

Federal Partners Meeting on BPD

Summary





Federal Partners Meeting on BPD Summary

Introduction

The Substance Abuse and Mental Health Services Administration (SAMHSA), U.S. Department for Health and Human Services (HHS), gathered national experts and Federal agency representatives (see Appendix A) in Rockville, MD, on November 9, 2011, for a meeting titled, “Federal Partners Meeting on the Borderline Personality Disorder (BPD).” The meeting was cosponsored by the National Alliance on Mental Illness (NAMI) and the National Education Alliance for Borderline Personality Disorder (NEA-BPD). The purpose of the meeting was twofold: (1) to review progress made in understanding and treating BPD as described in the 2010 BPD Report to Congress and (2) to discuss how Federal partners can collaborate to disseminate new findings and understanding of BPD. Meeting participants heard from experts and consumers in the field of BPD and engaged in a facilitated discussion of opportunities for collaboration. Highlights of the meeting presentations and group discussion follow.

Welcome

Mark Jacobsen, Ph.D., Public Health Analyst
Center for Mental Health Services
Substance Abuse and Mental Health Services Administration

Dr. Jacobsen welcomed meeting participants and acknowledged the work from SAMHSA’s partners that went into preparing a Report to Congress on BPD last year. BPD is a serious but treatable disorder, Dr. Jacobsen said. This meeting is an important opportunity for the Federal sector to understand BPD and formulate its response.

Perry Hoffman, Ph.D., President
National Education Alliance for Borderline Personality Disorder

NEA-BPD is an all-volunteer organization that started 10 years ago to promote awareness, education, and research, Dr. Hoffman explained. With support from the National Institute of Mental Health (NIMH), NEA-BPD hosts conferences for its members and professionals in the field. Staff co-edited a book with Dr. John Gunderson, published by the American Psychiatric Press, and worked with Congress to declare May as BPD month. The organization has also worked with NAMI to make BPD a priority population. A new public service announcement features NFL player Brandon Marshall, who recently announced he has BPD, Dr. Hoffman reported. NEA-BPD also supports a call-in series and hosts the Family Connections Program.

**Mike Fitzpatrick, Executive Director
National Alliance on Mental Illness**

NAMI is the Nation's largest grassroots mental health organization, Mr. Fitzpatrick said. It has partnered with NEA-BPD to educate Congress and the Nation about BPD, which is a serious and misunderstood mental illness that causes a great deal of suffering. Stigma about mental illness stops people from getting needed treatment and we need to invest in enhanced research, treatment, and services for people with BPD and their families, Mr. Fitzpatrick said. He noted that NAMI understands there are workforce training issues, and he has no illusions that sufficient resources are available given nationwide cutbacks in services for persons with serious mental illnesses. Partnerships across the Federal government are essential to get treatment to people when they need it and to conduct research, he said.

**A. Kathryn Power M.Ed., Director
Center for Mental Health Services
Substance Abuse and Mental Health Services Administration**

BPD is a common, complex, and poorly understood condition affecting 18 million individuals and their families each year, Ms. Power said. She noted that clinicians, researchers, and individuals in recovery have struggled with the name "borderline personality disorder." "When we label, we marginalize," Ms. Power said. The goal in transforming health and behavioral health care in America is a high-quality, self-directed, satisfying life in the community for every man, woman, and child in America. This includes four dimensions: health, home, purpose, and community.

In 2009, the Institute of Medicine released a report called Preventing Mental, Emotional, and Behavioral Disorders among Young People: Progress and Possibilities. Commissioned by SAMHSA's Center for Mental Health Services (CMHS), the report provides concrete evidence that many mental, emotional, and behavioral disorders in young people are preventable, Ms. Power said. Interventions that strengthen families, individuals, schools, and communities build resilience and reduce problem behaviors. Ms. Power noted that untreated trauma in childhood exerts a powerful influence on adult emotional and physical health (e.g., 40 to 70 percent of BPD patients report childhood sexual abuse). More important, she added, acknowledging trauma helps us begin to understand that seemingly self-destructive behaviors are coping mechanisms which allow individuals to survive unspeakable acts.

Ms. Power praised Dr. Marsha Linehan's humility and courage in the face of her own struggles with untreated mental illness, which led to the development of dialectical behavior therapy (DBT), now considered an evidence-based practice (EBP) for BPD. Ms. Power acknowledged the importance of family psychoeducation and pointed to two well-known programs—Family Connections (offered by NEA-BPD) and Family-to-Family (offered by NAMI). SAMHSA's evidence-based toolkit on family psychoeducation is available online free of charge, she added.

Ms. Power said the BPD Report to Congress reflected SAMSHA's commitment to work closely with NEA-BPD, NAMI, Federal partners, individuals in recovery, and champions in Congress. SAMHSA is working to provide a full range of prevention, treatment, and recovery support services to individuals with mental and substance use conditions, including individuals with BPD, their families, and communities, she said.

Borderline Personality Disorder

Overview of Borderline Personality Disorder

**John Gunderson, M.D., Director,
Psychosocial and Personality Research,
McLean Hospital Professor,
Harvard Medical School**

Dr. Gunderson provided a historical review of BPD. Before 1970, BPD was widely considered untreatable, Dr. Gunderson said. Otto F. Kernberg is credited with raising the national consciousness about BPD and stimulating a generation of treaters and researchers. His theories (e.g., unstable distributed state of self) continue to contribute to an understanding of BPD, as does psychoanalytic literature from this time, Dr. Gunderson noted.

After 1970, BPD was recognized as a syndrome. According to Dr. Gunderson, Hagop Akiskal famously said, “It’s a syndrome that is an adjective instead of a noun,” igniting what has become a recurrent theme about BPD, that it’s an atypical form of another psychiatric disorder. In 1975, Dr. Gunderson wrote a paper with Margaret Singer that set the stage for acceptance of BPD as a diagnosis in the official nomenclature. Clinically, these individuals are known as difficult patients with dramatic fluctuations; neither psychoanalysis nor drugs appear to help. The literature of this era described people with BPD as intractable and treatment resistant, in part because ineffective treatments only made their problems worse, Dr. Gunderson noted.

In the 1980s, BPD was considered an atypical form of major depression, posttraumatic stress disorder (PTSD), and bipolar disorder, though research clearly documented major differences between and among these conditions, Dr. Gunderson explained. Literature about BPD grew, including a descriptive overlap with substance use disorders—about 50 percent of BPD patients

have substance use disorders, and as many as 50 percent of patients who appear for treatment of substance use disorders have BPD.

In the 1990s, BPD became a subject for biological psychiatry and began to be described as a treatable condition:

- Dr. Linehan pioneered the idea of BPD-specific treatments that could be empirically validated. DBT emphasizes the need for common goals and skills building. The therapist is seen more as a coach who self-discloses, admonishes, and gives directives, which is quite different from the psychodynamic tradition.
- Peter Fonagy developed the theory behind mentalization-based treatment (MBT). He identified exchanges between caretakers and children that failed to help children learn how to identify feelings and led to systematic misattributions about what was going on in others. Therapy helps patients examine and read situations correctly.
- Neurobiological advances show there are other treatments for BPD, with magnetic resonance imaging (MRI) and positron emission tomography studies demonstrating BPD patients have a hyper-responsive amygdala and impaired inhibition that leads to emotional and interpersonal instability.
- Neurohormones such as oxytocin and opioids have been shown to heighten fear of abandonment and rejection.

In the 2000s, BPD was identified as a disorder that is considered highly heritable, Dr. Gunderson reported. Four phenotypes for BPD have been defined: emotional hyperbolic, behavioral dyscontrol, interpersonal hypersensitivity, and cognitive. Twin studies reveal a common pathway to development of the disorder. Research also reveals that only about 12 percent of BPD patients who recover end up relapsing, which Dr. Gunderson called “a remarkable statistic, unlike the course of any other major psychiatric disorder.” However, even given this positive prognosis, many BPD patients remain

socially dysfunctional throughout life; similar to schizophrenia, positive symptoms go away, but negative symptoms persist. Co-occurrence with other conditions, particularly substance use disorders, complicates treatment, Dr. Gunderson noted. BPD needs to be treated in order to successfully address comorbid conditions; treatment for BPD is rarely successful in the presence of active substance use, he said.

Ongoing challenges include the fact that BPD is rarely diagnosed, with one study indicating that only 1 out of 40 people who meet the criteria receive the diagnosis, Dr. Gunderson said. Health care reimbursement structures don't support often lengthy BPD treatments and there is a shortage of trained clinicians and young BPD researchers. Further, 70 percent of mental health professionals report actively avoiding patients with BPD, Dr. Gunderson reported. Federal funds to research this disorder (about \$6 million) are disproportionate to the number of people affected. There are exciting new developments in the field, but ongoing Federal support is needed to continue research, he said.

Stigma in Psychiatry/ Helping Professionals

John Oldham, M.D., President American Psychiatric Association

Dr. Oldham provided background on BPD and psychiatrists' role in treating it. He noted that personalities exist on a continuum, much like blood pressure; both are needed to survive, but too much or too little can be problematic.

