illnesses, including BPD. While SAMHSA does not have a specific program targeting people with and at risk for BPD, many of our programs as described in the report help to meet the needs of this population. In addition, several are designed to address issues that are particularly relevant for people diagnosed with BPD or living with its symptoms. For example:

- Suicide prevention is a policy priority at SAMHSA, with more than $48 million dedicated for this purpose in fiscal year (FY) 2010. SAMHSA's suicide prevention initiatives include the Garrett Lee Smith Suicide Prevention Resource Center and the Suicide Prevention Lifeline, which encompasses both a national toll-free suicide hotline and a range of online tools including a Facebook page, Lifeline "tweets" on Twitter, and an online Lifeline Gallery sharing more than 550 personal stories of hope and recovery. In FY 2010, more than $37 million will be provided in grants to States, tribes, and colleges and universities to fund early intervention and prevention strategies to reduce suicide among youth, adolescents, and young adults. Since the suicide rate among people diagnosed with BPD is 50 times the national average, these life-saving initiatives are critical for this population.

- SAMHSA supports numerous initiatives, including the National Traumatic Stress Network, the National Child Traumatic Stress Initiative, and the National Center for Trauma Informed Care, that are designed to facilitate early identification of trauma, effective trauma-specific treatment, and trauma-informed care in a broad range of service settings. Given the high incidence of trauma among people diagnosed with BPD, these initiatives are particularly important in addressing the needs of certain individuals with BPD.

- Several SAMHSA initiatives focus on providing treatment and other alternatives to incarceration, including grants to promote jail diversion and technical assistance to improve mental health service delivery in criminal justice settings. These initiatives are especially important for people with BPD and others with increased likelihood of criminal justice involvement.

- SAMHSA's activities to promote evidence-based practices in service delivery for people with co-occurring mental and substance use disorders include (1) State Incentive Grants for Treatment of Persons with Co-occurring Substance Related and Mental Disorders to support infrastructure development and implementation of best practices; (2) the Co-occurring Mental Health and Substance Abuse Disorder (COD) Knowledge Synthesis, Product Development and Technical Assistance Center to provide tools and resources to support state activities; and (3) a national evaluation to measure progress and program outcomes. In addition, SAMHSA's Evidence-Based Toolkit on Co-occurring Disorders provides specific tools and guidance for providers to increase the

effectiveness of services to people with both substance use and mental disorders. These targeted resources are especially important to providing effective services for individuals who have been diagnosed with BPD and who face increased risk of co-occurring disorders.

- Additional tools and resources related to co-occurring substance use and mental disorders are provided through various SAMHSA-funded technical assistance centers, including the regional Addiction Technology Transfer Centers (ATTCs). One of these tools includes an influential series of Treatment Improvement Protocols (TIPs) designed to promote best practices among the addiction treatment community. TIP 9, Assessment and Treatment of Patients with Coexisting Mental Illness and Alcohol and Other Drug Abuse,[12] features a module specifically on BPD.

- SAMHSA's National Registry of Evidence-Based Programs and Practices (NREPP) lists two specific evidenced-based practices for BPD: dialectical behavior therapy and psychoeducational multifamily groups.[6,13]

- SAMHSA has and will continue to provide funding, training, and technical assistance to support psychoeducation and other support for families of loved ones who have mental disorders, including those diagnosed with BPD. SAMHSA's Evidence-Based Toolkit on Family Psychoeducation is available online free of charge, and many States use flexible SAMHSA funding such as the Community Mental Health Services Block Grant to support NAMI's Family-to-Family initiative and other family psychoeducation programs. These programs have been found not only to be effective in helping families better understand their loved one's behavior and develop their own coping strategies, but also correlate positively with improved outcomes for the individual who has been diagnosed with BPD.

SAMHSA shares a commitment to use existing programs and communication tools to:

- Increase knowledge about BPD;

- Provide education to consumers and families;

- Expand the availability of evidence-based treatments and services in our communities; and

- Promote resilience and recovery of persons living in our communities with BPD.

We are committed to providing individuals with BPD, their families, and the communities in which they live with a full range of prevention, promotion, and treatment services. Our ultimate goal is healthy individuals, healthy communities, and a healthy Nation.

V. Borderline Personality Disorder: Diagnosis, Treatment, and Recovery

What is Borderline Personality Disorder?

Borderline personality disorder (BPD) is a complex and often misunderstood diagnosis. The *Diagnostic and Statistic Manual of Mental Disorders*, Fourth Edition (DSM-IV),[14] places BPD among Axis II disorders[vi] and describes it as "a pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked by impulsivity beginning by early adulthood and present in a variety of contexts." A diagnosis of BPD may be made in the presence of five or more of the following DSM-IV criteria:

1. Frantic efforts to avoid real or imagined abandonment;
2. A pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation;
3. Identity disturbance: markedly and persistently unstable self-image or sense of self;
4. Impulsivity in at least two areas that are potentially self-damaging (i.e., spending, sex, substance abuse, reckless driving, binge eating), excluding suicidal or self-mutilating behavior (covered in Criterion 5);
5. Recurrent suicidal behavior, gestures, or threats, or self-mutilating behavior;
6. Affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days);
7. Chronic feelings of emptiness;
8. Inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights); and
9. Transient, stress-related paranoid ideation or severe dissociative symptoms.

