

Dual Diagnosis: Mental Health and Intellectual/Developmental Disability

Obtaining a Comprehensive Evaluation, Thorough Assessment and Accurate Diagnosis

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Obtaining a Comprehensive Evaluation

A comprehensive evaluation may involve a number of professionals who assess the individual from different perspectives. A comprehensive evaluation might include a general medical exam, a neurological exam (particularly if your relative has a seizure disorder or a known neurological disorder), laboratory work, medical testing, a psychiatric evaluation, a psychological assessment, and a behavioral assessment.

A comprehensive evaluation should also include an assessment of your home environment and other appropriate settings such as school, day program, work, or any other location your relative spends time during the day. The purpose of such a comprehensive assessment would be to identify factors that may be contributing to changes from characteristics or “normal” functioning and behavior.

Most people with disabilities are challenged in obtaining a good mental health assessment because of problems with regarding access, capacity, competency and parity. There are widely reported problems in availability of trained professionals, access to qualified professionals and parity (or equality) of treatment for individuals with I/DD. The above mentioned may result in a significant gap of services for individuals who are in need of mental health treatment and should be reported to managed care companies responsible for paying for the individual’s behavioral health treatment such as Medicare, Medicaid, and the Arc of NJ Medical Mainstreaming. The lack of adequate mental health treatment, in general, but particularly for individuals with intellectual and developmental disabilities, constitutes an important issue to advance through advocacy. You will see ways in which you can advocate for mental health services later in the Handbook.

If you or someone whom you support is prescribed medication for a mental health disorder, you will probably want to know the following information:

1. What is my diagnosis?
2. What is the medication prescribed to medically treat my mental health needs? Ask the prescribing physician the reasons for the medication.
3. How will this medication address my problems? For example, can I expect that the medicine will reduce my mood swings, end my troubling hallucinations, help me better manage my anxiety or help me sleep?
4. How long can I expect that medication will take to work? How will I know that it is working?

5. Should I be looking out for any possible side effect or reactions to the medication? What should I do if I think I am having a reaction to the medication?
6. If I become concerned about anything (e.g. side effects, changes in behavior) how can I best communicate this to the prescribing practitioner?
7. In addition to medical treatment, you may want to know the following regarding non-medical treatments and approaches to mental health needs:
8. What are my options for non-medical treatment for my condition?
9. How does therapy, counseling or behavioral intervention work? What am I expected to do and what will the therapist/counselor/behaviorist be expected to do?
10. How will this treatment or approach address my problems?
11. If I follow the treatment guidelines, how long can I expect before I will feel better?
12. If I become concerned about anything related to my treatment (e.g. increased distress, thoughts about harming myself, lack of desire to continue treatment), how can I best communicate these concerns to the clinician?

If you are interested in additional information about dual diagnoses (MI/DD), you may want to read about particular mental health issues within the DM-ID-2 (Diagnostic Manual for Intellectual Disabilities), which is the companion volume to the DSM-5 (Diagnostic and Statistical Manual, 5th Edition) especially developed for individuals with intellectual and developmental disorders. The DM-ID-2 is available through the NADD bookstore (National Association for Dual Diagnosis). The website for the national organization dedicated persons with intellectual disability and co-occurring mental health needs has many resources listed to help understand dual diagnosis: www.thenadd.org.

Obtaining a Thorough Assessment and Arriving at an Accurate Diagnosis

The term “dual diagnosis” (MI/DD), as used within this Handbook, refers to individuals with intellectual and developmental disability who may have either mental health needs or significant behavioral challenges that put them or others around them in danger. The term “MI/DD” is a shorthand way of referring to individuals who live with a Mental Illness and a Developmental Disorder. People with disabilities, Families and Staff may wonder whether unwanted behaviors are due to mental health problems, developmental disabilities, unsafe behavioral habits or a combination of all of these challenges. Unless the individual is thoroughly assessed by knowledgeable professionals, it may be difficult to know why people may act in unsafe ways and what to do in order to keep everyone safe.

Just as is the case for the general population, people with a dual diagnosis (MI/DD) may live with such mental health problems as depression, mood disorders, thought disorders and anxiety disorders. However, unlike the general population, persons with intellectual and developmental disabilities may display their mental health needs in the form of unwanted and unsafe behaviors such as threatening behavior, assault, self-injury, property damage or elopement. These behaviors may be ineffective and interfere with the person pursuing independent living and self-

determination. The person with a dual diagnosis may have extra difficulty in pursuing preferences, goals and valued outcomes at school, at work or within relationships.

Although individuals with developmental disabilities may exhibit behavioral problems, there is nothing about either an intellectual disability or a developmental disorder that automatically explains a person engaging in such unsafe behaviors as aggression, self-injury, property destruction, or elopement. Some individuals may have genetic disorders that can be associated with self-injury. Some people may display unwanted behaviors that are associated with mental health problems. There can be as many explanations for problem behaviors as there are people who exhibit them.

The first step to getting a clearer picture of what is going on is to have the person with a question about mental health or behavioral issues thoroughly assessed. It is imperative that potential medical issues be identified when someone with a dual diagnosis (MI/DD) is experiencing a behavioral health crisis. Individuals exhibiting unwanted behaviors might also be suffering from health problems such as infections and pain. This is why it is important to have the individual comprehensively evaluated. This is the best way to attempt to identify all factors that relate to the individual's behavioral issues.

The first step in obtaining treatment is to obtain an accurate diagnosis. Sometimes individuals with intellectual and developmental disabilities are difficult to diagnose because of their languages and cognitive challenges which may affect their ability to understand questions during assessment and may limit their ability to report distress. Individuals with disabilities may be non-traditional communicators. The clinicians who assess them may not be aware of these challenges to use of assessment tools applied to the general population of individuals without disabilities. As a result, we see people who live with mental health needs which have never been properly identified and treated and we see people who are mistakenly diagnosed with mental health disorders although they do not suffer from a mental illness. The result can be either unaddressed mental health needs or people who are unnecessarily receiving medication or being hospitalized.

The first step in obtaining an accurate diagnosis is to see a medical doctor who can rule out any medical conditions that may be affecting thinking, mood or behavior. If there are no known medical problems that need treatment, referral to a psychiatrist or psychiatric advanced nurse practitioner with experience in assessment of psychiatric issues of persons with disabilities or referral to a psychologist or other non-medical clinician who is familiar with the diagnosis of mental health needs of individuals with disabilities.

Even if someone displays behavioral outbursts, it does not mean that person meets criteria for a mental health disorder or that the individual requires medication or hospitalization. It is not uncommon for people who are on the autism spectrum to display aggressive outbursts in response to sensory overload or out of frustration over the failure of others to understand or meet their needs because limited communication skills. When aggression is the individual's response to environmental stressors, the best approach is to arrange an evaluation by a Board Certified Behavior Analyst who is familiar with conducting functional behavioral assessments and can develop a behavioral shaping plan or support guidelines to address elimination of those conditions that lead to a behavioral outburst. This assessment is best accomplished within the person's natural setting and behavioral shaping plans are best implemented by the individual and his/her supports across all usual settings in which the behavioral outbursts occur.

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

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 change 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.