

Severe and Persistent Mental Illness and Developmental Disability

Covered Diagnoses:

The individual with a co-occurring disorder presents with both an Axis I diagnosis of a psychiatric disorder as defined in the DSM-IV-TR or ICD-9, Axis II Developmental Disability (Mental Retardation) such as:

317	<i>Mild Mental Retardation</i>	<i>IQ level 50-55 to approximately 70</i>
318.0	<i>Moderate Mental Retardation</i>	<i>IQ level 35-40 to 50-55</i>
318.1	<i>Severe Mental Retardation</i>	<i>IQ level 20-25 to 35-40</i>
318.2	<i>Profound Mental Retardation</i>	<i>IQ level below 20 or 25</i>
319	<i>Mental Retardation, Severity Unspecified</i>	

or a Pervasive Developmental Disorder such as:

299.00	<i>Autistic Disorder</i>
299.80	<i>Rett's Disorder</i>
299.10	<i>Childhood Disintegrative Disorder</i>
299.80	<i>Asperger's Disorder</i>
299.80	<i>Pervasive Developmental Disorder NOS</i>

Persons with developmental disabilities suffer from the full range of psychiatric disorders: Any mental illness which has been identified in persons with typical intelligence can occur in someone with a developmental disability. (Fletcher, 1993 cited in Nugent, 1997, p. 33)

Diagnostic Definitions:

1. Establish diagnostic accuracy on Axis I and Axis II.

Mild—“...As a group, people with this level of mental retardation typically develop social and communication skills during the pre-school years (ages 0-5 years), have minimal impairment in sensorimotor areas, and often are not distinguishable from children without mental retardation until a later age. By their late teens, they can acquire academic skills up to approximately the sixth-grade level. During the adult years they usually achieve social and vocational skills adequate for minimum self-support, but may need supervision, guidance, and assistance, especially when under unusual social or economic stress. With appropriate supports, individuals with Mental Retardation can usually live successfully in the community, either independently or in supervised settings.” (DSM IV-TR, p. 41)

Moderate—“Most individuals with this level of mental retardation acquire communication skills during early childhood years. They profit from vocational training and, with moderate supervision, can attend to their personal care. They can also benefit from training in social and occupational skills but are unlikely to progress beyond the second-grade level in academic subjects. They may learn to travel independently in familiar places. During adolescence, their difficulties in recognizing social conventions may interfere with peer

relationships. In their adult years, the majority are able to perform unskilled or semiskilled work under supervision in the general workforce or other supervised vocational educational programs..." (DSM IV-TR, p. 43)

Severe—"During the early childhood years, they acquire little or no communicative speech. During the school-age period, they may learn to talk and can be trained in elementary self-care skills. They profit to only a limited extent from instruction in pre-academic subjects, such as familiarity with the alphabet and simple counting, but can master skills such as learning sight reading of some "survival" words. In their adult years, they may be able to perform simple tasks in closely supervised settings..." (DSM IV-TR, p. 43)

Profound—"...Most individuals with this diagnosis have an identified neurological condition that accounts for their mental retardation. During the early childhood years, they display considerable impairments in sensorimotor functioning. Optimal development may occur in a highly structured environment with constant aid and supervision and an individualized relationship with a caregiver. Motor development and self-care and communication skills may improve if appropriate training is provided. Some can perform simple tasks in closely supervised and sheltered settings." (DSM IV-TR, pp. 44)

Diagnostic and Treatment Guidelines: the following list appears in The Habilitative Mental Healthcare Newsletter: January/February 1995, Vol. 14, No.1. Sovner, Beasley, Hurley. How Long Should a Psychiatric Inpatient Stay be for a Person with Developmental Disabilities?
<http://thearc.org/faqs/inpatien.html>.

- Mental illness often presents in a nonspecific way, usually with maladaptive behavior.