The American Psychiatric Association (APA) practice guideline, written in 2001, emphasizes the grave and often disabling nature of BPD characteristics, which "result in clinically significant impairment in social, occupational, or other important areas of functioning".[15] This is supported by a recent study by Stepp et al. in 2009[16] that examined interpersonal experiences of individuals with and without personality disorders, including BPD. They found that "patients with BPD reported

[vi] DSM-IV categorizes psychiatric diagnoses into five axes. In this report, we discuss only Axis I and Axis II disorders. Axis I comprises clinical disorders (e.g., depression, anxiety disorders, bipolar disorder, schizophrenia). Axis II comprises personality disorders and mental retardation.

engaging in more disagreements and experiencing more anger during social interactions with family members. Additionally, patients with BPD experienced more emptiness during social interactions in the context of romantic partners, family members, and friends." The authors concluded, "Given the negative valence that characterizes these social interactions, it is not surprising the chronic state of misery that engulfs many of these patients' lives."

Prevalence of Borderline Personality Disorder

In 2008, the first-ever large-scale, community study of personality disorders found a lifetime prevalence of 5.9 percent (18 million people) for BPD, with no significant difference in the rate of prevalence in men (5.6 percent) compared with women (6.2 percent).[2] The authors concluded, "BPD is much more prevalent in the general population than previously recognized, is equally prevalent among men and women, and is associated with considerable mental and physical disability, especially among women."

This 5.9 percent lifetime prevalence of BPD is a significant increase over earlier estimates of 1-2 percent lifetime prevalence and a 3:1 ratio of diagnosis in women compared with men. It is also substantially higher than the estimated lifetime prevalence of approximately 0.4 percent for schizophrenia[17] and 1.4 percent for bipolar disorder.[18] Previous studies on prevalence of BPD were based on considerably smaller sample sizes and had a number of critical limitations including variations in screening/diagnostic tools and failure to control for comorbid conditions. By contrast, the 2008 study by the National Institute on Alcohol Abuse and Alcoholism,[2] relied on interviews with nearly 35,000 adults participating in the 2004-2005 Wave 2 National Epidemiologic Survey on Alcohol and Related Conditions (NESARC), using DSM-IV diagnostic criteria. Findings included a higher prevalence of BPD among Native American men; younger adults who are separated, divorced, or widowed; and individuals with lower levels of education and lower socioeconomic status. BPD was found to be less prevalent among Hispanic men and women and Asian women.

Prevalence of BPD in the clinical setting is considerably higher than in the general population, at an estimated 10 percent of outpatients and 15-20 percent or more of inpatients.[19-21] BPD and borderline symptoms are also overrepresented in civil, criminal, and child custody forensic settings. Individuals with BPD have an increased likelihood of involvement in the legal system, both as perpetrators and victims of crime.[22] BPD also carries a very high public health impact and cost, as individuals who have been diagnosed with BPD are high users of emergency room and crisis resources.[23] These costs

are in addition to those caused by BPD symptoms' detrimental impact on employment, life in the community, and family interactions.

In a 2007 study of male and female offenders who recently entered prison, Black et al. found diagnosable BPD in 29.5 percent of their random sample (N=220) and at least one DSM-IV criterion for BPD in 93.2 percent.[24] The authors concluded, "Borderline personality disorder is relatively common among both male and female offenders in prison, and is associated with substantial psychological stress and impaired quality of life. Early recognition and treatment of BPD in prisons may be warranted."

Diagnostic Challenges and Controversies

BPD was added to the list of Axis II disorders in the DSM-III in 1980 but has been discussed in the literature in some form since the late 1930s and early 1940s, when Stern began using the term "borderline" to identify patients who seemed to be somewhere between neuroticism and psychosis.[25] Wrote Gunderson,[26] "The identification of patients as 'borderline' first arose in an era when the psychoanalytic paradigm dominated psychiatry and our classification system was primitive. At that time classification was tied to analyzability: patients with neuroses were considered analyzable—and therefore treatable—and those with psychoses were considered not analyzable—and therefore untreatable." Since its introduction, the name and even the validity of the BPD diagnosis has been a topic of hot debate.

In 1985, Akiskal characterized "borderline" as "an adjective in search of a noun," which has proved an apt description.[27] The answer to the question, "Border of what?" has varied over the years. In the 1950s and 1960s, a diagnosis of BPD was considered to mean that individuals were on the "border" of being diagnosed with schizophrenia—"almost" schizophrenia, but not quite. From the 1970s to the present, BPD has been considered to be a diagnosis that is on the border or edge of depression, posttraumatic stress disorder (PTSD), or bipolar spectrum disorders.[26]

Although BPD may share some characteristics with the diagnoses it has been thought to "border," a large and growing evidence base shows that it has the clear characteristics of a discrete disorder. Studies comparing BPD alone with PTSD alone versus comorbid BPD and PTSD have shown distinct differences between the two illnesses.[28-34] The same is true of studies comparing BPD with bipolar disorder.[35-39]

Clinicians also report clear differences among BPD, PTSD, and bipolar disorder, particularly as evidenced by the frequently poor response of BPD to treatment approaches designed specifically for the other two disorders.[vii,viii]

The literature also reflects the overall inadequacy of current services for meeting the needs of individuals with BPD.[40] Wrote Lieb,[41] "Because public mental-health outpatient services have traditionally focused on the needs of patients with schizophrenia and bipolar disorder, these facilities might not meet the needs of individuals with borderline personality disorder, which could account for poor treatment compliance and subsequent hospitalisation."