The definition of personality disorder in the DSM-IV is "an enduring pattern of inner experience and behavior that deviates markedly from expectations of the individual's culture in two or more of four areas (i.e., cognition, emotion, interpersonal functioning, and impulse control)," Dr. Oldham said. Individuals with BPD have a severe impairment in trusting others, high internal anxiety, and stormy relationships. They are overemotional and impulsive and can have self-injurious behavior (e.g., 8-10 percent commit suicide, 60-70 percent make suicide attempts). There is high comorbidity with mood disorders, anxiety, and substance use disorders.

Dr. Oldham pointed out that, according to the World Health Organization, five of the 10 leading causes of disability worldwide are psychiatric conditions; however, this study did not include personality disorders. In 1990, an American Psychiatric Association (APA) Task Force found that treatment for BPD is difficult, transference is typical, and outcomes are variable.

The Australian and New Zealand Journal of Psychiatry reported that, although 80 percent of Australian psychiatrists see BPD patients in their practice, 40 percent would not treat them, and 5 percent felt there was no treatment—demonstrating just how difficult it is to change perception about BPD, Dr. Oldham said. Similarly, APA's Practice Research Network sampled 1,500 psychiatrists, asking how many BPD patients they see, and got an answer of about .05 percent,

which is much less than the condition's known prevalence. "We figured out they were coding them as other conditions because, at the time, they couldn't get paid if it was coded as BPD," Dr. Oldham explained.

Dr. Oldham noted there are four essential elements for effective BPD treatment: strong therapeutic alliance, availability of skilled therapists, funds/insurance coverage, and time. Types of psychotherapy for BPD include DBT, MBT, Cognitive Behavioral Therapy (CBT), Schema-Focused Therapy, Transference-Focused Therapy, Systems Training for Emotional Predictability and Problem Solving, and general psychiatric management. The APA's Division of Government Relations examined the kind of coverage that is available for BPD and found that most treatment plans cover it, though there must be a "medically necessary" reason to do so.

Despite advancements, fears persist, Dr. Oldham said, pointing to a recent magazine headline that read, "Borderline Personality Disorder: The Disorder Doctors Fear Most." In the Army, where personality disorders are considered to have existed prior to service, soldiers are honorably discharged but do not qualify for veterans' benefits.

Another challenge is a possible change in name to "emotion dysregulation disorder." Though BPD is now considered a spectrum of mood/impulse control disorder, it is still on the border of other things, Dr. Oldham explained. To call it something else might threaten insurance reimbursement and progress made toward understanding and treating the disorder, he said. Ultimately, the greatest challenge remains the stigma that attaches to BPD and those who treat it, Dr. Oldham concluded.

Treatment and Community

Dialectical Behavior Therapy

Marsha Linehan, Ph.D., Professor University of Washington

Dr. Linehan described how she developed DBT. She began her work in the 1980s while researching suicide and noted that all of her subjects met criteria for multiple Axis I and Axis II disorders. They were a severely disabled group with significant interpersonal dysregulation. Dr. Linehan realized these patients had low distress tolerance, which is a critical problem for individuals with BPD.

BPD is a pervasive disorder of the emotional regulation system, Dr. Linehan explained. Emotions are evolutionarily adapted to serve as a rapid response system to help solve problems and motivate action. Inability to communicate one's emotions creates significant problems and, without stable emotions, it is hard to have an identity, she said. Most therapists now understand this; however, trying to control a patient makes the disorder worse. On the other hand, excessive empathy interferes with the therapist's ability to teach new skills. The solution, Dr. Linehan discovered, is to provide a dialectical approach that validates the individual's experiences while helping the person develop more effective responses.

DBT requires patients to come to a radical acceptance of their problems, including their past, present, and future limitations, Dr. Linehan said. This approach focuses on teaching the individual to tolerate distress without reacting impulsively. Dr. Linehan cited data which show that DBT significantly decreases suicide attempts and emergency room and inpatient admissions for suicidality. Still, she noted that, while standard DBT is good at treating many symptoms of BPD, it

is not as effective at treating anxiety. Dr. Linehan described a study of DBT alone compared with DBT combined with case management. Both treatments decreased suicidal behavior; however, DBT with case management was perceived as more therapeutic by patients after 1 year. DBT also needs to be adapted to treat adolescents, she pointed out.

Treating individuals with BPD can lead to burnout, Dr. Linehan acknowledged. To treat patients effectively, the therapist needs to practice his or her own sort of radical acceptance of the client, together with “a spaciousness of mind and a degree of humility,” she said. Therapists can also become emotionally dysregulated, leading to excessive fear, anger, and hostility that result in attempts to control the patient, rejection, and attack. This is counterproductive when dealing with a person who is suicidal, Dr. Linehan noted.

Part of the problem is lack of training for clinicians and no standards of care for treating BPD. She noted that competency reduces burnout and increases positive results. Another problem in dealing with BPD is that effective treatments are not implemented broadly or with fidelity. “What would it be like to have a disorder and not be able to get treatment?” Dr. Linehan asked rhetorically. She suggested the need to develop DBT protocols and program accreditation standards. The research and the will to do so are there, but funds are lacking, she said.

Community Perspectives

Ken Duckworth, M.D., Medical Director National Alliance on Mental Illness

Dr. Duckworth discussed the problem of parents being blamed for their child’s mental health problems and the trauma that results. He noted that NAMI was established, in part, to help families cope with these issues. Trauma-informed care is about preventing people from being retraumatized (e.g., through the use of restraint and seclusion) and is part of what NAMI cares passionately about, Dr. Duckworth said. He noted

that BPD continues to be misdiagnosed and mistreated, but once individuals understand there are effective treatments, they are more willing to come forward and seek care.

Dr. Duckworth spoke about Massachusetts’ experience with health reform. Though therapists say they provide DBT or CBT and are paid to do so, there are no standards against which to measure their use of these tools. This contrasts sharply with primary care, where everything is measured, Dr. Duckworth said. He believes the mental health field needs to be open to measuring outcomes. As the Federal government looks toward Accountable Care Organizations and payment reform, interest will increase in attending to people’s mental health as part of their overall health, Dr. Duckworth said.

Prevention/Early Detection

Blaise Aguirre, M.D., Medical Director, Adolescent DBT Center McLean Hospital

Dr. Aguirre talked about BPD in adolescents, questioning why it is not an official diagnosis for this age group. When working with adults who have BPD, he discovered that nearly all reported problems earlier in their childhood. A longitudinal study found BPD can be diagnosed in young people, occurring in 1 to 3 percent. The challenge, Dr. Aguirre pointed out, is to determine which internalizing behaviors (e.g., fear, distress) and externalizing behaviors (e.g., high novelty seeking, impulsivity, lack of constraint) are a normal part of adolescence and which point to potential mental health problems, including BPD. The key is to determine what a specific behavior means to the individual, he explained. For example, he noted that young children who self-injure use it as a way to regulate their emotions.

Dr. Aguirre reported on a study which found that internalizing symptoms have an especially strong effect on adult BPD when manifested between ages 11 and 14. In some retrospective

studies, conduct/oppositional behavior and ADHD are connected with BPD. Early adolescence is an important time to start looking at how young people deal with stress or anxiety, Dr. Aguirre said. Trauma is another important factor, with a significant number of BPD patients having experienced adverse childhood experiences. Some symptoms suggestive of BPD drop off in young adults ages 17 to 24, perhaps because they move away from home and leave a toxic environment, Dr. Aguirre theorized.

Opportunities for early intervention frequently are missed in part because it is controversial to diagnose personality disorders in youth, Dr. Aguirre pointed out. However, dedicated treatments are emerging and increasingly are empirically validated. Approaching BPD as a skills deficit problem (i.e., young people don't have an ability to regulate emotion) makes treatment habilitative. He concluded that there is no compelling evidence for the use of medications to treat BPD, and they should never be used as a primary treatment for adolescents or adults.

Question & Answer Session

Alexander F. Ross, Sc.D., of the HHS Health Resources and Services Administration (HRSA) asked what mental health treatment would look like from a primary care perspective, noting that this is the type of operational guidance HRSA could use.

Dr. Linehan spoke about DBT training groups given in primary care settings that include nurses, physicians, and hospital staff. She said BPD patients frequently have comorbid physical disorders but are unwilling to go to physicians for treatment. She recommended an alliance between primary care and mental health.

Dr. Gunderson added that 6 percent of primary care visits are by people with BPD, and they typically receive medications, despite the fact that medications are likely to have only a modest effect for BPD patients. Primary care physicians need education on basic management strategies, he suggested.

Dr. Ross also asked about the role of tele-behavioral health. Dr. Linehan said she supports it, but getting a person with BPD to call and make an appointment is difficult. Involving nurses might help ease concerns that individuals with BPD have about interacting with doctors, she noted.

Charlotte Mullican of the HHS Agency for Healthcare Research and Quality asked how BPD impacts chronic illness, recognizing the role that trauma can play in rates of chronic illness. Ms. Power mentioned that HHS is moving toward the presence of multiple chronic conditions as the basis for funding programs for research, internships, services interventions, and infrastructure. Dr. Oldham said APA is working with the American Medical Association to address co-occurring conditions, which complicate treatment and recovery. He emphasized the need to provide education to primary care practitioners.

Working Lunch Address

Changing the Conversation about Borderline Personality Disorder:

Challenges and Opportunities

Pamela S. Hyde, J.D., Administrator Substance Abuse and Mental Health Services Administration

Ms. Hyde noted that State and Federal budget declines are affecting the ability of the behavioral health field to respond to increasing needs. At the same time, she pointed out, capacity is growing in primary care, and SAMHSA is looking at ways to make behavioral health part of overall health care. SAMHSA has eight Strategic Initiatives, with a focus on prevention and recovery. This does not leave out treatment, Ms. Hyde said; treatment is a path to recovery.