"Because of the lack of good communication skills and sophisticated defense mechanisms, this population usually presents global behavior problems as symptoms of mental illness. (Ryan, 1996 quoted and cited in Nugent, p. 33). Behaviors such as self-abuse or aggression can be an expression of psychological discomfort. Therefore, the behavior may be the person's way of communicating his psychic pain." (Nugent, p. 33) "An acute psychiatric disorder may present as an exaggeration of a long-standing maladaptive behavior." (Nugent, p. 34)

- Staff cannot rely on patient self-reports for diagnosing mental illness.
- Objective behavioral data is often necessary to make a valid psychiatric diagnosis.

"One behavior may mean different things at different times." (Nugent, p. 34) "...it is important to record and report behaviors which are not dangerous but which are unusual for the individual." These behaviors, for example a change in sleep pattern, may be more useful in making a diagnosis. (Nugent, p. 35)

- Outpatient treatment (including medication) may be masking diagnostically-relevant symptomology.

- Diagnostic evaluation should include an extensive review of records and meetings with caregivers and family members. A longitudinal history should be considered when evaluating current events and stressors, medical problems, and medication changes. As much as possible, baseline information on IQ, adaptive functioning, language, communication, social and developmental history, family history, and medical history should be established.

“Symptoms may differ depending on the person's level of intellectual functioning, [but] IQ does not predict prognosis.” (Nugent, p. 34)

- Medical evaluation should be thorough to rule out physical illness.

“Medical illnesses or medications can directly cause ,or contribute to symptoms which mimic those of a psychiatric illness.” (Nugent, 1997, p. 33)

- Psychiatric Symptoms May Present Differently with Dual Diagnosis

“Persons with DD are likely to have had a more limited range of life experiences than other people of the same age. They also have limited intellectual and social skills. These factors affect the presentation of psychiatric disorders, including those in which delusions or hallucinations are present.” (Nugent, 1997, p. 34)

- There is a lack of precise diagnostic instruments for dual diagnosis; however, there are some guidelines and tools available through www.thenadd.org.

- Outward social manifestations may be less obvious

“Mental illness is partly socially defined, and is often revealed by changes in the way in which a person interacts in his/her various social environments.... It may take months before anyone notices that someone’s participation in a day program has declined or the person is more socially isolated.” (Nugent, 1997, p. 36)

- The interview process must take into account several factors common to the DD population

- High levels of egocentricity
- Limited understanding / concrete processing of language and concepts
- Unique connections between events, objects and people
- Avoidance of issues involving intense feelings
- Blindness to inconsistencies
- Being conditioned to please
- Having a history that is hard to believe (extensive traumatic experiences)
- Being numbed to negative feedback about their behavior resulting in potential disengagement from the interview process
- Socioenvironmental control – escalated behavior may be a way an individual communicates wanting to be removed from a situation due to physical or emotional discomfort

- Ongoing communication between the care providers and the mental health center clinical staff or the private practitioner is critical to the success of treatment.

Treatment concerns:

- Treating professionals should be alert for subtle signs of sexual abuse. Individuals who are developmentally disabled are more vulnerable to sexual abuse.

Recognition and diagnosis of post traumatic stress disorder in the developmentally disabled population has only recently come to the forefront. Individuals with a developmental disability are more vulnerable to sexual abuse.

“More than 90 percent of people with developmental disabilities will experience sexual abuse at some point in their lives. Forty-nine percent will experience 10 or more abusive incidents (Valenti-Hein & Schwartz, 1995). Other studies suggest that 39 to 68 percent of girls and 16 to 30 percent of boys will be sexually abused before their eighteenth birthday. The likelihood of rape is staggering: 15,000 to 19,000 of people with developmental disabilities are raped each year in the United States (Sobsey, 1994). [quoted and cited by Reynolds, <http://thearc.org/faqs/Sexabuse.html>, People with Mental Retardation & Sexual Abuse, p. 2].

“People with Mental Retardation may not realize that sexual abuse is abusive, unusual or illegal. Consequently, they may never tell anyone about sexually abusive situations. People with and without disabilities are often fearful to openly talk about such painful experiences due to the risk of not being believed or taken seriously. They typically learn not to question caregivers or others in authority. Sadly, these authority figures are often the ones committing the abuse...” (Turnbull, et.al., 1994). [quoted and cited by Reynolds, <http://thearc.org/faqs/Sexabuse.html>, People with Mental Retardation & Sexual Abuse, p. 2].

