

The Other Dual Diagnosis

The term "dual diagnosis" in psychiatric circles usually refers to an individual with both a primary mental illness and a substance-related disorder. There is, however, another dual diagnosis - that of mental illness combined with a developmental disability. These dually diagnosed individuals often face challenges in having their mental illness recognized and effectively treated.

The legal definition for "developmental disability" in Wisconsin includes having one of six of diagnoses:

- autism
- brain injury
- cerebral palsy
- epilepsy
- mental retardation
- Prader-Willi Syndrome

Beyond this legal definition, there are hundreds of genetic diagnoses, syndromes, and environmental insults that can result in a developmental disability. Often the cause is unknown. The variability of the disability, added to the normal variability between individuals, increases the challenges in diagnosis and treatment.

Several socially mediated factors can make psychiatric treatment more challenging in the developmentally disabled population. For many years, persons with developmental disabilities were isolated in residential institutions - separated from family and community influences. This loss, combined with the adverse effects of institutional living, sometimes resulted in individuals using unusual and problematic behaviors to get their needs met. Lack of familiarity with traditional social behaviors, difficulty with cooperation (often due to fear or lack of understanding), and aggression or self-abuse can interfere with the person's ability to obtain psychiatric care and sometimes result in misinterpretation of symptoms as voluntary behaviors. These problems are undoubtedly complicated by the presence of language deficits. Further, the reliance on substituted judgment to provide information about an individual can result in failure to recognize or accurately interpret symptoms or behaviors.

When communication and cognition are limited, the person may use similar methods to communicate different things. For example, fear, pain, hunger, anger, sadness, or anxiety may all be communicated using similar behaviors such as self-abuse, aggression, loud vocalizations, or elopement. It takes attentive providers and thorough investigation skills to identify what is actually the cause of distress. Sometimes the cause is physical, such as unrecognized pain or fatigue. Other times the cause is related to an environmental problem such as excessive noise, discomfort in crowds, lack of stimulation, or conflicts with a roommate or support staff person.

Finally, the diagnosis of mental illness may be challenging due to difficulty in applying the DSM-IV diagnostic criteria to persons who may not meet all of the criteria for a given

condition, or for whom the criteria cannot be ascertained due to their developmental disability.

The majority of developmentally disabled individuals rely on public funding of their medical care. Many psychiatrists will not accept new patients on Medical Assistance, and this can result in long waiting lists and other difficulties in accessing care. When these individuals are able to find a psychiatrist, they may find that the provider is unfamiliar with the significance of the developmental disability. In some cases, the traditional clinic office is not hospitable to disabled individuals. Sometimes a larger room is necessary to provide space for support teams and /or an individual who needs space to pace or separate from others. Additional personnel may be necessary to provide support during the appointment, and the room may need to be surveyed for safety concerns.

In general, there is relatively poor integration of the “DD” and psychiatric treatment systems. This tends to create unique challenges for treating dually diagnosed individuals. Case management services and their respective funding sources do not typically operate in concert, and many individuals end up receiving suboptimal care from both systems. This can be quite frustrating for a psychiatrist attempting to coordinate care in the community. A partial remedy is to put effort into facilitating communication with (and between) the team, at every stage of the assessment and treatment process.

Effective psychiatric treatment of developmentally disabled individuals necessitates close monitoring of medical comorbidity. A number of medical problems, including seizure disorder, GI disease, chronic pain, and intercurrent neurodegenerative conditions can complicate diagnosis and treatment. It is always good to have competent primary care and neurology colleagues available for consultation and referral.

Comorbid mental illness and developmental disability may complicate many aspects of a person’s life. Oftentimes the person cannot understand the significance of their mental illness or comply with treatment. People, other than the individual being treated, may have significant influence on whether treatment is initiated or successfully accomplished. The ability, knowledge, and opinions of the guardian, family, and support staff can greatly influence how information is disseminated amongst the team, and this may ultimately determine treatment course and success.

What recommendations can be made regarding provision of comprehensive and appropriate mental health care to persons dually diagnosed with developmental disabilities and mental illness?