In part because of the evolving debates about the nature of BPD—coupled with the discrimination and bias surrounding this disorder and the lack of awareness, education, and training on effective evidence-based interventions—this illness is frequently misdiagnosed or overlooked.[8,42,ix] Following is a brief discussion of challenges related to accurately classifying and diagnosing BPD.

Development of Borderline Personality Disorder

Despite decades of research and its status as the most widely studied personality disorder,[23] the etiology of BPD remains unclear. There is general consensus that the illness arises from a combination of genetic and biological factors; trauma—including abuse (emotional, physical, and/or sexual) or neglect during childhood; family dynamic and interactions; and sustained environmental influence.[9,23] However, there is no one clear path to the onset of BPD.

Studies have suggested that BPD, or at least the traits that underlie the disorder, is highly heritable; thus, having a family member with BPD is a risk factor for developing the illness.[20,43,44] Forty to 70 percent of individuals with BPD in inpatient and outpatient settings report childhood sexual abuse. Although traumatic experiences that include sexual abuse in childhood is clearly a strong risk factor for later developing BPD, less than 10 percent of people with this history develop the diagnosis, so it cannot be considered a determining factor for the illness.[9,45,46]

[vii] P. Hoffman, Ph.D., J. Gunderson, M.D., B. Palmer, B. Elliott, J. Hall, T. Woodward, and J. Payne representing the National Education Alliance for Borderline Personality Disorder, personal communication, January 6, 2010.

[viii] M. Fitzpatrick, K. Duckworth, and J. Payne representing the National Alliance on Mental Illness, personal communication, January 7, 2010.

[ix] P. Hoffman, Ph.D., J. Gunderson, M.D., B. Palmer, B. Elliott, J. Hall, T. Woodward, and J. Payne representing the National Education Alliance for Borderline Personality Disorder, personal communication, January 6, 2010.

Neuroimaging and genetic studies suggest that some parts of the brain that regulate emotion and impulsivity are different in volume and level of activity in individuals with BPD compared with healthy controls.[41,47-50] Because some of these anatomical differences appear in studies of other diagnoses, it is not yet clear whether the brain's anatomy causes BPD or borderline symptoms or whether external events cause the brain to change over time in people with the diagnosis.[51,52] There are some important variations in the brain between men and women, so gender may influence neurobiology[50,53] and its relationship to those who do and do not develop BPD.

Leading researchers synthesizing the available evidence conclude that BPD results from interactions between genetic and environmental factors. "What begins as a biological vulnerability may lead to a cascade of environmental events," wrote Bradley et al.,[23] "just as what may begin as an environmental effect may become 'hard-wired.'" The multiple possible contributing factors complicate diagnosis and treatment of BPD. Additionally, factors such as trauma can contribute to diagnoses other than BPD, so there is no absolute correlation between any individual element and an eventual borderline diagnosis.[23,47]

Variation and Comorbidity within Borderline Personality Disorder

Another diagnostic challenge with BPD is the heterogeneity within the diagnosis itself. DSM-IV includes nine criteria for BPD with five required for diagnosis.[14] This means that any two individuals with a diagnosis of BPD can have as few as only one criterion in common, and there are 256 possible combinations of criteria that could constitute diagnosable BPD.

Further complicating the issue is overlap and comorbidity with other personality disorders as well as PTSD and bipolar disorder.[39,54-56] Significant comorbidities with Axis I and other Axis II disorders can complicate variation in symptoms while masking or distracting clinicians from the presence of BPD.[x] This all adds to the complexities associated with accurately diagnosing this disorder. Among individuals with BPD, there is high prevalence of bipolar disorder (10-20 percent), major depressive disorder (41-83 percent), substance misuse (64-66 percent), panic disorders (31-48 percent), obsessive-compulsive disorder (16-25 percent), social phobia (23-47 percent), and eating disorders (29-53 percent).[49] Co-occurring personality disorders are also common among individuals diagnosed

[x] DSM-IV Axis I diagnoses comprise clinical disorders (e.g., depression, anxiety disorders, bipolar disorder, schizophrenia). Axis II comprises personality disorders and mental retardation.

with BPD, including avoidant (43-47 percent), dependent (16-51 percent), and paranoid personality disorders (14-30 percent).[49]

The Wave 2 National Epidemiologic Survey on Alcohol and Related Conditions (NESARC)[2] and other studies show that symptoms and comorbidities vary by gender.[57] Johnson et al.[58] found that men are more likely to present with substance use disorders, whereas women are more likely to present with comorbid PTSD. The NESARC results indicated that women have significantly higher prevalence of mood disorders in general, as well as major depressive disorder specifically. Comorbid anxiety and panic disorders were also much higher in women than in men.

Inadequacy of Diagnostic Tools

As discussed above, there are widely varying symptom patterns and high rates of comorbidity with other mental and substance use disorders among those diagnosed with BPD. To diagnose BPD, clinicians typically rely on consumers' self-reports of symptoms and behaviors obtained through structured interviews or questionnaires.