A 6-point treatment protocol is recommended by Ruth Ryan to be utilized with individuals who have developmental disability and post traumatic stress disorder. The following points are quoted and cited by Nugent, 1997, in the *Handbook on Dual Diagnosis*. p. 106.

1. Judicious use of medications
2. Identification and treatment of medical problems: physical discomfort or medical problems have been associated with treatment resistance and more frequent dissociation.
3. Minimization of iatrogenic complications: ...we require accurate diagnosis of the person's condition or we might also unintentionally do something that makes things worse for the person.
4. Psychotherapy
5. Habilitative changes to control dissociative triggers: dissociative triggers are elements which remind the person of the original trauma and thus provoke flashbacks...
6. Education and support for staff: education will assist staff to more quickly recognize the potential symptoms of a post traumatic stress disorder and pursue appropriate treatment...

Elements of treatment:

Care should be taken in the choice of treatment modalities for individuals with developmental disability. The selection of therapeutic modality is dependent on the client's ability to respond.

- "Psychopharmacology. There are many disorders that can be controlled or alleviated with medication. However, there has been a tendency in the past to over-medicate people with mental retardation and not to carefully monitor the behavioral effects of medications. Even when used appropriately, medications are only part of an effective total treatment program. (Reiss, Goldberg, Ryan, <http://thearc.org/faqs/mimrqa.html>, Mental Illness in Persons with Mental Retardation.)

The following points are quoted and cited from various sources by Nugent, 1997, in the *Handbook on Dual Diagnosis*. pp. 118-120.

"use drugs to treat a disorder, not a behavior."

"ensure that the person has a psychiatric diagnosis"

"ensure that the specific medication is appropriate for the specific diagnosis"

"medications are one part of a complete treatment plan"

"the right drug does not fix the wrong environment"

"first, do no harm"

"each person has his/her own definition of quality of life"

"when possible, use enhancers, not blockers...the brain prefers to have its neuroreceptor activity increased rather than antagonized..."

"remember the common error of overprescribing antipsychotic medications and underprescribing antidepressants"

"psychotropic drug therapy is NOT a second line intervention"

"a drug withdrawal programme is not an automatic feature of drug therapy."

- Counseling/Psychotherapy. People with developmental disability, mental illness, and/or behavior problems can benefit from supportive therapy that is problem focused and aimed at identifying and intervening in symptomatic behavior and emotions. Therapy must include active collaborations and training of natural caregivers with the goal of transferring practical intervention skills to caregivers and converting therapy to an episodic correlative model.
- Approaching the treatment of the individual with developmental disability as one would approach the treatment of an individual from a different culture will assist the clinician in understanding the client. However, even if the person is viewed as coming from a different culture, he or she is more like the clinician than different. (Nugent, 1997, p. 133)
- Issues of transference and countertransference are more prominent in treatment with developmentally disabled individuals. Transference reactions are noted to be "more rapid, pronounced and primitive" and the consumer usually place non-disabled adults in a role of

authority or as a person who will provide care. (DesNoyers Hurley, A. 1996, quoted and cited by Nugent, 1997).)

