Dual Diagnosis
A Guide for Caregivers

An Developmental Disability and a Mental Illness

What is the prevalence?

• Statistics range from 10-40% of people with a DD have a mental illness.
• People with a DD have extra risk factors.

Proper Diagnosis
Where do you start?

- First assess the basics:
  - Capacity to consent
  - Collateral history (multiple caregivers)
  - The level of a person's ability
    - The person's skills, functioning and community involvement
  - The cause of the ID
    - Epilepsy, autism, Down syndrome
  - Review previous medical case notes
    - Past drugs and other treatments

Gathering of a Collateral History

- Information from multiple caregivers
  - Parent:
    - Past medical, psychiatric problems
    - Family history of these problems
    - Knowledge of skill level
    - Is there regression
  - Others:
    - How many others are involved
    - Who well is the care coordinated
    - How well do the caregivers follow up

A Person's Support Package---

- Using a semi-structured approach - What do you need to know?
- A detailed history
- Recently established - informants don't get the "whole" or bigger picture (only report what they see, e.g. aggression), omit other information, i.e. social withdrawal or loss of energy.
Medical Model versus Developmental Model

- Genetic
- Biochemistry
- Neuroanatomy
- Drug treatment
- PHYSICAL HEALTH

- The medical model, though essential in treating the symptoms of the mental illness, does not take into consideration the underlying issue so commonly seen in the dually diagnosed, which is a lack of access to quality of life spheres.

The Developmental Model of Care

- The Biopsychosocial perspective
  - Severity of ID
  - Causes of ID
  - Level of Education
  - Sensory Impairments
  - Other medical conditions
  - Life experiences
  - Social supports

The Developmental Model-Quality of Life

- Other areas that should be considered include, the availability of transportation, a proper diet, assistance with daily living skills, exercise, sleep, friends and other social supports and meaningful vocational or day habilitation services.
Biological-psychological-social-developmental Framework

**Whole Population**
- Family history/genetic vulnerability
- Neurological disorders
- Physical disorders
- Use of alcohol/substances
- RX drug side effects

**People with ID**
- Behavioral phenotypes-psychiatric sequelae of genetic disorders
- Neurological/metabolic/infective causes of ID
- Epilepsy
- Sensory Impairments
- Multiple Disabilities
- Multiple Medications

Behavioral Phenotypes

- Genetic causes of ID
  - Angelman's syndrome
  - Prader-Willi Syndrome
  - Autism
  - Down Syndrome
  - Partial complex Seizures
  - Epilepsy
  - Drug side effects

Psychological

**Whole Population**
- Adverse experiences in early life affecting development of personality, confidence, self-esteem, coping strategies, traumatic experiences at any stage of life

**People with ID**
- Parent-infant bonding and family dynamics (learned experiences)
- Time spent outside family home, residential school, hospital
- Consistency of parenting
- Exploitation, neglect, abuse
- Bullying, harassment
- Establishing trust, confiding, low self-esteem, limited coping
- Repeated broken relationships
Social

Whole Population
- Life events
- Poverty
- Unemployment
- Limited social networks
- Social exclusion

People with ID
- Life events are often multiple:
  - e.g. death of mother often results in change in residence + change in day center + move from familiar neighborhood + loss of previous social network + intimate care now provided by a stranger + sharing a home with new people
- Low income (benefits)
- Limited choices and opportunities

Social Issues ID continued

- Poverty of environment
- Problems accessing transport
- Limited social networks
- Limited one-to-one attention
- Repeated pattern of broken relationships (support workers retire, move, are promoted, change job, take maternity leave)
- Exploitation and abuse
- Stigma
- Social exclusion
- Career strain

Developmental

Whole Population
- None

People with intellectual disabilities
- Difficulties understanding social rules, events, etc.
- Limited communication skills
- Difficulty sharing worries and problems (trust and communication)
- Developmental phase impacting on behaviour
Diagnostic Overshadowing

- The term diagnostic overshadowing refers to the tendency clinicians have to attribute all the behavioral and emotional problems to the developmental disability instead of the mental illness.

1 plus 1 = 3 or 4

Research suggests that mental illnesses are the result of a complex interaction of genetic, biological, personality and environmental factors.

Dual diagnosis -- pathoplastic

- Pathoplasticity is the “variability in a symptom’s specific form and content, shaped by events in a patient’s life.
  - Personality factors
  - Culture
  - This effect is greater the more severe the person’s ID
Measurement of Developmental Level

- Enables appropriate interpretation of psychopathology.
- Determines the usual pattern of behaviors and skills (sleep).
- Reduces the likelihood of diagnostic overshadowing.
- Treatment plans must reflect the appropriate level.

- At what age is head banging common?
- At what age is oppositional behavior common?
- At what age are fears and phobias common?

What are the mental illnesses

- There are major and less severe mental illnesses.
- The serious mental illnesses include major depression, schizophrenia, bipolar disorder, obsessive compulsive disorder (OCD), panic disorder, post traumatic stress disorder (PTSD) and borderline personality disorder.