Although structured interviews and questionnaires have many strengths, including reliability and direct correlation with DSM-IV criteria, they do not present a complete picture of an individual's mental health. It may be difficult to determine an accurate diagnosis based on only one or two encounters with an individual. Longitudinal studies show that trait-like, attitudinal symptoms are more fixed and thus better indicators of the diagnosis, whereas behavioral and reactive symptoms are more likely to change over time. Relationship instability and pervasive feelings of emptiness are considered particularly stable,[59-62] but are more subtle and may not be obvious during a brief evaluation.

Combining clinical interviews with valid rating instruments can yield greater accuracy[23] and should be emphasized in clinical and quality improvement developments. Many clinical settings have implemented trauma-informed approaches to facilitate more effective and open therapeutic relationships. Given the high incidence of trauma histories among people diagnosed with BPD, providers in clinical and other service settings need the skills to deliver trauma-sensitive and trauma-informed care.

Because of the overlap, heterogeneity, and potential uncertainty surrounding current BPD diagnostic criteria, many have suggested revising the definition of the disorder to further clarify whether BPD

is a discrete diagnosis or simply a variation of depression, PTSD, or bipolar disorder. A possible solution would be to maintain the current structure but revise the criteria to be more specific to what we now know about BPD. One way to do so is to replace the current categorical diagnosis (i.e., yes/no) with a dimensional diagnosis that more accurately reflects the mental health status of an individual and the extent to which he or she shows characteristics of BPD.[23] Regardless of the structure of the diagnosis itself, Bradley et al. wrote, "Future research using all assessment procedures needs to triangulate data gathered from multiple sources, including self-reports, qualified clinical judgments, informant ratings (e.g., friends and family), and laboratory tasks".[23]

Early Detection and Early Intervention

DSM-IV advises extreme caution in diagnosing BPD before the age of 18 years, in large part because of the belief that personalities and behavioral patterns during adolescence are in large part transient. In other words, teens may "outgrow" borderline symptoms, so diagnosing them before age 18 is premature.[63,64] However, reviews of the BPD literature and studies on personality development in general indicate that symptoms of BPD may very well be valid for diagnosing BPD in this age group. Wrote Miller et al,[65] "…ignoring BPD as a possible disorder for consideration among adolescents may hamper effective clinical intervention."

Experts also report that self-harm routinely begins in some form in the "tween" years, ages 10-12.[66,xi,xii] This suggests an important opportunity to provide screening and early intervention services for children and their families.

One widely implemented program that could incorporate screening for BPD is the TeenScreen program, which provides "mental health check-ups" for children and adolescents ages 11-18 years—the core timeframe in which overt symptoms of BPD typically appear.[xiii]

A 2009 report from Australia demonstrated the effectiveness of indicated prevention and early intervention for BPD in teens in a program called the Helping Young People Early (HYPE) Clinic.[67] The program's goal is "to offer optimal effective treatment as early as possible in the course of BPD

[xi] P. Hoffman, Ph.D., J. Gunderson, M.D., B. Palmer, B. Elliott, J. Hall, T. Woodward, and J. Payne representing the National Education Alliance for Borderline Personality Disorder, personal communication, January 6, 2010.

[xii] M. Fitzpatrick, K. Duckworth, and J. Payne representing the National Alliance on Mental Illness, personal communication, January 7, 2010.

[xiii] P. Hoffman, Ph.D., J. Gunderson, M.D., B. Palmer, B. Elliott, J. Hall, T. Woodward, and J. Payne representing the National Education Alliance for Borderline Personality Disorder, personal communication, January 6, 2010.

and to ensure that this intervention is appropriate to the phase of the disorder and to the developmental phase of the individual and his or her family." It aims to promote appropriate self-care and self-management skills for participants to live in the community through psychotherapy (Cognitive Analytic Therapy), case management, and support by pharmacotherapy as needed to treat comorbid Axis I conditions. Randomized controlled trials evaluating HYPE showed an average 50 percent reduction in behavioral problems and depressive and anxiety symptoms.[67] Suicide attempts and nonsuicidal self-injury were also reduced measurably. At 24-month follow-up, HYPE participants had lower levels of and significantly faster improvement in internalizing and externalizing psychopathology compared with those receiving treatment as usual.

Treating Borderline Personality Disorder

Discrimination and Barriers to Treatment

Individuals with a diagnosis of BPD are subject to a great deal of discrimination and bias, both in society at large and within the mental health treatment community. Characteristics of BPD, particularly anger, suicidality, and a tendency to vacillate between extremes of idealization and devaluation, have contributed to a common view among many clinicians that individuals with BPD are "difficult," "noncompliant," "manipulative," "troublemakers." "unresponsive," "impossible," and numerous other pejorative descriptions.[8,26,xiv]

In the preface to his 2008 book *Treatment of Borderline Personality Disorder: A Guide to Evidence-Based Practice,*[68] Paris articulates the reasons that many providers simply will not treat individuals with BPD or significant borderline symptoms.[23,xv]

Paris wrote:

> Patients with borderline personality disorder (BPD) …. can challenge even the most experienced therapists. The most frightening symptoms of BPD are chronic suicidal ideation, repeated suicide attempts, and self-mutilation. These are the patients we worry about—and are afraid of losing. …All too frequently, [BPD] is diagnosed as a variant of major depression or bipolar

[xiv] P. Hoffman, Ph.D., J. Gunderson, M.D., B. Palmer, B. Elliott, J. Hall, T. Woodward, and J. Payne representing the National Education Alliance for Borderline Personality Disorder, personal communication, January 6, 2010.