- An expectation of adult behavior is important no matter what the mental age of the client. However, the individual with a developmental disability has likely been taught compliance so part of therapy should include teaching such skills as self-sufficiency and assertion. (Nugent, 1997)
- “Cognitive Therapy. This treatment teaches people with mental retardation to recognize the situations in which they get into trouble and to develop alternative behavior and solutions to their problems. Although widely used with the general population, cognitive therapy has been adapted only recently for use with people with mental retardation (Benson, 1992), [(Reiss, Goldberg, Ryan, <http://thearc.org/faqs/mimrqa.html>, Mental Illness in Persons with Mental Retardation.)].
- “Social Skills Training. This is a cost-effective, time-limited approach that often produces noticeable improvements in quality of life and interpersonal behavior. Individuals are gradually taught effective social interactions and appropriate social behavior.” (Reiss, Goldberg, Ryan, <http://thearc.org/faqs/mimrqa.html>, Mental Illness in Persons with Mental Retardation.)
- "Relaxation training can be a very useful form of therapy for problems related to anxiety such as phobias." (Rickard, 1986, cited by Nugent, 1997).
- Group therapy, anger management training, problem-solving skills training and various other modalities can be adapted for use with clients who have a developmental disability according to Nugent, 1997.
- Provision of support and training to care givers can be a critical element in the successful treatment of dually diagnosed individuals. Every effort should be made to include family members, caregivers, medical professionals, and other interested parties in the treatment planning for these individuals.
- “Behavior Management. This approach is widely used with people with mental retardation, especially to control behavior problems. The approach often leads to significant behavioral improvements, at least during the time period when the treatment is in effect. The Arc has called for the complete elimination of aversive (punishment) behavior management techniques and the reliance instead on positive behavioral techniques.” (Reiss, Goldberg, Ryan, <http://thearc.org/faqs/mimrqa.html>, Mental Illness in Persons with Mental Retardation.)
- “Activity Therapy. Music and art therapy are relatively cost-effective services that help build positive experiences and self-confidence. Some individuals with mental retardation have considerable artistic skills. Occupational and physical therapy can be helpful for some individuals.” (Reiss, Goldberg, Ryan, <http://thearc.org/faqs/mimrqa.html>, Mental Illness in Persons with Mental Retardation.)

Educational Websites Regarding the DD/MI Population

National Association for the Developmentally Disabled
<http://www.thenadd.org/>

Mental Health Aspects of Developmental Disabilities
<http://www.mhaspectsofdd.com/>

Best Buddies
<http://www.bestbuddies.org/index.asp>

Our Kids
<http://www.our-kids.org/>

MedLine Plus: Developmental Disabilities
<http://www.nlm.nih.gov/medlineplus/developmentaldisabilities.html>

American Association for People with Disabilities
<http://www.aapd-dc.org/>

Co-Occuring Disorders Assessment Format
http://www.adoctorm.com/docs/DD-MI/pages/co-occurring_do_asses_format.htm

Bibliography

DesNoyers Hurley, *A Vocational Rehabilitation Counseling Approaches to Support Adults with Mental Retardation*. The Habilitative Mental Healthcare Newsletter, 15-2, 1996.

Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Test Revision, 2000
Washington, D.C.: American Psychiatric Association.

Fletcher, R. J. *Individual Psychotherapy in Persons with Mental Retardation* in Fletcher, R. J. and Dosen, A., Editors. *Mental Health Aspects of Mental Retardation: Progress in Assessment and Treatment*. New York, Lexington Books, 1993

Nugent, Jo Anne, *Handbook on Dual Diagnosis. Supporting People with a Developmental Disability and a Mental Health Problem*. Second Edition, 1997, Nugent Training and Consulting Service.

Reiss, Goldberg, Ryan, <http://thearc.org/faqs/mimrqa.html>, Mental Illness in Persons with Mental Retardation.

Reynolds, <http://thearc.org/faqs/Sexabuse.html>, People with Mental Retardation & Sexual Abuse, p. 2.

Rickard, H. C. *Relaxation Training for Mentally Retarded Persons*. Psychiatric Aspects of Mental Retardation Reviews, 5-3, 1986.

Ryan, R. M. *Handbook of Mental Health Care for Persons with Developmental Disabilities*. Denver, Colorado, S & B Publishing, 1996.

Ryan, R. M. *Post Traumatic Stress Disorder in Persons with Developmental Disabilities*. Community Mental Health Journal, 30-1, 1994

The Habilitative Mental Healthcare Newsletter: January/February 1995, Vol. 14, No.1. Sovner, Beasley, Hurley. How Long Should a Psychiatric Inpatient Stay be for a Person with Developmental Disabilities?