By 2020, mental and substance use conditions will surpass all physical diseases as a major cause of disability worldwide, Ms. Hyde reported. However, she noted that the United States is not focused on behavioral health conditions as preventable diseases. In contrast to diabetes, for which 84 percent of people receive treatment, only 38 percent of individuals receive treatment for mental illnesses and only 12 percent receive treatment for substance use disorders. She pointed out that, although an estimated 18 million Americans will develop BPD in their lifetimes, making it more common than schizophrenia and bipolar disorder, it is frequently misdiagnosed.

Ms. Hyde noted that suicide is one of the 10 top leading causes of death in America; deaths by suicide outnumber homicides or deaths from HIV/AIDS. The suicide rate of people with major depression is eight times that of the general population, while individuals diagnosed with BPD have a suicide rate 50 times higher. Collaboration between primary care and behavioral health is essential; Ms. Hyde noted that nearly half of the individuals who die by suicide have seen their primary care provider within a month of their death, but the

issue is never raised. Health care professionals need training in how to recognize, assess, and manage patients at increased risk for suicide. She also noted that about one-third of adult mental health issues are caused by trauma, and children are especially vulnerable.

Despite high rates of suicide and self-injury associated with BPD, Ms. Hyde commented that this diagnosis has a positive prognosis. However, there are challenges in implementing EBPs with fidelity. Ms. Hyde said she believes we need a recovery construct that includes individuals and families at its center. In short, treatment is not the point; people's lives and how they live them is the point, she explained.

Finally, Ms. Hyde discussed the fact that Americans treat behavioral health as a social problem, not a public health problem. This results in blame, discrimination, and social exclusion; attention to symptoms rather than to individuals; and ineffective and dangerous treatment responses. She spoke about the need to help Americans understand that mental and substance use conditions can be prevented and called on meeting participants for help. "We have to change the conversation," Ms. Hyde said.

Question & Answer Session

Bradley E. Karlin, Ph.D., of the U.S. Department of Veterans Affairs (VA) asked what's really important for effective policy change. Ms. Hyde noted that public response depends on how the problem is perceived (e.g., restricting guns for people with mental health problems vs. promoting mental health). Just as they learn the basic signs of heart attack or stroke, Americans need to learn how to recognize and seek help for mental and substance use conditions, Ms. Hyde said.

Dr. Linehan said a large part of the problem is overall attitudes toward mental health disorders. Changing the conversation requires educating children about behavioral health issues. Ms. Hyde agreed about the need for a basic public health campaign to shift how people think about BPD, similar to the shift in public attitudes about HIV/AIDS.

Federal Partners Think Tank on Borderline Personality Disorder

Consumer/Family Member Perspective on Borderline Personality Disorder

Perry Hoffman, Ph.D., President National Education Alliance for Borderline Personality Disorder

Dr. Hoffman said she titled her presentation “Help” because this is the request she most often hears from families. The impact of mental illnesses on families has been termed a “catastrophic event,” Dr. Hoffman said. She showed several clips from an educational video series for families about BPD called “If Only We Had Known,” produced by Kevin Dawkins.

Early research on mental illnesses and families revealed that expressed emotion (i.e., family members’ attitudes and beliefs toward their relative) is a predictor of relapse, Dr. Hoffman said. Family psychoeducation programs evolved to help lower expressed emotion in families, which can reduce relapse rates for individuals with mental illnesses by as much as 20 percent, she explained. Another study found that families using skills learned through DBT felt less burdened. They experienced less depression and grief and their sense of mastery increased.

Dr. Hoffman spoke briefly about two effective psychoeducation programs: (1) NAMI’s Family-to-Family Program, which is the largest family psychoeducation program in the United States and considered an EBP for individuals with mental illnesses; and (2) NEA-BPD’s Family Connections, which is a 12-week community-based program specific to families who have a loved one with BPD. Family Connections is free and co-led by trained family members, but demand is greater than availability, Dr. Hoffman noted.

State of the Research Report from NIMH

James Breiling, Ph.D. National Institute of Mental Health

Dr. Breiling applauded the work that family members have done to raise awareness and support for critical research through such organizations as the BPD Research Foundation and National Alliance for Research on Schizophrenia and Depression. He noted that BPD is a disorder that has a relatively young, small body of research, with several significant contributions from other countries such as Germany, Holland, England, and Australia. NIH’s PubMed lists fewer citations for studies on BPD than other major mental illnesses, but that does not indicate lack of progress, Dr. Breiling explained. For example, two powerful intervention models emerged from research on juvenile delinquency. However, he said, young people continue to receive ineffective treatment because of limited adoption of proven practices.

Today, a diagnosis of BPD offers hope, not hopelessness, Dr. Breiling pointed out. There are effective treatments but, due to stigma, even therapists do not want to diagnose and treat this disorder. Once a person receives a diagnosis, he or she needs to receive an evidence-based treatment that is promoted universally, much the same as flu vaccines and glaucoma screenings. Dr. Breiling noted. He pointed out that pharmaceutical companies have effective ways to disseminate medication and there are guidelines and training available on how to use them. However, he said, psychiatric treatments are not as well promoted.

Dr. Breiling discussed the difficulty of diagnosing BPD. He noted there are hundreds of combinations of symptoms that make up this disorder, which frequently co-occurs with other personality and Axis I disorders. Dr. Breiling suggested making the diagnosis of symptoms clearer by perhaps defining three core symptoms. He also noted that many social workers see

individuals with BPD but have no evidence-based training for dealing with this condition.

Further, Dr. Breiling noted, even if a person is said to have recovered from BPD, two to three symptoms can persist, and real-time assessment of BPD is a challenge. The future of psychiatric treatment is ongoing measurement, similar to regular blood pressure checks, he said. He pointed to a new tool NIH has developed called the Patient Reported Outcomes Measurement Information System (PROMIS®), a series of flexible and responsive assessment tools that measure patient-reported health status (<http://www.nihpromis.org/default>). Nine scales cover anger, anxiety, depression, fatigue, pain, behavior, physical function, satisfaction with social activities, and satisfaction with social roles. PROMIS® helps physicians better understand which treatments work for specific individuals and how to help them better manage their diseases. He said he believes that real-time computer assisted assessment has the potential to begin to separate more durable traits in individuals with BPD from those states which are influenced by mood or other triggers that could be avoided.

Though there currently are promising interventions for BPD, Dr. Breiling said NIMH is always looking forward. He pointed to a new research program that is testing two interventions which teach individuals with BPD how to use distancing techniques. Investigators will measure their effectiveness using MRI scans. He reiterated his belief that families are making a significant difference in understanding and treating BPD and added that young researchers will “transform the field.”

Dissemination of Research into Practice

Kathryn Power opened the afternoon discussion session by noting that SAMHSA seeks to reduce the impact of mental and substance use conditions across the United States with a focus on services, infrastructure, and interventions. This includes efforts to bring EBPs to scale. There is not a lot of money to invest in new programs, she noted, and the challenge is how to get BPD research into the hands of clinicians and practitioners. She suggested that SAMHSA and NIMH could consider a joint meeting around dissemination of practices and implementation research. NIMH Director Tom Insel, M.D., explained that NIMH seeks to conduct science that has “high impact.” Its findings are disseminated through SAMSHA and other venues. He noted that NIMH has a new online brochure on BPD that was a collaborative venture with NEA-BPD.

Ms. Power opened the floor to comments. An edited transcript of the discussion that followed is included in Appendix B. Key themes that emerged during the discussion follow.

Public Awareness/Support

A number of meeting participants agreed with Ms. Power that there is a need to build public awareness about the fact that mental illnesses are common; nearly half of Americans will develop one in their lifetime. She said it is important to name BPD in SAMHSA’s recovery campaigns and to frame it as a condition from which people recover. One way to do so, noted Richard McKeon, Ph.D., Chief of the CMHS Suicide Prevention Branch, is to promote understanding of the interaction between BPD and suicide. SAMHSA’s National Suicide Prevention Lifeline network has counselors in 152 participating crisis centers who could be trained to screen for BPD, he said. The National Action Alliance for Suicide Prevention is a potential partner, as well; Dr. McKeon noted they have a task force focused

on the behavioral health workforce. In addition, SAMHSA's Garrett Lee Smith grants focus on youth suicide prevention, and SAMHSA's Mental Health Block Grant requires grantees to be more aware of suicide and suicide prevention, as well as trauma-informed care, Ms. Power said.

Several meeting participants pointed to the power of the media in raising the visibility of health issues. The U.S. Department of Veterans Affairs (VA) is launching a national anti-stigma campaign called "Make the Connection," reported Dr. Bradley Karlin, National Mental Health Director for Psychotherapy and Psychogeriatrics at VA. Public service announcements will air nationally, including during the Super Bowl, and a Web site will include stories of veterans who have recovered from mental health conditions. In a similar vein, Real Warriors is an award-winning anti-stigma campaign that promotes mental health treatment, reported Dr. Kate McGraw, Acting Deputy Director of Psychological Health Clinical Standards of Care for the Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury.