[xv] P. Hoffman, Ph.D., J. Gunderson, M.D., B. Palmer, B. Elliott, J. Hall, T. Woodward, and J. Payne representing the National Education Alliance for Borderline Personality Disorder, personal communication, January 6, 2010.

> disorder. Moreover, patients with BPD are often mistreated. They receive prescriptions for multiple drugs that provide only marginal benefit. They do not always get the evidence-based psychotherapy they need. (p. vii-viii)

The symptoms that make treating clients with BPD so challenging for many professionals are the same that make it difficult for so many of those diagnosed with the illness to maintain a treatment relationship despite a desire for recovery. Just as borderline symptoms contribute heavily to unstable and stormy interpersonal relationships, they can have the same impact on the therapeutic relationship.[23,68,xvi] Many clinicians report challenges in establishing the rapport and alliance necessary for effective treatment,[68-70] which can be a contributing factor to many individuals' terminating the therapeutic relationship early.

Suicide Risk

BPD carries an 8-10 percent rate of death by suicide, which is 50 times greater than in the general population.[71,72] More than 70 percent of individuals with BPD will attempt suicide at least once.[73,74] Suicide attempts tend to peak when consumers are in their 20s and 30s, though suicidality is not by any means restricted to these age groups.[26] In addition, the estimated rate of self-harm (i.e., self-destructive behaviors such as cutting or other self-injury with no suicidal intent) is as high as 60-80 percent of those with the diagnosis.[73,74] The constant fear of a client's suicide, whether intentional or accidental, is extremely concerning and stressful for clinicians, and managing this risk is of the utmost importance to maintain client safety.

Evidence-Based Practices for Borderline Personality Disorder

SAMHSA's National Registry of Evidence-Based Programs and Practices (NREPP) lists two evidence-based practices for this disorder: dialectical behavior therapy and psychoeducational multifamily groups,[13] which are described below along with other interventions used to treat BPD. The literature identifies a number of additional treatments and techniques supported with some empirical base. Borderline personality disorder is "the only major psychiatric disorder for which psychosocial interventions remain the primary treatment",[26] but medication has proven a useful

[xvi] P. Hoffman, Ph.D., J. Gunderson, M.D., B. Palmer, B. Elliott, J. Hall, T. Woodward, and J. Payne representing the National Education Alliance for Borderline Personality Disorder, personal communication, January 6, 2010.

supplement to therapy in many cases. Regardless of the specific treatment, effective case management is critical and should be part of the training for every psychologist and psychiatrist.[xvii]

Psychotherapeutic Interventions

Although the specific techniques used vary among the most commonly applied therapeutic approaches to BPD, there are a number of common factors linking them:[23]

- A clear framework for treatment that outlines expectations and boundaries for both the clinician and the client;
- Frequent (often biweekly) contact over a period of a year or longer;
- Close attention to the clinician-client relationship and discussion thereof as central to treatment;
- Development of skills and coping mechanisms to manage impulsivity and emotional dysregulation; and
- A progressive approach to treatment that follows essentially a three-step pattern: (1) stabilizing the client, (2) understanding how past experiences inform current behaviors, and (3) reorganizing and reconceptualizing thoughts and behaviors affecting interpersonal relationships.

Dialectical Behavior Therapy (DBT). DBT has a large empirical base compared with other treatments and is largely considered one of the best, if not the best, treatments for BPD. DBT is a type of cognitive-behavior therapy pioneered by Marsha Linehan in the early 1990s.[68,75-79] It combines weekly individual therapy with weekly group skills training in mindfulness (i.e., awareness of present experiences), distress tolerance, emotion regulation, and interpersonal effectiveness over a period of at least 12 months. Clinicians complete intensive training to learn how to provide DBT and adhere closely to Linehan's treatment manual. Between DBT therapy sessions, individuals complete homework assignments geared toward improving and reinforcing the new skills they learn. SAMHSA's NREPP identifies DBT as an evidence-based practice.

Because training can be expensive and the treatment itself is resource intensive, some clinicians may provide DBT-like treatments or implement elements of DBT to improve functioning even if they do not provide formal DBT.[68] However, in conducting interviews for this report, we heard concerns

[xvii] P. Hoffman, Ph.D., J. Gunderson, M.D., B. Palmer, B. Elliott, J. Hall, T. Woodward, and J. Payne representing the National Education Alliance for Borderline Personality Disorder, personal communication, January 6, 2010.

expressed about clinicians who purport to be offering DBT but whose services lacked fidelity to the model and thus were not attaining the outcomes found in the controlled research studies.[xviii,xix] The development of a DBT certification program is one potential solution to this problem. Whereas some aspects of DBT may leave room for customization or adaptation, it is important to identify those specific characteristics and interventions that must remain consistent for providers to ensure fidelity to the core model. Clearly, this is an important issue meriting further attention and discussion in the field.

