Bringing the Gifts of Those on the Margin into the Center: Prevention, Treatment, and Recovery for Borderline Personality Disorder

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Attached is the text prepared for delivery; however, some material may have been added or omitted at the time of delivery.

Thank you, Mark. Good morning. I'm honored to welcome you to this meeting, which represents the next step in our critical

partnership to address borderline personality disorder—a common, complex, and poorly understood condition that affects an estimated 18 million individuals and their families each year.

It truly "takes a village" to transform individuals' lives. When SAMHSA submitted its *Report to Congress on Borderline Personality Disorder* last May, it reflected our commitment to work closely with the National Education Alliance for Borderline Personality and NAMI, our Federal partners, individuals in recovery, and our champions in Congress. I want to acknowledge Representatives Chris Van Hollen (D-MD), Frank Wolf (R-VA), Nita Lowey (D-NY), Grace Napolitano (D-CA), and Tim Murphy (R-PA). Representatives Napolitano and Murphy co-chair the Congressional Mental Health Caucus. Together, we share a commitment to:

- Increase knowledge about borderline personality disorder;
- Provide education to individuals and families;

- Expand the availability of evidence-based treatments; and
- Promote resilience and recovery.

Clinicians, researchers, and individuals in recovery have struggled with the name “borderline personality disorder” or BPD. As one observer noted, “borderline” is an adjective in search of a noun. Sadly, for many individuals who are diagnosed with this condition and their families, “borderline” means on the border of society.

Symptoms of BPD can be severe, debilitating, and isolating and individuals with the disorder are subject to discrimination and bias. They are called “difficult,” “noncompliant,” and “manipulative.” Their family members report feeling “helpless,” “hopeless,” and “excluded.”

Borderline personality disorder symptoms can interfere with an individual’s ability to enjoy the things that make life meaningful—optimum health, meaningful relationships, and secure

employment. Individuals diagnosed with BPD may be unable to contribute fully to community life. But are they isolated because they are suffering, or are they suffering because they have been isolated by the labels they've been given?

The behavioral health field has been built on individuals' deficiencies, by labeling, diagnosing and managing "cases."

When we label, we marginalize. Our goal, in transforming health and behavioral health care in America, is to bring the gifts of those on the margin into the center.

Gifts that belong to the individual who wrote:

> I have borderline personality disorder. Will I ever get to live a normal life? I just want to have a sense of purpose and have someone who cares about me. Is this possible?

The answer is a resounding YES. At SAMHSA, our goal is a high-quality, self-directed satisfying life in the community for every man, woman, and child in America. This life includes:

- HEALTH: A physically and emotionally healthy lifestyle;
- HOME: A safe, stable, and supportive place to live;
- PURPOSE: Meaningful daily activities and the independence, income, and resources to participate in society;
- And COMMUNITY: Relationships and social networks that provide support, friendship, love, and hope.

Health, home, purpose, and community. These are the elements of SAMHSA's Recovery Support Strategic Initiative, which I am honored to lead. They also are the very definition of services and supports that individuals need to recover from mental and

substance use conditions, including borderline personality disorder.

At SAMHSA, together with our partners in this room, we are creating the conditions for individuals to recover by focusing on (1) prevention and early intervention, (2) evidence-based treatment, and (3) recovery support services.

Prevention and early intervention are critical to reduce the negative impact of borderline personality disorder. Research overwhelmingly demonstrates that BPD symptoms and risk factors can be observed in even very young children. Self-injuring behaviors that are so often present in individuals with BPD frequently emerge in the preteen years.

In 2009, the Institute of Medicine released a much anticipated report called *Preventing Mental, Emotional, and Behavioral Disorders among Young People*: *Progress and Possibilities*. Commissioned by SAMHSA's Center for Mental Health Services,

the report provides concrete evidence that many mental, emotional, and behavioral disorders in young people are, in fact, preventable.