Training/Education

There was a great deal of discussion about the need to train the behavioral health workforce to assess for and treat BPD. Dr. Linehan pointed out that BPD clients are not 9 to 5 patients; mental health professionals need training to deal with suicide and other facets of this disorder. Many mental health professionals are afraid to treat BPD, and there is a lack of funding to train them in the use of effective treatments, she said. Even more fundamental, she pointed out, is that most academic settings lack people who can teach DBT or other EBP treatments and oversee graduate students and programs. Ultimately, Dr. Linehan remarked, the professionals who might be trained don't want patients with BPD, and the professionals who aren't trained see them largely in community health centers.

New models of training are needed to address the changing workforce, which increasingly is composed of individuals with master's and bachelor's degrees, as well as peers, noted Dr. Bruce Cuthbert, Director of the Division of

Adult Translational Research and Treatment Development at NIMH. He reported that NIMH has issued a proposal to measure elements of empirically supported therapies for an early stage cognitive intervention. Researchers will determine whether the elements of the intervention are delivered with fidelity to the model, a problem for staff in the field. In addition, he reported that one of NIMH's preeminent behavior therapists, Edna Foa, is working with VA to implement a range of exposure therapies she developed for PTSD, obsessive-compulsive disorder, and other anxiety disorders. The VA started an extensive program that trains staff to deliver these exposure therapies; the most promising clinicians are identified to train more therapists, Dr. Cuthbert reported.

Primary care practitioners need to be trained about BPD, as well, Dr. Oldham noted. Professional support is also important, especially after new graduates have been in practice for several years and are less likely to be connected to their peers. Dr. Hoffman pointed out that mental health professionals look for issues that are comorbid with BPD, but other health care providers don't screen for BPD. Dr. Duckworth recommended videotaping meetings such as this to be shown to residents, psychology trainees, or primary care doctors. He pointed to the challenge in getting education about BPD into residency training programs and said it is important to understand the Federal levers that impact training programs. The goal is to build capacity for people who live with BPD and for their family members.

Dr. Duckworth also pointed to the importance of providing training for families and communities. NAMI's Family-to-Family Program is the most widely employed psychoeducation program in the country, but it is not specific to BPD, he noted. NAMI and NEA-BPD are looking at partnering to bring in the specific expertise of NEA-BPD. Ms. Diane Hall, parent and NAMI liaison for NEA-BPD agreed with the need to add information on BPD into NAMI's Family-to-Family packets. Further dissemination of these programs depends on infrastructure and funding, Dr. Hoffman pointed out.

Ms. Power suggested the possibility of tying Mental Health First Aid training, which mentions BPD, to NAMI's Family-to-Family Program. Ms. Ruby Neville, Public Health Advisor in SAMHSA's Center for Substance Abuse Treatment, suggested a potential partnership with the Association for Medical Education and Research in Substance Abuse (AMERSA). AMERSA's membership includes a wide range of professionals who treat individuals with substance use disorders, which frequently co-occur with BPD.

Dissemination of Evidence-based Practices

In a related vein, many meeting participants talked about closing the science-to-service gap. There are a number of successful interventions for BPD but they are not widely disseminated or used with fidelity, Dr. Linehan pointed out. Ms. Power highlighted the fact that SAMHSA has eight EBP toolkits it promotes as approaches needed to support a recovery-focused system. SAMHSA grantees are required to choose EBP treatments and, in some cases, to be trained and certified in their use.

Dr. Karlin reported that VA has developed 13 national EBP psychotherapies, along with 13 national staff training programs, which provide clinicians with the opportunity to receive intensive training in these therapies (e.g., CBT, interpersonal therapy, motivational interviewing etc.). Fidelity to these EBP psychotherapies is measured through review and feedback of actual clinical performance, and clinicians who meet performance-based criteria receive a certificate. In addition, there is a local EBP psychotherapy coordinator at every VA medical center to help with peer groups. The VA is developing a template for each EBP that will be incorporated into its electronic medical record system, Dr. Karlin said. This will enable VA to capture data session-by-session to look at the extent to which a therapist is delivering the therapy with fidelity.

Understanding barriers to implementation of EBP therapies is also critical, noted Mr. William Hudock, Senior Public Health Advisor in the CMHS Office of Program Analysis and Coordination. Issues about implementation and scalability have not been well addressed for BPD therapies, he said. Dr. Karlin discussed VA research on why evidence-based psychotherapies are not delivered and, when they are delivered, why they are not delivered with fidelity. Two issues emerged: lack of competency-based training and organizational implementation issues. There is a need for interventions that can be implemented in real-world settings, Dr. Karlin said. Also, technology should be used to disseminate information (e.g., Web-based information/training and mobile apps). Finally, he suggested that family members and consumers put pressure on payers, insurers, and health care providers to make these treatments more widely available.

Dr. Insel noted that the changing health care landscape opens the possibility of direct-to-consumer approaches using technology (e.g., creating a Yelp.com for health care). He pointed to a new treatment for anorexia in adolescents, which is demonstrating a 50 percent recovery within 12 months. Like BPD, anorexia has a high mortality rate, Dr. Insel explained. Training parents in the use of such therapies might be an option, but especially for BPD, the interventions are intensive and require a great deal of resources. Disseminating evidence-based therapies quickly and to large groups of people is also a challenge, he said.

Finally, Dr. Insel noted the tendency in behavioral health to use only one psychosocial treatment for a mental health disorder rather than thinking more broadly. In other areas of medicine, he pointed out, "We never assume just one medication or lifestyle change is going to be sufficient. Mental health is one of the few areas where people think there has to be a single intervention, as if mental health conditions were so much simpler and responsive. We should be asking what else can be done."

Summary and Next Steps

Ms. Power thanked presenters and Federal partners for sharing their expertise and their interest in the needs of individuals with BPD. She pointed out that, even in the absence of new resources, there are opportunities for strategic partnerships to help move the agenda forward. She thanked consumers and family members for sharing their powerful experiences. “Without your voice, we don’t have any work to do,” Ms. Power said. She indicated that SAMHSA will distribute a summary of this meeting and suggested that future discussions will be shaped by the good work that was accomplished today.

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Appendix B:

Facilitated Afternoon Discussion

Collaboration Discussion-Dissemination of Research into Practice

Following are edited responses of participants during the facilitated afternoon discussion.

DR. MARSHA LINEHAN: Almost every talk covered that we have effective treatments for BPD, and we need more effective ones. That is not the point. We have effective treatments, and people cannot get them. If they get them, they often get them from inadequately trained people, and we don't have fidelity (e.g., certifications and accreditations) out there, as well as lack of funding for training. More importantly, we can't seem to get the mental health community to even believe it's important to have fidelity. I would love to hear thoughts about how to do this.

DR. KEN DUCKWORTH: Dr. Duckworth expressed interest in Federal levers that impact training programs (e.g., medical, mental health) and build capacity for people who live with BPD and family members. Also, suggest videotaping next time, as there is no other condition in mental health where you can listen to the people who conceptualized a disorder from the beginning and developed the first and best treatments. I wish any resident, psychology trainee, or primary care doctor who's frustrated could have this opportunity. The challenge is getting this into residency training—who sets those standards?

DR. MARSHA LINEHAN: The people who control clinical psychology are going to be the ones who develop the most behavioral interventions, and they're controlled by the APA. The problem is what mental health professionals learn is not what they do. Even if you teach them evidence-based treatments, people believe that "it is an art, and I should be able to do what I want."

DR. RICHARD MCKEON: About a year ago the National Action Alliance for Suicide Prevention was launched, and they developed 12 different task forces (e.g., suicide prevention and workforce). They have a work plan on the workforce and might be a very important group to involve and get input. They're trying to think of how to deal with the issue that people are not trained in suicide risk assessment and evidence-based treatments.

MS. A. KATHRYN POWER: This gives us an example of an influence strategy we can use. We don't set the rules about training, but we can influence strategies.

DR. BRUCE CUTHBERT: NIMH couldn't agree more about fidelity. Fortunately, we have Varda Shoham with us for a couple of years from the University of Arizona, who's a well-known

clinical scientist and led an internal effort to issue an RFA to measure elements of empirically supported therapies in an early stage cognitive intervention, and then figure out ways to measure if those elements are being delivered with fidelity in empirically supported treatments. Obviously, the issue is not simply, “Are they delivering it?” but “What are they delivering?” and “How do we know what the essential elements of DBT are?” The criterion can’t be that the therapy was delivered by a female with initials M.L.—that’s not good enough. An RFA such as this makes it known to the field that this is something NIMH is interested in and worried about. We’re hoping it generates a lot of other applications in this area down the road. So, we agree very strongly.

Regarding workforce training, we recognize in clinical psychology the model has been the scientist practitioner model (i.e., the scientist delivering a 50-minute hour therapy), but in our current climate that’s not the treatment workforce. Our workforce is people with master’s degrees, bachelor’s degrees and, increasingly, peers. A couple of weeks ago at the University of Delaware, NIMH co-organized a conference devoted to new models of training in clinical psychology that train students to do science at all levels in treatment and prevention from basic research in early treatment development to efficacy, effectiveness, and dissemination in big behavioral health care systems. So, the clinical scientist might get trained not to do an fMRI or random response theory modeling, but to know how to conduct experiments that look more like program evaluation in the context of messy, real world settings. In order to do that, it is important to make sure that people are trained in empirically supported therapies and that they deliver those therapies effectively.