1. One significant challenge to obtaining psychiatric treatment for persons with developmental disabilities is the inadequate reimbursement under the current Medical Assistance program. This disincentive is especially acute when the person's needs require more than the average time allotment and may require environmental or personnel modifications. Increasing reimbursement and adding more flexible billing arrangements require advocacy for policy reforms.
2. Psychiatrists and other mental health care providers need access to necessary information about developmental disabilities. They need to know about

community support systems for people with developmental disabilities. Extensive educational material is available: web resources, classes, seminars, and interested specialists. This information is not always well disseminated to the psychiatric community. In some cases it is not available in a format (time, dates, locations, or certification for MD continuing education) that promotes use by busy professionals. Creating opportunities for specialists providing day-to-day support to individuals with developmental disabilities and psychiatrists and other mental health practitioners to share perspectives, knowledge, and practice tips would "demystify" the two aspects of this dual diagnosis for both groups.

3. The settings that are available for providing mental health care are sometimes not well designed for persons with developmental disabilities. Larger rooms may be needed to accommodate presence of support teams at appointments. Some individuals with developmental disabilities may need room to move about or maintain additional personal space during the appointment. Accessible entrances and facilities are necessary for people who require physical accessibility due to brain injury, cerebral palsy, or other mobility problems. Design of rooms and furnishings needs to be done with consideration to safety for people with unusual behaviors. Reception personnel need methods to adapt their interactions to meet the needs of people with a dual diagnosis. Waiting rooms and clinic rooms need to have entertainment activities that are cognitively, developmentally, and age appropriate. Information about diagnoses and treatments needs to be provided in forms accessible to persons who may not read, or whose cognitive level is below the average.
4. Ability to provide effective psychiatric services to persons with developmental disabilities is greatly improved by a knowledge of how the developmental disability community support system functions. One needs to know how medications and treatments are delivered in the supported living community and what resources are available to provide assistance to the person, provider, and team. The presence of community behavioral support specialists can provide adjunct support in modifying behaviors and can help patients learn to generalize desired behaviors in different settings. Crisis support teams and "safe houses" can help avoid unnecessary institutionalization during behavioral or environmental crises.

What are the benefits of providing psychiatric care to persons dually diagnosed with developmental disabilities and mental illness?

There are many benefits to be gained from providing psychiatric care to persons dually diagnosed with developmental disabilities and mental illness. Access to appropriate psychiatric care can make the difference between successful community living versus a lifetime in an institution or in a very restricted setting. Successful treatment for mental illness can be the beginning of wonderful new life opportunities. Observing the person's symptoms decrease and watching him / her make progress toward life goals can be very professionally satisfying for providers and teams.

The presence of support teams in a person's life can help to improve compliance with medication regimens. It can also improve reliability of attendance at appointments, and provide assistance in helping a person learn new coping strategies. Collaborating with support providers can make the role of the psychiatric provider much more satisfying and less stressful. Knowing how to best utilize all the members of the support team can result in better care for the individual involved.

Community support providers can provide helpful assistance and suggestions. They may be able to give important information about the person's behavioral history, previous reactions to medication, or periods in the person's life when they were more emotionally and behaviorally stable. Support persons can also be very valuable in reporting the benefits and adverse effects of medications. The psychiatric provider can request (from the support staff) documentation of symptoms or side effects, and reports of how these things differ in different settings (work, recreation, home).

In summary, individuals with developmental disabilities are as susceptible to mental illness as any other person is, and they can and do benefit from treatment for their mental illness. The dual diagnosis of developmental disability and mental illness can present challenges to accurate diagnosis and treatment. However, with careful history taking, thorough documentation of symptoms and treatment effects, appropriate use of treatments, and effective use of support teams, successful treatment is not only possible, but often life-changing for the individual and professionally satisfying for the provider.

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For information about use of psychotropic medications by persons with developmental disabilities, see: <http://wcdd.org/Publications/noeasyanswers.pdf>

For information about developmental disabilities and resources see:

<http://www.familyvillage.wisc.edu>

<http://www.wcdd.org>