Systems Training for Emotional Predictability and Problem Solving (STEPPS). Similar to DBT, STEPPS is another manual-based type of cognitive-behavior therapy that combines skills training with cognitive-behavioral techniques.[68,80-82] In the STEPPS model, participants meet once a week for 2 hours in groups of 6-10 with two leaders and complete weekly homework assignments. The program lasts 20 weeks and focuses on emotion management and behavioral self-management to help individuals learn effective coping methods to replace destructive patterns. A core component of STEPPS is the "reinforcement team" of family, friends, and significant others. These individuals receive training to help support the individual during times of distress or crisis. STEPPS has demonstrated effectiveness in multiple studies.[80,82] It has also been implemented in correctional facilities in the Midwest to help inmates reenter society after involvement in the criminal justice system.[81]

Cognitive Analytic Therapy (CAT). Although literature from U.S. researchers is largely silent on the topic of cognitive analytic therapy,[83] research from the United Kingdom and Australia points to this approach as promising, particularly when coupled with the evidence-based practice of intensive case management.[67] In CAT, the individual diagnosed with BPD and the clinician create a shared understanding of the individual's problems and difficulties, and how those issues may have developed in the individual's life. They then work together to replace problematic patterns, behaviors, and thoughts with more effective coping mechanisms. Because of its collaborative nature and integrative approach, CAT is particularly effective in helping clients with BPD to better manage comorbid conditions such as other Axis I and II disorders and substance use disorders.

Mentalization-Based Therapy (MBT). MBT is a type of individual psychodynamic psychotherapy that focuses on improving individuals' ability to make sense of their own emotions

[xviii] P. Hoffman, Ph.D., J. Gunderson, M.D., B. Palmer, B. Elliott, J. Hall, T. Woodward, and J. Payne representing the National Education Alliance for Borderline Personality Disorder, personal communication, January 6, 2010.

[xix] M. Fitzpatrick, K. Duckworth, and J. Payne representing the National Alliance on Mental Illness, personal communication, January 7, 2010.

and the emotions of others—that is, to identify emotions correctly and learn how to respond appropriately.[68,84,85] It is based on the idea that most people learn how to understand emotions and develop attachments during childhood, but whether for biological or environmental reasons, individuals with BPD did not develop this skill and need to learn it later in life. The typical recommended treatment duration is 18 months, but studies in the U.S. and abroad have also shown long-term effectiveness by using MBT as a short-term intervention.

Transference-Focused Therapy (TFT). TFT is another type of individual psychodynamic psychotherapy. It resembles traditional psychoanalysis in many ways in that it analyzes and reframes individuals' emotional understanding. In this approach, clinicians help individuals identify and correct distorted perceptions. Data on its effectiveness show mixed results,[68] but some studies have found evidence that TFT is effective for improving control of impulsivity and reducing suicidality.[75]

Pharmacologic Interventions

Although there is no drug approved by the U.S. Food and Drug Administration specifically for treatment of BPD, some "personality dimensions" such as anger and impulsivity can be improved with pharmacotherapy targeted toward specific symptoms.[72] Pharmacotherapy can also relieve symptoms of comorbid Axis I and II disorders, which may make it easier to treat the underlying BPD. The APA practice guideline for BPD discusses seven main classes of drugs that include antidepressants, mood stabilizers, anxiety agents, opiate agonists, and others. Selective serotonin reuptake inhibitors (SSRIs), monoamine oxidase inhibitors (MAOIs), and tricyclic and heterocyclic antidepressants are among those used most commonly.

Family Psychoeducation

Family therapy and family psychoeducation are related but not identical, and both can be useful for some individuals with BPD and their families. For the purposes of this report, family can refer to both the biological family and what might be called the "family of choice," which includes spouses, romantic partners, close friends, roommates, or others who form the individual's personal support network.

In traditional family therapy, the focus is on helping the family to function better as a unit, which may include developing family coping skills around one or more members' behaviors and needs.

Family psychoeducation also works to improve functioning in the family unit, but in this intervention the focus is on helping the family to understand their loved one's illness, learn techniques to cope with problematic behaviors, and play an active role in the treatment and recovery process. Family psychoeducation often equips family members with the skills to set and enforce boundaries; manage crises; and create a supportive, validating, and recovery-focused environment.

Whereas clinicians report that treating individuals with BPD is frequently stressful—particularly as a result of threats of suicide, suicide attempts, and the intense anger often associated with the disorder—these issues touch families directly and in deeply personal ways. Family members report feeling "helpless," "hopeless," "overwhelmed," "angry," and "excluded," and they frequently experience discrimination and bias similar to that expressed toward individuals with the diagnosis.[8,86,87] Family members also report feeling "blamed" by the treatment community for a child or other loved one's illness.[8,11]

Engaging family members is particularly important because "family members' feelings of exclusion…coupled with their lack of awareness of how to react to the client's pathology [i.e., behaviors or symptoms] will make the task of effectively treating the client more difficult".[10] Studies indicate that successful therapeutic interaction with families has a positive correlation with substantially better client outcomes. In addition, when they understand their loved one's illness and treatment, family members can develop the coping skills they need to maintain their own mental health by setting boundaries; eliminating blame; and dealing with reasonable feelings of frustration, anger, fear, or sadness surrounding the diagnosis of BPD.[8-11]

Two of the more well-known family psychoeducation programs that serve family members of individuals diagnosed with BPD are Family Connections (FC), provided by the National Education Alliance for Borderline Personality Disorder (NEA-BPD)[86,87] and Family-to-Family (F2F), provided by the National Alliance on Mental Illness (NAMI).[88] FC groups are led by trained leaders who are themselves family members, or by specially trained therapists, and is manualized. It is specific to BPD, and there is a small charge for materials. F2F, on the other hand, provides information and support for other Axis I and Axis II disorders in addition to BPD and is free of charge. Groups are led by trained family members. Both FC and F2F are 12-week group interventions. These and other family psychoeducation programs provide knowledge to participants about their loved one's disorder, while empowering family members with practical strategies for problem solving and managing day-to-day challenges.