DR. JOHN GUNDERSON: A priority is the need to train professionals as a first step. Most professionals are reluctant to give the diagnosis in part because they feel they do not have training in what to do with this diagnosis. We want to develop a training institute, but it’s very expensive to do that. There is no money for salaries for trainers. Perhaps there’s a way for the major institutes to be a partner in something like this with support from private donors.

DR. MARSHA LINEHAN: I support 100 percent what you said about having to get graduate schools changed. I’ve been funded to work on this, and the biggest problem is getting supervisors. I’ve gone around to my former graduate students, and they’re all running training programs in their own universities, but they can’t find supervisors. You can’t train people to do things in graduate programs without at least a group of knowledgeable people in the community or on the faculty who know what you’re training them in. Part of the problem is that we don’t have the faculty or clinical scientists in the community. I don’t like to have out-of-town supervisors for a first-time client. There has to be a solution. We can’t let the academic groups do it until we have active faculty who know what they’re doing, which we don’t have.

DR. BRUCE CUTHBERT: Several years ago, Edna Foa, one of our preeminent behavior therapists, who spent the earlier part of her career developing exposure therapies for OCD, PTSD, and other anxiety disorders, decided to get into intervention. After the Gulf War, she got in touch with the Department of Veterans Affairs (VA), and they have started a very extensive program that brings an evidence model to a site where lots of staff are trained to deliver the exposure therapy. She identifies the most promising clinicians, and they become the lead clinician for that site to train more therapists. She’s developed a way to increase trained therapists who can supervise at the site in a rapid way. DBT may be more difficult because there are more elements.

DR. MARSHA LINEHAN: We do something similar in the community; however, in academic settings, there are not people who can teach it.

DR. BRUCE CUTHBERT: Yes, this is a problem that NIMH is trying to address. It has to be grown. It can't develop overnight and, at the least, we don't have the resources.

MS. A. KATHRYN POWER: Perhaps the National Suicide Action Alliance, the National Child Traumatic Stress Network, and the National Depression Center Consortium know people who are in academia. They work with people who have been traumatized and are a younger population, and we need to start looking at a younger ages. They might be a pool of people we could influence to look at BPD because they have to be looking at people who have been traumatized, and this gets you academic connections.

MR. WILLIAM J. HUDOCK: Why isn't this able to be brought to fidelity in the field? One of the things we've learned is that oftentimes there are barriers to implementation such as financing. People think this is the only barrier, but in reality it's usually only one of many. For example, SBIRT [Screening, Brief Intervention, and Referral to Treatment] allows private and public payers to pay for treatment. We do not understand the other barriers. There's an implementation science piece for everything that has not been well addressed. There's also the question of scalability. It's possible the models we are looking at to train people are not viral enough. We need to re-conceptualize how we can create scalability at a faster rate so as to have both clinical supervision and training resources. It sounds like you'd be cannibalizing one to get the other unless you can create the scalability.

DR. KATE MCGRAW: I have two suggestions. One is Uniformed Services University of the Health Sciences (USUHS), which is the place where psychologists and psychiatrists are trained for the military. It's an academic environment and possible connection. The other is looking for a larger system to do this and identifying which aspects of the treatment might be most salient to scale it down. The military might be interested in partnering because there are lots and lots of sites and patients. There is some CBT [Cognitive Behavioral Therapy] that has gone around the military, and they've done a lot of supervision by phone in clinics for that particular type of intervention. These may be other partnerships that could be gleaned too.

MS. A. KATHRYN POWER: The same with Defense Center of Excellence and other components of the military training system that are trying to get at the heart of looking at some of those psychological issues.

DR. BRADLEY E. KARLIN: The VA developed 13 national initiatives to disseminate evidence-based psychotherapies. We've developed about 13 national staff training programs that are competency-based training programs where clinicians have an opportunity to receive intensive training in an evidence-based psychotherapy (e.g., PE, CPT, CBT, interpersonal therapy, MI, and social skills training). We now have outcomes associated with these initiatives and some published articles. We're trying to get information out, and we have trained over 5,000 staff throughout our system in one or more evidence-based psychotherapies. When we started, we delved into the research to look at why evidence-based psychotherapies are not delivered, and when they are delivered, research shows they're delivered with low fidelity. We looked at the issues. There are two issues: lack of competency-based training and organizational implementation issues. Someone can receive the best training from Marsha or Edna, but if this person does not have support to implement the new intervention,

it will not be done. We need to have interventions that are implementable; otherwise, it's not going to be delivered. It's important to look at both of these factors. I think Bill's comments about scalability are really important. We need to think about interventions that are more feasible to implement, especially in real world settings because you can develop wonderful training mechanisms, but if it's not something that can be implemented, then it's not going to have yield.

If we're really thinking about this being a public health approach, then think about Web-based approaches and mobile apps. The VA recently developed one for PTSD. It seems within the context of BPD, given the fact there are issues of emotion dysregulation and interpersonal sensitivity that technology could really help from a public health perspective. SAMHSA is committed, and the VA is committed. I have a lot of thoughts on this, but maybe just helping to frame some of this conversation is the most important thing to do. Competency-based training and implementation issues are not sufficient to address all the problems. We need to think about how we can approach this from a truly public health perspective.

DR. TOM INSEL: To follow up on this and go back to Marsha's original question, how at the VA do you deal with the fidelity question? How do you know that people are ultimately doing what you're hoping?

DR. BRADLEY E. KARLIN: We've developed training mechanisms that emphasize the importance of fidelity through review and feedback of actual clinical performance. In our training programs, we have clinicians who have their sessions taped, and these are sent to a training consultant. We don't call it "supervisor." For legal purposes, these are experts in the psychotherapies. They're not clinical supervisors. They're training consultants. They review the tapes, provide feedback, and conduct small group consultations that meet weekly for at least six months. We have training consultants within the VA, as well as outside of the VA. Part of the formal consultation is focused on promoting fidelity.

We've also developed longer-term mechanisms to support sustainability, which include peer consultation groups, and we have a local evidence-based psychotherapy coordinator placed at every VA medical center to help lead peer consultation groups. We're now developing documentation templates for each evidence-based psychotherapy that will be inputted into VA's electronic medical record system. This enables the VA to capture data session by session (e.g., intra-session characteristics and patient characteristics) or to go into the note and look at the extent to which the therapist is delivering that therapy or that component of the therapy with high fidelity. We'll map out into each of these templates the core components of the psychotherapies.

About seven templates for seven different psychotherapies have been developed and will be deployed later this fiscal year to every medical center in our system. It's really challenging to address the fidelity issue. It's also challenging to know the extent to which therapies are delivered because CPT [billing] codes don't tell you how specific therapies are delivered. The templates are designed to allow us to monitor delivery of specific psychotherapies. We want to make sure they're available and provided to patients, but are also looking at fidelity in the longer term. After clinicians participate in these training programs, there are performance-based criteria they have to meet to receive a certificate that they've successfully completed the

training program. We want to be able to look at the fidelity with which they continue to deliver the therapy outside of these training programs.

DR. JOHN OLDHAM: I think these are tremendously important areas, and there is no simple solution. We've made headway in some places. For example, in most of our training programs in psychiatry there is pretty good awareness of BPD and DBT. That's progress. One of the things I've done for the APA is set up a task force for the board of trustees on early career psychiatrist/resident and new technology to get the ECPs and the MIPs to teach us how to communicate with them better. They speak the language of social networking, and we need to get them to help us with this.

There's a critical place in time where we're not doing a very good job, and this is when residents finish their training and are a few years out into practice or go into jobs. At this point, they report feeling as if they've fallen off a cliff. They lose a network of support and accessibility of mentors that they had when they were residents.

If we're proposing for them to take patients with BPD into their practices and that it's covered by insurance, I think they end up feeling pretty isolated, and they don't have team support. Building team supports for therapists to help each other is not easy. Before long, they're going to back away from patients with BPD and say, "Well, I'll take other kinds of patients." This is a place where I think we need to concentrate.

DR. JOHN GUNDERSON: An issue more basic than training is public awareness and stigma. On television other major illnesses are brought into the home. There's no reason why BPD should be any different from depression, PTSD, or schizophrenia. It's a major mental health problem, and public awareness is growing. The government could do something that's broader to give it a public imprimatur so it's not just something clinicians can hide behind and not tell their patients about for years.

MS. A. KATHRYN POWER: It's also something we can name. In other words, if we do social messaging in SAMHSA's campaigns on recovery, we should name BPD as one of the health conditions around which recovery can be framed. I think that's a very good suggestion to take upon ourselves to say here are chronic conditions, and here are mental illnesses such as BPD.

DR. MARSHA LINEHAN: We have to pay attention to the fact these are difficult to treat patients that are not 9-to-5ers. You can't have a 45-minute session because half the time they "have to go" or are suicidal. Most mental health professionals have no training or have adequate training with suicide and are worried about being sued.

I'm working with someone in Seattle who asked me what we should do, and I said, "I'd go to State legislatures and get them to mandate training for suicide prevention." If the State can tell you have to have AIDS training, they can tell you have to have suicide training. Most people are too afraid to treat patients with BPD, and also if you can make a lot of money not seeing these patients, then why see them?