Common Medical Problems

- Common medical problems that should be considered and eliminated as a possible cause include:
  - constipation,
  - blood sugar fluctuations associated with diabetes mellitus,
  - sleep apnea,
  - GERD or heartburn,
  - abnormal sodium levels,
  - seizures,
  - pain,
  - infections and medication side effects.
Behavior = Communication

• Behavior is a form of communication, so exploring what the behavior is communicating is very important.

• Medical factors are often behind behaviors of concern in intellectually disabled people. For example people with Down Syndrome frequently have hypothyroidism. This may look like the symptoms of depression.

Special Considerations for Assessing a Person with a Dual Diagnosis.

• Identify what behaviors are coming from the intellectual disability, the mental illness, or an interaction between the two.

• Separating out the behaviors is essential for an accurate diagnosis, and only with an accurate diagnosis can the person be treated properly.

How do they interact?
Other areas that should be considered include, the availability of transportation, a proper diet, assistance with daily living skills, exercise, sleep, friends and other social supports and meaningful vocational or day habilitation services.

Identification and treatment of the mental illness

PAS-ADD

• The Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) checklist is a questionnaire for staff and families to identify potential cases of mental illness. It requires training to use, but can be an excellent tool to identify mental health care needs in the ID population (DM-ID, p. 20).
The DM-ID

- The Diagnostic Manual – Intellectual Disabilities (DM-ID) is a comprehensive clinical guide that offers adaptations of the diagnostic criteria for mental illnesses in intellectually disabled people.

Functional Behavioral Assessments are valuable

- Remember that most appointments are initiated because the person is presenting with a behavior of concern. The behavior(s) of concern should be thoroughly evaluated.

- In order to do this a Functional Behavioral Assessment (FBA) may be necessary. A FBA helps the clinician determine if the behavior(s) of concern is caused or influenced by a need.

Positive Behavioral Support

- The most common behaviors of concern are aggression, self-injury, property destruction and oppositional or non-compliance behavior.

- An analysis of the causes of the behavior(s) may result in a recommendation for environmental changes or positive behavioral support or both (DM-ID, p.11).
• The functional behavior assessment identifies multiple strategies to effectively reduce problem behavior including changing systems, altering environments, teaching skills, and focusing on positive behaviors.

Positive Behavior Support

• The PBS process results in the creation of effective intervention plans that will impede problem behaviors, teach new skills, and create support systems for the person.

Multi-modal approach

• Treatment of a mental illness involves many aspects of a person’s life and people with additional supports and comprehensive treatment plans do better.
Are medications necessary?

- In many cases the answer is yes.
- Both medications and psychosocial therapies are major treatment options that can be components of a treatment plan and assist with getting better.

Medications

- SSRIs
- OCD, depression and anxiety
- Atypical antipsychotics
  - aggression
- ADHD
  - non compliance
- Tricyclics
  - Sleep

Medications Off label

- Seizures medication
  - Mood stabilizers
- Blood Pressure Medications
  - Anxiety
N-acetylcysteine

- Grooming disorders
- Nail biting
- Skin picking
- Hair pulling (Trichotillomania)
- Anxiety associated with autism
  - It reduces anxiety at its core-glutamate receptors
  - High efficacy, low side effect profile

Generalized Anxiety Disorder

Chronic or exaggerated worry and tension. Often physical symptoms accompany this disorder, such as trembling, muscle tension, headache and nausea.

Generalized Anxiety Disorder and ID - There are six symptoms associated with GAD: restlessness, easily fatigued, difficulty concentrating, irritability, muscle tension and sleep disturbance (falling asleep or staying asleep).

In persons with a severe ID or children, only one of these symptoms is required. For persons with a moderate or mild ID, three symptoms are required.

Specific Phobia

- An extreme, disabling fear of a specific object or situation that poses no real or immediate threat. Often referred to as an irrational fear of something. Fear of closed spaces, elevators, heights, animals, blood, and needles (injections) are common.

- Specific Phobia and ID - In persons with ID this may be expressed by crying, tantrums, freezing, or clinging in persons with severe ID.
- Children and persons with severe ID can see that it is excessive and unreasonable. (DM-ID, pg. 197)
Social Phobia-

• A fear of being the focus of attention or scrutiny, or doing something embarrassing or humiliating. A marked fear of social or performance situations.

• Social Phobia and ID- In persons with ID this may be expressed by crying, tantrums, freezing, or shrinking from social situations with unfamiliar situations. The person should be able to recognize that this fear is excessive or unreasonable. In persons with severe ID this feature may be absent. (DM-ID, pg. 199)

Obsessive-Compulsive Disorder (OCD) -

• Repeated, intrusive and unwanted thoughts that cause anxiety. In an attempt to relieve the anxiety the person performs a ritualized behavior.

• The obsessions are the intrusive thoughts and the compulsions are the repetitive, purposeful and intentional behaviors that are performed in response to the obsessions.

Obsessive-Compulsive Disorder and ID- 

• Obsessive-Compulsive Disorder and ID- Not all repetitive behaviors in persons with ID should be considered obsessive-compulsive behaviors. For example, repetitive behaviors with a physiological-rewarding property should not be considered in this diagnosis.