Consumers and experts in peer support and trauma-informed care praise a multifaceted approach to treatment—a "whole village" approach that encompasses comprehensive treatment, peer support, family support, and knowledgeable clinicians.[xx,xxi] Psychoeducation is an important vehicle for improving the effectiveness of family support and needs to be made more widely available. SAMHSA's NREPP identifies psychoeducational multi-family groups as an evidence-based practice.

Recovery

Despite the frequent severity of symptoms and extremely high rate of suicide and self-injury associated with BPD, this diagnosis has a very positive prognosis. Up to three-quarters of individuals diagnosed with BPD will experience measurable improvement with treatment, with many of the most debilitating and high-risk symptoms abating significantly.[26,67,89,90]

The 2003 McLean Study of Adult Development (MSAD)[91] followed adults with BPD for 6 years, conducting an assessment at baseline and every 2 years thereafter. The participants were men and women who were admitted to McLean Hospital in Belmont, Massachusetts, for inpatient treatment sometime between 1992 and 1995 and who met diagnostic criteria for BPD. At 2-year follow-up, 34.5 percent of participants no longer met study criteria for BPD; at 6-year follow-up, the number climbed to 68.6 percent; and at one or more subsequent follow-up periods, 73.5 percent no longer met study criteria for BPD. Of those who no longer met study criteria after 2 and 4 years, only 6 percent again met study criteria for BPD at 6-year follow-up.

These findings were consistent with the 2002 Collaborative Longitudinal Personality Disorders Study (CLPS),[92] which reported that 59 percent of participants with a diagnosis of BPD met fewer than 5 criteria for BPD for each of 12 consecutive months after baseline assessment, as reported by participants at 6- and 12-month follow-on assessments. All study participants were either in or seeking treatment, or had a previous treatment history. Armed with such encouraging evidence, one researcher deemed BPD "the good prognosis diagnosis".[91,93]

The MSAD study reported the greatest decline in impulsive symptoms, with the least in affective symptoms. Cognitive and interpersonal symptoms were intermediate over time. What Zanarini et al. identify as "acute" symptoms, such as suicidal behavior and self-harm, were quickest to resolve,

[xx] K. Van Gelder and A. Wang, personal communication, January 13, 2010.

[xxi] M. Fitzpatrick, K. Duckworth, and J. Payne representing the National Alliance on Mental Illness, personal communication, January 7, 2010.

whereas "temperamental" symptoms such as unstable relationships and chronic anger and fear of abandonment were much slower.[94] It is important to note that individuals who no longer meet the diagnostic criteria for the disorder may still experience one or more significant symptoms. Results of small-scale, short-term studies suggest that individuals who have been diagnosed with BPD can have substantial difficulty in certain areas of functioning, especially socially, for anywhere from 6 months to 7 years after diagnosis.[90]

Consumer and Family Experiences

Discrimination and Blame in the Clinical Setting

Despite its positive long-term prognosis, the diagnosis of BPD carries with it heavy discrimination and bias, and symptoms can and often do inflict intense emotional pain on those living with this illness. Consumers, providers, and researchers almost universally describe BPD as being very isolating for both individuals and their families. This isolation extends into the clinical setting as well as in the community at large. A 2007 study by Horn et al.[42] identified five themes in interviews conducted with individuals about their diagnosis of BPD:

- Knowledge as power;
- Uncertainty about what the diagnosis meant;
- Diagnosis as rejection;
- Diagnosis as about not fitting; and
- Hope and the possibility of change.

Some consumers in the study reported feeling that the diagnosis of BPD gave them a feeling of clarity, focus for the future, and a sense of control by providing "something I could firmly grasp." Others said that the diagnosis left them feeling out of control because they did not understand what it meant and their providers were not forthcoming with information, nor did they communicate any hope for recovery. Whether consumers felt relieved or even more distraught after receiving a diagnosis seemed to rely heavily on the extent to which they were empowered with knowledge of their disorder and what they could do to recover.

Participants also consistently reported feeling that receipt of a diagnosis was quickly followed by withdrawal of services. One consumer said that the response to his persistence in trying to find more answers about his diagnosis and treatment options was "I'd be put under the hat of being a difficult client…which as it turned out kind of reinforced the label for them." Other consumers echoed feelings of being "labeled," "rejected," and "fit in a box." Said one, "It was a dustbin label…just a diagnosis where you don't fit into other categories".[42]

The theme of rejection within the clinical setting appears throughout the literature and is reflected strongly in consumer comments as well. A 2009 article in *Mental Health Today*[95] said that part of the reason for this often accurate impression may be the diagnosis itself:

> …many clinicians feel that it is impossible to treat a person's personality, and therefore people with this personality type only really receive treatment for their acute symptoms in times of crisis rather than for the disorder as a whole. As a crisis often appears brief…the time span in which professionals intervene is often short, so the opportunities for making any real difference to the service user's life is [*sic*] very limited. This reinforces the professional view that the condition is untreatable, and strengthens the stigma attached to it. Many service users diagnosed with personality disorder do indeed feel stigmatized by services, and feel they are viewed as difficult, manipulative, and attention-seeking. Many feel blamed by services for their condition, when all they seek is legitimacy and basic acceptance.