Communal health ends up being the group that has to see them, and they don't have the money to get their people well trained. So we're in this terrible position. The people who might be trained don't want them, and the people who aren't trained get them. I don't know what

you can do about this. There may be some movement that States might be able to do that the Federal government can't do, and we need to support the States.

MS. A. KATHRYN POWER: That's why the States become key to me. Washington has done this and there's other States that have taken this approach. This year on the block grant, SAMHSA has told grantees that they need to become more aware of suicide and suicide prevention, as well as be skilled in a suicide prevention plan. We're expecting them to be more trauma-informed and trauma-focused. We should start using this technique with communities, providers, and States on issues surrounding BPD.

MS. RUBY NEVILLE: Due to fiscal constraints we're facing in this country and in the Federal government, I think it's always good to use what we have. Just thinking about some of the programs with influences on Federal training grant programs, I think HRSA has some, and I'm sure there are other agencies that have Federal training grants. If there was a possibility or potential to include language to target high-risk populations (e.g., BPD), I think is a good move. The Center for Substance Abuse Treatment (CSAT) is interested in that people who are getting treatment for BPD have a drastic reduction in substance use disorders. In other words, it improves their recovery as far as substance use.

CSAT partnered years ago with the Association for Medical Education and Research in Substance Abuse (AMERSA), and HRSA has also partnered with AMERSA to help clinicians understand substance abuse. This is a good avenue that could yield potential collaboration to train clinicians on BPD.

There are different scholarship loan repayment programs run by States and the Federal Government that have a lot of extra funding. One area of focus is not just primary care clinicians, which would include substance abuse. Practitioners who are getting trained through the Federal Government should be able to learn about BPD.

DR. LISA PATTON: For a long time, providers and clinicians implementing community mental health have not looked at BPD in that way, and that's a major shift that needs to take place through new education and training. One of the things that happens is clinicians think at intake or early in the therapy that a person may have BPD but never bring it up, talking instead about trauma and depression but never discussing BPD for a lot of reasons. Addressing stigma within the mental health and provider community is critical to get EBPs out there and available for people.

MS. CHARLOTTE A MULLICAN: AHRQ has a distinct interest in what we call the complex patients (i.e., multiple chronic illnesses). We have had a number of different funding announcements out, and there will be more in the future. For instance, AHRQ is very interested in "teamness," especially as it relates to the patient-centered medical home. We have standing program announcements out for large research grants as well as demonstration and dissemination grants (R18s). AHRQ spends millions on health IT research and has standing open announcements related to developing any type of project around this (e.g., improving patient awareness, increasing or improving medication management, or improved decision-making by provider or patient). People can contact me to figure out how they fit. There are five different topic areas, and I can help figure out where you fit. I encourage everyone to go to the new PCORI [Patient-Centered Outcomes Research Institute] to search for new announcements.

DR. JOHN OLDHAM: This is the kind of forum that I'm glad to be a part of, and I think we need to have regular ones. We need to be careful and not forget there is also educating, providing information, and providing clinicians with skills in primary care settings. People with BPD often come to the family doctor or primary care physician, and they don't always know what to make of the problem. They're more likely to label it as depression or anxiety and start going down the medication trail. There is not a careful screening process that ever raises the question early on about a personality disorder. If there was, then you can cut a lot of pain in terms of shortcutting years and years of trial and error that doesn't work very well, as we heard from family members today. This is an area where we've also got to put a lot of energy.

DR. BRADLEY E. KARLIN: A key contextual variable is consumer, family, and public perceptions/attitudes toward BPD. The extent to which information is available that this is a treatable condition and treatments are available that can effectively manage BPD is important. We've been trying to do this within the VA. Pharmaceutical companies have mastered this with direct advertising to patients or consumers. If we can get family members and consumers to put pressure on payers, on insurers, and on health care providers to make these treatments available, then we're going to be much more likely to see these treatments make their way into clinical settings.

With respect to getting the message out, social media provides real opportunities. The VA has been working for a while on a national anti-stigma campaign that will launch next month. It's designed for veterans and nonveterans called "Make the Connection." PSAs will air nationally (e.g., Super Bowl), and a Web site will go live next month with 80 stories of veterans who have struggled with a variety of mental illnesses but have recovered as a result of treatment. It connotes the idea of making an interpersonal connection with someone who cares, as well as making the connection to treatment. There may be opportunities to build on this effort (e.g., partnership); we'd love to do that.

MS. A. KATHRYN POWER: Bradley, will one of the videos on veterans profile BPD, or do you know which conditions are going to be named in your videos?

DR. BRADLEY E. KARLIN: I have to check the final content.

MS. A. KATHRYN POWER: It would be interesting if it was one of them.

DR. BRADLEY E. KARLIN: We can certainly check; I know some veterans voluntarily participated. They were selected by the Defense Sciences Office (DSO). Providers and administrators didn't want to go to the patients and say, "Would you participate?" There is a potential conflict there. It was entirely up to the veterans to talk about their experiences. And a lot of them didn't talk about the specific therapies they received, but some of them talk about the conditions. Obviously, the experience of veterans seeking treatment in VA tends to lean more toward PTSD, depression, substance abuse—less so, but certainly still to an extent borderline personality disorder.

MS. A. KATHRYN POWER: Naming and building awareness is important. We found with suicide prevention that talking with people about suicide helps tremendously to move the issue forward about suicide being such an incredible and common thought experience for people.

DR. TOM INSEL: I'm so impressed by what the VA is doing. I think the reputation of the VA hasn't caught up with the reality of what you're able to do now. It's a great model and demonstrates what you can do when you have a health care system. The rest of us don't have that yet, and maybe we will.

I spent yesterday in New York City at the Faster Cures meeting, which is an annual meeting of about 100 different advocacy groups, mostly for cancer and some for heart disease, hypertension, and diabetes. The Juvenile Diabetes Research Foundation (JDRF) is a big player. It's an extraordinary annual meeting with hundreds of participants because there are so many people who come from each of these organizations.

This year, the theme was empowering families and patients. I thought it was fascinating because so much of what we heard was that the whole landscape is going to be different. They weren't looking to Federal partners for direction. They are going to drive this, and we can come along or not. They have a message that can go viral, and this has real power, particularly for the next generation.

There was a lot of discussion about how to get the direct-to-consumer approach, and even themes such as fidelity. So how do you crowd-source outcomes or experience? Could you develop a Yelp.com for health care, where every person begins to share his or her experience? There are a whole series of efforts around this that it's probably important for us to keep an eye on.

It was conspicuous there was almost no one from the mental health community (out of 60 some advocacy groups). As we talk about what Federal partners can do, it's important to recognize the next generation may not look to Federal partners to push things along and do more themselves. When you think about increasing awareness, changing standards, altering accreditation, making sure there's fidelity, there are other tools out there that we ought to be talking about as well.

MS. VALERIE J. KOLICK: CMHS is trying to leverage training programs such as a peer-to-peer program. There must be a way to engage people doing these trainings to talk about BPD and DBT therapies that are available to broaden the horizons and get the word out.

MS. A. KATHRYN POWER: There's some work that we need to think about in terms of how do you get peer support and peer service component into some of these approaches and interventions. There's an answer, I just don't know whether we have the answer.

DR. KATE MCGRAW: The Real Warriors campaign has been up and running for a year; it's an award-winning media campaign destigmatizing mental health treatment and different diagnostic categories. Also, T2 (Center for TeleHealth and Technology) has developed a number of mobile apps. One teaches how to do a response, which may be useful, or at least the technology is useful.

MS. CHARLOTTE A MULLICAN: HRSA has a specific behavioral health-training workforce going on, and they also have a workgroup focused on this, and I think Quita Mullan heads it up. Also, the Behavioral Health Coordinating Committee is focused on the workforce (headed by Sarah Wattenberg) and may be able to incorporate BPD into training efforts.

DR. PERRY HOFFMAN: Those of us who work with patients with BPD are always looking into comorbid issues, but I don't think other practitioners are looking for BPD. We've experienced at conferences when we ask this question about BPD, and they say, "Well, no, we don't really look at that." This is an important thing we need to do with substance abuse and all the other disorders. How do we educate those people and those areas of interest that borderline is important?

MS. RUBY NEVILLE: I work with the Adolescent Family Treatment Program at CSAT, and some of our grantees are required to choose evidence-based treatment. One particular treatment for adolescents is the Adolescent Community Reinforcement Approach (A-CRA) and the Assertive Continuing Care, which are six-month substance abuse treatment programs. All of our grantees are required to utilize the Global Assessment for Individual Needs (GAIN), which looks holistically at whatever is going on in the person's or child's life.

Similar to the VA, clinicians have to be certified and trained in Community Reinforcement and Family Training (CRAFT) and in A-CRA. They have to help us to get these individuals trained, and they have to record their clinical sessions and upload them on this Evidence-Based Treatment System (EBTS). We have people who listen to them to determine if they are maintaining fidelity. They are scored, and if they do not pass, they don't get certified.

This works, and the other key is to bring everybody onboard. To be in isolation does not work (e.g., one clinician and one supervisor, but not the project director onboard). At CSAT, there is a requirement that everyone needs to come onboard, particularly key staff. We have rave reviews. Clinicians who really didn't like it at first are writing me saying, "This is a wonderful program. We've never done something this intense, as far as evidence-based treatment." We had one program that actually was a subcontractor for the provider that received the grant, and they were only supposed to use a portion of their program to do the A-CRA, but now they have expanded it throughout their program, and it wasn't even a requirement.