The report's authors noted that interventions that strengthen families, individuals, schools, and communities build resilience and reduce problem behaviors. They concluded, "The Nation is now well positioned to equip young people with the skills, interests, assets, and health habits…needed to live happy, healthy, and productive lives…in caring relationships that strengthen the social fabric." This should be our vision for the future of health in America.

Attending to a young person's health means paying attention to the impact of trauma. 40 to 70 percent of individuals with BPD in both inpatient and outpatient settings report childhood sexual abuse. Untreated trauma in childhood exerts a powerful influence on adult emotional and physical health.

More important, when we acknowledge that the individuals we serve have experienced unspeakable acts, we begin to relate to them in a different way. We understand that seemingly self-destructive behaviors—such as self-injury, drug use, and risky sex—are coping mechanisms that allow them to survive. In their book, *A Developmental Model of Borderline Personality Disorder*, Patricia Judd and Thomas McGlashan write, "Humility in the face of the tragic and heroic efforts of the [individual] to survive and maintain human connection provides…perspective."

Later this morning you will have the distinct privilege to hear from Dr. Marsha Linehan. Her humility and courage in the face of her own struggles with untreated mental illness led to the development of dialectical behavior therapy (DBT). DBT is now considered to be an evidence-based practice for borderline personality disorder, and is built on the notion of "radical acceptance." Healing begins when we accept that individuals' behaviors make sense given what they have experienced.

SAMSHA supports the development, dissemination, and widespread use of empirically based treatment approaches like DBT. These tools exist but are not widely disseminated and used, which is why we are actively involved with our partners at NIMH to move science into service. SAMHSA sponsors the National Registry of Evidence-based Programs and Practices and continues to develop evidence-based practice toolkits. We also are working with a robust Theory of Change that is helping us make the most efficient use of resources to bring innovative practices to scale.

We promote evidence-based treatment because we know that individuals with BPD recover. In fact, despite its severity and burden, BPD has a surprisingly good long-term prognosis with a high rate of recovery.

Peer support expert Beth Filson identifies the most effective recovery supports as those that are compassionate, that reinforce

the dignity of the individual, and that are founded on shared respect. The common denominator is that individuals with mental and substance use conditions are human beings. They need and deserve compassionate relationships that embody healing and hope.

However, individuals with behavioral health conditions don't recovery in isolation—they recover in community. Illnesses such as BPD occur in a larger context than just the individual with the diagnosis.

Spouses, partners, parents, children, friends, and co-workers of individuals with BPD are affected by the illness in someone they know and love. Family members of individuals with a diagnosis of BPD report very high levels of depression, grief, isolation, and hopelessness. They may be at risk for developing their own psychiatric problems.

To effectively treat this disorder, we must also provide education and recovery support tools for consumers and their personal networks. Family psychoeducation is an evidence-based practice that is crucial to fostering an environment of recovery. Not only does this practice help families develop critical coping skills, it has also been shown to produce better client outcomes.

Two of the more well-known family psychoeducation programs are Family Connections, provided by the National Education Alliance for Borderline Personality Disorder, and Family-to-Family, provided by NAMI. In addition, SAMHSA's *Evidence-Based Toolkit on Family Psychoeducation* is available online free of charge.

Prevention, treatment, and recovery support services are designed to help individuals with behavioral health conditions reclaim their rightful place. Their place is at the center of their treatment and care.

Person-centered care is garnering a renewed focus in the United States in health and behavioral health services because individuals have both a right and a responsibility to care for themselves. They can do so given appropriate services, respect, and hope.

Elyn Saks, law professor and author of *The Center Cannot Hold: My Journey through Madness,* has written:

> There's a tremendous need to implode the myths of mental illness, to put a face on it, to show people that a diagnosis does not have to lead to a painful and oblique life. Those who struggle with these disorders can lead full, happy, productive lives, with the right resources.

At SAMHSA, we are committed to working with you to provide a full range of prevention, treatment, and recovery support services to individuals with BPD, their families, and the communities in which they live.

Our ultimate goal is healthy individuals, healthy communities, and a healthy Nation.

Thank you.