

Lived Experience: The Importance of an Accurate Diagnosis

The following scenarios illustrate the importance of an accurate diagnosis that can help explain behavior and give a direction for treatment, services and supports:

Joe is a 16-year-old male who is high functioning on the autism spectrum with a co-occurring diagnosis of Bipolar disorder.

His developmental disability (autism) is associated with sensitivity to noise and his difficulties with change. His mental health issue (Bipolar Disorder) may cause sleep disturbance, mood changes, and increasingly impulsive and reckless behaviors. When he is depressed he cannot get out of bed, he sleeps and does not eat on a regular basis. He has thoughts about being different and less adequate than his friends at school. When in a manic mood, he will stay up all night playing music, be on the computer or watch television all night. When in the active phase of mania, he may sleep no more than a half hour at a time. He can become more irritable and reactive. He is sometimes destroys property and will become physically aggressive by pushing his mother or younger sister. When in either an actively depressed or actively manic phase of his illness, Joe is unable to maintain a schedule, go to school, complete his academic work or participates in chores. His parents sometimes worry about his ability to be safe. In addition to the challenges posed to him by his developmental disorder (autism), he experiences excess disability due to his mental health needs.

Jennifer is a 35-year-old female with history of anxiety disorder, depression and borderline personality disorder.

Jennifer resides in a structured community living arrangement. Although her anxiety and depression are adequately managed with medication, she presents on a frequent basis to Psychiatric Emergency Services because of her relationship problems with staff and other people with disabilities. Jennifer is at risk for losing her residential supports and she has already had multiple short-term hospitalization from which she does not appear to obtain benefit. Her mental health needs are disrupting her chances for community success. Although medication has addressed her anxiety and depression, there is no medication that has addressed her borderline personality style. Jennifer's family and staff do not seem to know about non-medical ways to help her. As a result, at this time, Jennifer is not yet getting a complement of supports that fully meet all of her complex needs.

Fred is a 58 year man who has Down syndrome, mild intellectual disability and dementia.

His family and staff have noticed changes in his behavior and personality. When he was last brought to his primary care physician, the health care practitioner told his mother that there was nothing to be done about this and that this is what happens when individuals with Down syndrome are over the age of 59. His family and staff are discouraged because they witness his decline in cognitive, adaptive and behavioral functioning and do not know how to best support him within the community.

Post-Script to “The Importance of an Accurate Diagnosis”

In all of these cases, individuals of different ages with intellectual and developmental disabilities have mental health needs due to psychiatric illness or a mental health condition. The best approach to support individuals with mental health needs is to understand their condition and the best practice is to provide both medical management and non-pharmacological supports. Medical management often involves therapeutic medications that are prescribed for a mental health diagnosis such as antidepressants for depression, anti-anxiety medications (anxiolytics) for anxiety, anti-psychotic medications (psychotropics) for psychosis, etc. Non-medical ways of addressing mental health needs may include lifestyle changes, psychosocial programs, therapy, behavioral approaches and environmental modifications. Best practice for the treatment of most mental health conditions involves both medication and non-medical approaches.

Steps to better understand the mental health needs of individuals with developmental disabilities:

- If you notice changes from what is characteristic and baseline in appetite, sleep, mood, activity level and behavior that persist for more than two weeks, bring the individual to the attention of his/her primary care physician to rule out medical problems that may affect mood, thinking or behavior.
- Collect information about changes leading up to the visit with a physician so that you dialogue with your health care provider about changes you have observed at home, school or work that may not be observable during an office visit.
- Obtain a mental health assessment from a clinician who is familiar with dual diagnosis (developmental disabilities and mental health disorders).
- Obtain a functional behavior assessment from a behaviorist to determine the role of environment, interpersonal relationships and everyday stressors in driving behavior change.
- Involve the multidisciplinary team in problem solving changes that may support the individual and reduce depression, anxiety or stress-related behaviors.
- Involve PerformCare **1-877-652-7624** that can provide in-home supports and Mobile Response and Stabilization Services (MRSS) to youth under the age of 21 with intellectual and developmental disabilities and co-occurring mental health and/or behavioral needs.
- Involve CARES **1-888-393-3007** as an outreach and engagement mental health team that specializes in adults 21+ with intellectual disabilities and co-occurring mental health needs.