I'm not pushing A-CRA, but there are multiple evidence-based treatments that can be utilized when serving the client (e.g., cognitive behavioral treatment, the community reinforcement and family treatment, and the CRAFT). I think it's important for grantees to learn about BPD and issues that surround it.

In April 2012, we'll have what we call the Joint Meeting on Adolescent Treatment Effectiveness, and we welcome people to submit abstracts. We also welcome anybody who wants to help co-sponsor and you get to participate. Just let me know if you're interested. My name is in the back of the book. It is important to not leave the family out of treatment. Family is part of the treatment.

DR. BLAISE AGUIRRE: As we look at any illness state, the people who make the most impact are the people who are often most affected at a personal level (e.g., Doug Flutie and the Flutie Foundation). Generally speaking, no one is going to come to a borderline meeting unless they are impacted by it. One of the things that happens at the NEA-BPD is families find out about this disorder, and then say, "Oh, my God. That's what we've been facing all along."

They become involved in very powerful ways—this happens time and time again. If you think about a disorder that occurs in 2 percent of the population, there's a parent out there, a husband, a wife that has someone who's got BPD and never even knew it. They just called it something else. Getting back to psychoeducation, it is important that people and families

recognize that this disorder is affecting their lives. It's not an abstract thing. There have to be empirically validated treatments, and we have to make sure we're defining the disorder we're seeing. Public awareness is critical so that we can begin to answer some of the questions families are experiencing.

MS. A. KATHRYN POWER: The issue about public awareness and destigmatization comes back to the alliance with NAMI and with NEA-BPD. At SAMHSA, we're very concerned about it, but people don't get it. We can tell people that in your lifetime you have a 50 percent chance of having a mental illness, but they don't get the notion that mental illnesses are common, that they're everywhere, that you know people who have them, you have them, and it just doesn't resonate at a public awareness level. What would be the one thing we can do collectively to change this? From a consumer/family perspective or from an education perspective, these are all good ideas about how to get BPD talked about and engaged. Ken [Duckworth] talked about how it changed NAMI as an organization by becoming more exposed to this particular health condition. How is your organization going to take this information and change the direction of your messaging? We've gotten a couple ideas about how we might build some different messaging. What do you think are some things that we can do?

DR. KEN DUCKWORTH: NAMI has Family-to-Family that consists of families across the country who are dealing with mental illness, but it doesn't really attend to this issue in a fundamental way such as addressing the family's experience and helping people who live with the condition. It was created for a different problem, but it's the most commonly employed psychoeducational strategy in the country. The question is do we do something with Family Connections with NAMI? Perry [Hoffman] and I were talking about this earlier. So that's a question for us. How do you fund these things? Are there Federal resources to fund this type of work? We could find other ways, but most of them are less pleasing. Is it possible to find some support for an educational Family-to-Family program? It may not be something that you can answer today. It's mostly volunteer run, but somebody has to develop the curriculum. Somebody pursues it, chases down leads on free space. There's still an infrastructure need and staffing.

DR. PERRY HOFFMAN: NEA-BPD has an effective psychoeducational program for BPD and a manual for it. We get space at NAMI and at community hospitals. We'll go anywhere, but it's getting it to the next level and being able to respond to people right away by getting them in a group. We don't have the infrastructure to provide this program nationwide.

MS. DIANE HALL: How about adding information on BPD into NAMI's Family-to-Family packets? The Family Connections Program is designed and out there; but NEA-BPD is a small group compared to NAMI and cannot service the entire United States as NAMI does. We would love to be more involved with NAMI and have a BPD program for families.

As for consumers, NAMI's Connection program is a support group that invites those with BPD. It works quite well, but a lot of people don't realize BPD patients are invited to come to that support group. There are a lot of things in place; it comes down to exposure and resources.

DR. KEN DUCKWORTH: The advocacy groups have some work to do to figure out how to best leverage specific expertise at NEA-BPD and NAMI's vast support network of families. These things do have a way of growing and developing to become national movements.

MS. A. KATHRYN POWER: Scalability involves the need for the public to push out the message. SAMHSA is doing a little bit of that work and had some transformation money used by two of our transformation States to bring Mental Health First Aid into their States. Missouri had everyone go through Mental Health First Aid training, which discusses BPD. This gets at how to deal with mental health issues on a societal level, a family level, and a community level.

The National Council for Community Behavioral Health Care, the State of Missouri, and the State of Maryland have the franchise rights to Mental Health First Aid (i.e., the American version because it was adapted from Australia). If this training mentions BPD and this is connected with a larger Family-to-Family army, this might have some power to leverage a larger public awareness campaign.

The other issue is whether a clinician's competency is skill based. We're never going to have enough therapists to do what we think needs to be done. So, we've got to figure out tools (e.g., Web-based technologies and mobile apps) and other ways to get the message out so people can access effective interventions, support, recovery services, and peer support services. We can try to have holographs of Marsha across the United States, but more effective is public awareness and public messaging so people can recognize and understand this disorder. Once this is achieved, we need to figure out other techniques and tactics to get those interventions to work.

DR. RICHARD MCKEON: One important continuing interaction is between the BPD community and suicide prevention community to get information out to the public. Pretty much every State has a suicide prevention coordinator. They may have lots of other responsibilities, but 49 out of the 50 States have suicide prevention plans. SAMHSA has started to ask for these to be submitted as part of the block grant applications.

The Garrett Lee Smith grants for youth suicide prevention by statute focus on ages 10 to 24, but there may be a number of different possibilities in terms of prevention and early detection efforts in youth. If you're thinking about issues around emotional dysregulation, there are things that can be supported in that grant (e.g., new interventions, widespread dissemination, and training for suicide prevention for youth). For example, a Garrett Lee Smith grant could be used to train a youth workforce in DBT. About 60 percent of funds from Garrett Lee Smith grants go to training in different areas of suicide prevention for youth.

Also, the National Suicide Prevention Lifeline answers over 60,000 calls a month and, without a doubt, many are people who have BPD. The 152 crisis centers participating in the National Suicide Prevention Lifeline are places where information and resources about BPD can be sent for individuals and families because many calls are third-party calls—a family member or a friend saying, "My husband, my wife, my son, my daughter is talking about suicide now, and I don't know what to do." It's the crisis center's role to help them; the more awareness of resources that exists about BPD, the better. Further discussion can help find ways to move forward.

DR. BLAISE AGUIRRE: One word that captures public awareness is C-SPAN. They are able to disseminate broadly. Is there a way to use Federal funds for dissemination through TV?

MS. A. KATHRYN POWER: That's a good idea.

MR. WILLIAM J. HUDOCK: One of the things we have to be really careful about is how we message in terms of it being bite size so people can digest it (i.e., simple enough and put in terms the average person can understand). We have a tendency to get too dynamic, which is a problem.

DR. TOM INSEL: There is a 13-part series that started this week on mental illness on The Charlie Rose Show; however, no one outside of New York City watches it regularly.

The cited amounts of funding for mental health research are pretty close (i.e., \$6 million for BPD compared to \$100 million for other disorders), but everything is going down. So, it's not going to get better. However, this is a little misleading because there's a lot of relevant research that doesn't have the term "borderline" in it. For instance, research on mood regulation was probably not being counted.

DR. BLAISE AGUIRRE: In the current political arena, there is a lot of talk about public-private partnerships. Does NIMH have the ability to join up with private funders to dedicate some of the money this way?

DR. TOM INSEL: Absolutely, we do this. For instance, there is about \$300 million going into autism research, but only a fraction is Federal. The Simons Foundation (i.e., Autism Speaks) contributes to research, and at least a fourth of all the dollars going into hard science for autism is coming from private sources. The issue is there's not a lot of private money coming into the science.

DR. PERRY HOFFMAN: About the R13s [Conference and Scientific Meeting Applications], are they going to come back?

DR. TOM INSEL: R13s will not come back until NIMH's budget starts to recover. It's a painful decision, not to put money into meetings and to reserve that money for R01s [Research Project Grant Program] to the extent that we can. It's not a huge amount of money, but it was harder and harder to defend meetings when we were turning away outstanding grants.

DR. PERRY HOFFMAN: Could NIMH and SAMHSA do a conference on BPD?

MS. A. KATHRYN POWER: SAMHSA has money to do meetings due to multiple logistics contracts that are sources of support for meetings. However, our budgets and our contracts are being reduced. The possibility exists if there is an issue SAMHSA and NIMH agree upon. We're going to take a look at the other individuals and groups who wanted to be informed about this issue. I don't know whether we can actually replicate part of what we've done today, but it seems there are many other people who have an interest in the BPD report to Congress. And, now NIMH has come out with a new Web-based piece that's a nice packaging of information for people. Future meetings around dissemination, implementation of practices, and implementation research could make a nice combination and a shared agenda.

DR. TOM INSEL: We have treatments that work. We've got to figure out how to disseminate these better. Now would be a great time to focus on implementation science, dissemination science, and policy issues.

DR. BRADLEY E. KARLIN: From an intervention research and implementation perspective, it would be valuable if there could be additional investigations looking at interventions that are more feasible for BPD. The interventions we currently have in BPD are very good, but they are multicomponent interventions that require extensive resources. Therapist availability during off hours together with having teams, individual sessions, and group sessions is challenging to implement to fidelity. Even while it might be challenging to implement 12 sessions of CBT that are 50 to 60 minutes in length, it's a lot more challenging to implement some of the very nice, well-established interventions for BPD, which are much, much more intensive.