Families also often feel blamed by clinicians for their loved one's illness. Although a large body of evidence points to the disorder's development from the interaction of multiple factors, there remains a strong sense that the disorder is someone's "fault." One family described blame as a myth, saying:[8]

> I actually just recently read something that said it was earlier believed that the lack of mother's nurturing as a young child was to blame…Also that anyone who has [BPD] had to have some sort of trauma…some sort of abuse, either physical or sexual abuse when they were younger. And I think people just automatically assume that that's the given.

A positive development during the last several decades has been the increased attention and respect that is now paid to the voice and experience of those who have psychiatric diagnoses as well as their families. Although this is not yet a universally embraced or applied value, mental health systems and professionals have come a long way in appreciating how much can be learned in terms of treatment and service design, delivery, and evaluation by creating opportunities for consumers and families to provide input. A byproduct of this development is the hope and expectation that redefined

relationships between consumers, family members, and professionals will help reduce discrimination and bias and promote recovery.

Combating Discrimination and Bias with Peer Support and Consumer-Focused, Trauma-Informed Care

The single greatest obstacle for people with BPD may be overcoming widespread misconceptions at every level, including the nature of the disorder, its causes, diagnosis, treatment, and the coping skills necessary for dealing with it.[xxii] Placing the individual at the center of the treatment approach is essential to fostering recovery for BPD. Person-centered care is garnering a renewed focus in the U.S. not only in the arena of mental health services, but in health reform overall.

Although the potential etiology of BPD can offer important insight and guide treatment decisions, it should not be the sole or perhaps even the primary factor in determining how care proceeds. Consumer researcher and peer support expert Shery Mead warned that when a person who has been diagnosed with BPD is viewed as having a brain disorder that needs to be fixed, clinicians lose sight of how that person has learned to make sense of their experience.[xxiii]

Mead describes peer supports as "a fundamentally different framework for making meaning about our experiences and perceptions of our past, present, and futures. …In peer support, we can learn to form relationships outside of the definition or context of 'illness' and to talk about the effects of trauma and abuse in our lives".[96] She contrasts this supportive environment with the more traditional approach to treating trauma-associated disorders, which she believes labels pain "as a symptom to be treated":[96]

> We again learn to view ourselves and our experiences through others' eyes rather than through our own. We are again defined by others. Our most personal experiences are interpreted and named by others. We learn to believe that we are "mentally ill." …If we challenge the treatment, we are considered noncompliant, if we disagree with the label we are in denial, and if we ask too often for the help we've been told that we need, we are considered "frequent flyers." Yet all of those things seem to validate and justify others' opinions that we are the "problem"—that we are "sick" and in need of "treatment."

[xxii] K. Dawkins, personal communication, January 13, 2010.

[xxiii] S. Mead, personal communication, January 12, 2010.

Beth Filson, another consumer researcher and expert in peer support, also cites the need for providers to understand that individuals' behaviors have meaning and that those behaviors, however destructive from the clinician's point of view, are about communicating and relating the only way they know how.[xxiv] The aspect of choice is central to her view of treatment, and she identifies the most effective interventions as those that are compassionate, reinforce the dignity of the client, and are founded on shared respect. Filson calls peer support "beyond vital."

These comments bring to the foreground the importance of individualizing treatment. Consumers report that they need different things at different times in the course of their recovery, and effective treatment will take into account the course of the illness and the rights of each person to make his or her own treatment choices. The common denominator, says Filson, is that clients are human beings who need a compassionate relationship, one that embodies hope and healing.[xxv]

[xxiv] B. Filson, personal communication, January 12, 2010.

[xxv] B. Filson, personal communication, January 12, 2010.

VI. Conclusion

As this report makes clear, BPD symptoms can be severe, debilitating, and isolating, and individuals with this disorder suffer discrimination and bias. However, despite its severity and burden, BPD has a surprisingly good long-term prognosis with a high rate of recovery. Awareness, education, and access to treatment and services are critical to ensuring that individuals with BPD and their families have the tools and support consumers need to achieve recovery.

In particular, SAMHSA supports the development of accessible and appropriate early detection and early intervention, the use of evidence-based practices, and family education programs to help ameliorate symptoms and promote recovery and resilience for individuals with BPD and their families. SAMHSA is especially cognizant of the role that trauma in all its forms plays in the development of BPD and supports the development of trauma-informed services and trauma-specific interventions in categorical and discretionary grant programs.

SAMHSA's work on behalf of individuals with BPD and other mental health conditions is predicated on the knowledge that *prevention works, treatment is effective, and people recover from mental and substance use disorders*. We are committed to providing individuals with BPD, their families, and the communities in which they live with a full range of prevention, promotion, and treatment services. Our ultimate goal is healthy individuals, healthy communities, and a healthy Nation.

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