DR. JAMES BREILING: An NIMH-supported group in Iowa developed a treatment that reduces BPD symptoms and was replicated in the Netherlands as well as adopted there. It is well structured, highly efficient, and used in prisons as well as a whole range of settings to do exactly what was suggested is wanted. It doesn't touch suicide, which requires more intensive work. But, it can screen out a whole lot of lower-level symptoms that are troubling and do it at low cost, which saves resources for more targeted and costly things later.

DR. TOM INSEL: A couple of years ago, I went to the FDA to get them involved in working on EBP psychotherapies. They thought I was nuts and said, "Well, we could send this to our device division." This is from Janet Woodcock, who really has a pretty good sense of what the issues are. Part of it is it's just so complicated; it's not like giving a medication with just a few variables—a dose, an interval, and you have quality. This is a very different enterprise, and it's not like a device. So, it's really difficult. Unless we can make it simpler, it's going to be very hard to get this done.

DR. BRADLEY E. KARLIN: Implementation and clinical intervention have been separated into separate silos. To use the analogy of medications, a pharmaceutical company would never consider a pill nobody could swallow, nor would they support a medication taken eight times a day, but there are medications taken three times a day. The analogy with psychotherapies is to think along similar lines and what can really be implemented, and then bring these implementations and clinical interventions together.

MS. A. KATHRYN POWER: An approach SAMHSA has used in the past from CSAT's perspective is development of treatment improvement protocols (almost 42). From CMHS's perspective there are EBP toolkits on-line. There are currently eight EBP toolkits SAMHSA promotes as approaches needed to have a recovery-focused system. Our EBP toolkit on Assertive Community Treatment teaches this approach, and there are fidelity measures to keep it clear. We have Supported Employment, supported education, consumer-operated services, and services for older adults. Why don't we now push DBT? This works and SAMHSA should think about this in promoting recovery. The toolkits are done. Now, SAMHSA needs to disseminate and promote adoption of them, but this is a different issue. Why is SAMHSA not doing more targeted development of other evidence-based toolkits that have an imprimatur of what works? This is something to consider.

DR. TOM INSEL: NIMH does all of the original research (e.g., support of employment) and hands off the mental health pieces to SAMHSA to promote and disseminate—that's how this is supposed to work. We can help develop a DBT EBP; we'd love to do that. Something analogous is a new treatment for anorexia in adolescents, which also has a very high mortality rate similar to BPD. For 40 years, treatment for anorexia involved taking kids away from families and putting them in long-term treatment with pretty bad outcomes. We now have a treatment that says “stop the ‘parentectomy’” and train the parents as therapists. Outcomes are 50 percent recovery in 12 months—and have been replicated many, many times. We're doing the same thing with BPD. We're saying change what you do because this saves lives. But now, how will you get this disseminated? If there is only one person in the Washington, DC, area trained to do modulated treatments for anorexia, that's just not acceptable. How do you get 1,000 people trained up quickly?

MR. KEVIN DAWKINS: Similar to how involving families with anorexia patients improves outcomes; we need to bring families closer into BPD therapy through programs such as Family Connections. By helping family members understand the transactional nature of BPD, symptoms begin to go down, and in many cases remit. We need implementation tools to translate research into action at a community level. There should be a very clear emphasis on the role families play in changing symptoms of the person who has BPD.

DR. RICHARD MCKEON: Treating BPD involves complexities that go beyond the typical 50-minute hour delivery of evidence-based psychotherapies. One of the things we did for patients with BPD in our DBT program was to train them. They wrote up their crisis plans and how they wanted to be treated by our psych emergency service. Psych emergency service received each individual's plan. We taught patients about how psych emergency services reacted and behaviors that get you into hospitals, as well as how to stay out of the hospitals. Psychiatric emergency services are pretty predictable (e.g., very reactive to suicide), and there was no downside about being transparent. We also developed tools to train patients to know more about the system.

With today's technologies, more can be done to create systemic approaches that utilize DBT-type principles beyond the 50-minute hour or DBT group, for times when someone is not able to talk to their DBT therapist and comes into contact with the system. It's also individualized. In our Lifeline Network, we could certainly train our crisis centers to talk with individuals and collect criteria for BPD by identifying things that are more unique about BPD.

There are a number of opportunities even given the fact that this is a more complex area than delivery of a depression treatment or an anxiety treatment, in terms of dissemination of evidence-based psychotherapies. Plus, there's more of a payoff because those are things that generate acute care cost in the emergency department, as well as higher costs at inpatient units when interactions don't go well.

DR. CHARLENE LAFAUVE: I want to know about pharmacological therapy. Often we use certain medications that are helpful for BPD. To what extent is NIMH looking at developing combination treatments? To what extent can SAMHSA in any way influence the research agenda for NIMH on this type of issue and others like it?

DR. TOM INSEL: That's a great question, and in other areas of medicine, we never would assume just one medication or lifestyle change would be sufficient (e.g., treatment of hypertension or diabetes always considers combinations); in treatment of cancers, they almost always look at combinations of medications as well. Mental health is one of the few areas where people think there has to be some single magic intervention, and you wouldn't combine treatments, as if mental health conditions were so much simpler and responsive. Increasingly, we see in the real world that almost everybody is receiving a combination, but it almost never has research evidence behind it.

There are really interesting opportunities emerging such as a demonstration in treatment of phobias. Normally, it takes 10 to 12 sessions of CBT to achieve results, but when combined with d-cycloserine (a generic compound), these same results are achieved in two sessions. After a three-month and six-month follow-up, the group that got d-cycloserine did even better in the long-term, or just as well as those who didn't. There is reason to think those kinds of combinations could actually simplify these very complex psychotherapies.

DR. JAMES BREILING: On suicide, Barbara Stanley got preliminary results for a combination of DBT and Prozac in a low dosage that reduces the risk by 80 percent. We're now running a large trial. Also, Mike McCloskey, a junior investigator, developed something to look for risk of increased suicide at the early stage of medication, which is an issue that's come up in combination. We don't have a single FDA-approved drug. Lilly did a big trial, with the biggest effect being weight gain; otherwise, it was wipeout. Combinations can be very helpful in discrete cases to help get control.

DR. TOM INSEL: How many life-threatening illnesses have we decided only to use a psychosocial treatment for rather than thinking more broadly? We don't have anything today. But, we should consider the possibility that somewhere out there there could be a different kind of intervention that might be helpful. Maybe it wouldn't be medication. Maybe it would be some sort of cognitive intervention. We should ask what else could be done for people who have intense rejection, sensitivity, mood dysregulation, and prolonged suicidal ideation--this whole mix of things on which we just put this particular label.

DR. BLAISE AGUIRRE: On stigma, in autism there is this idea of moving away from autism as illness to neuro-typical and neuro-atypical. In our discussion earlier about BPD brains vs. normal brains, there is a somewhat pejorative inference from the use of the word "normal." I wonder as you look through the literature how often this is used. It's subtle. It's insidious. It is a small thing to look at, but if everybody rewrote literature to avoid this type of judgment, it may help. The language today didn't seem in any way judgmental, but there may still be brochures out there that people are putting out that have this kind of language.

DR. PERRY HOFFMAN: Could we come up with more steps to focus on moving forward, such as public awareness? I don't think we've come up with what we really think we're going to do.

MS. A. KATHRYN POWER: What I've heard is there are suggested routes for building public awareness that need to be captured. We are taking notes, and this is one route to figure out what might be the best way to build public awareness. I don't think we collectively can decide, but we can certainly put in the report from the meeting today what some of the suggested routes are (e.g., suicide prevention side, mental health first aid, using the NCTSN networks, and C-SPAN). The discussion has been so rich and that will tease out some of the potential ways in which we may build public awareness.

Whether anyone around the table can take action on them, we can figure this out as well. In other words, we will take responsibility for looking at suicide prevention connections. There might be people around the table who can help with other connections (e.g., Charlotte Mullican at AHRQ). The other issue is there are opportunities for us to build capacity in the workforce. We have people using appropriate interventions and there are opportunities to do some work collectively.

More importantly, with NAMI's and NEA-BPD's leadership, we are saying we're in an alliance to try to do something. The Federal partners need to be part of this alliance. How we go forward in the general sense of building a higher level of awareness and response to mental health conditions should include BPD, and we can do some things about this now. We can start talking about it in that way.

There is also an opportunity to think about where the field is, where we need to go, and what's currently in practice and in play. In doing this, we're going to go away from here thinking further about some other opportunities.

My pledge to you is that we will summarize discussion points. We certainly have the incredibly brilliant presentations that were in the book today, and there might be another conversation. I assume both NAMI and NEA-BPD will have further conversations, and we'll look at what can be done without any resources. There's things we can do, and that's why influence strategies are part of it. There are no new resources coming down the pike. But there are opportunities from educational training and logistics support standpoint.

We're not hijacking anybody's agenda. We simply want to see ourselves as a partner to help in something Congress asked SAMHSA to pay attention to, and there might be opportunities, either through grants and contracts or relationships that can help move this forward to another level. We've all shared a profound educational opportunity on a number of levels. The next discourse about this will be different. We're going viral. We're going to Facebook. That's it.

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