• The most common behaviors of this type are masturbation, stealing, hyperventilation, over-eating, over-drinking, smoking, humming, and pacing (DM-ID, pg. 210).
OCD cont.

- Among people with an ID, aggression may be the presenting concern. The aggressive actions are directed toward removing an obstacle that prevents the person with an ID from completing a ritual or a fixed way of doing things. There is a risk of diagnosing false positives and negatives in the ID population.
- The Compulsive Behavior Checklist for Clients with Mental Retardation can be very helpful in reducing those risks (DM-ID, pg. 210).

Panic Disorder-

- Characterized by panic attacks. A panic attack is a sudden and overwhelming burst of intense fear or discomfort and is accompanied by four or more physical or cognitive symptoms (characteristics of flight or fight).
- A panic attack is accompanied by an overwhelming sense of impending doom or impending danger and is not due to a specific phobia.
- The symptoms include: a pounding heart, sweating, shaking or trembling, shortness of breath, feeling of choking, chest pain or discomfort, nausea, feeling dizzy, lightheadedness, feelings of losing control, going crazy, fear of dying, chills or hot flashes, dizziness or light-headedness.

Panic Attack and ID-

- Panic Attack and ID- observed symptoms are important in making the diagnosis.
- Observed intense fear or discomfort, in which three (or more) of the following symptoms develop abruptly and reach a peak in 10 minutes: pounding or racing heart, sweats, trembling or shaking, shortness of breath, feeling of choking, chest pain or discomfort, nausea or abdominal distress, feeling dizzy or unsteady, and chills or hot flashes.
- Extreme panic attack may result in irritability, aggression and destructive behavior and may also cause lashing out of arms and legs and head banging. (DM-ID, pg. 190-191)
Panic Disorder with Agoraphobia-

- Anxiety about having a panic attack in a public place or anxiety about being in a place from which escape might be difficult. Common places include outside your own home or crowded places, like malls, large grocery stores, or airplanes (Mash and Wolfe, 2010).

- Panic Disorder with Agoraphobia and ID- Since many people with an ID have limited choices in their day-to-day lives, this disorder may show up as a refusal to go to certain places or when brought to a stressful place the person displays an increase in intensity of distress and anxiety which may lead to aggression, self-injury or destructive behaviors. (DM-ID, pg 192)

Post-Traumatic Stress Disorder (PTSD)-

- Persistent and frightening thoughts that occur after undergoing a frightening and traumatic event. Children with this disorder re-experience the traumatic event (flashbacks), avoid associated experiences, and display symptoms of extreme arousal.

- PTSD and ID- In people with an ID symptoms may appear in overt behavioral ways instead of as a mental phenomena such as flashbacks. Frightening dreams with unrecognizable content may occur. Non-compliance may represent the persistence avoidance of stimuli or events that are reminiscent of the traumatic event. Irritability and outbursts of anger may also be observed as a result of high arousal levels (DM-ID, p. ).

Mood Disorders in People with an Intellectual Disability

- The presentation of mood disorders in people with an ID often looks more like the symptoms seen in young children.

- It is important for a clinician to gather information about the person from someone who knew them before any symptoms of a mood disorder were present.

- In order to accurately diagnose depression or bipolar disorder a thorough understanding of the person's usual behaviors, skills and abilities are necessary to compare with (DM-ID, p. 157).
Mood Disorders

- Aggression and other externalizing behaviors are commonly seen as a reaction to any number of stressors in people with an ID and do not appear to be "diagnostically specific."
- Aggression, for example, can be a behavioral display of an irritable mood, frustration or anxiety (DM-ID, p. 160).

- Because people with an ID have a limited behavioral repertoire, the externalizing behaviors do show up more frequently.
- Problems with inhibiting behaviors are common and alternative coping strategies are rare.

Externalizing Behaviors

- The externalizing behaviors like screaming, property destruction, aggression and self injury tend to become the primary focus of families and staff.
- These intense problems can distract attention from the underlying problem and more relevant changes that may actually be driving the disruptive behavior.
Bipolar Disorder and ID:

- Cognitive symptoms of mania (i.e. inflated self-esteem or grandiosity) may be affected by the individual's developmental profile and delusions may be simplified.
- For example, during a manic episode the person with an ID may believe she is getting her driver's license. Pressured speech may appear as increased vocalization (rate or volume) or gesturing in individuals who have limited expressive language (DM-ID, pg. 162).

Schizophrenia and ID:

- In order to fully understand the complexity of diagnosing schizophrenia in a person with ID, several issues must be discussed. First, distinguishing a true hallucination from the "self talk" commonly seen in persons with ID is essential, but not easy.
- Second, the symptoms of disorganized speech are easy to identify in a person who is verbally fluent, but difficult to identify in a person who has speech problems resulting from the ID.

- On the other hand, hallucinations can be the easiest symptoms to recognize in a person with ID. Careful listening and observation for behaviors suggestive of hearing voices or seeing someone is important—for example, if the person is seen talking in a conversational style when alone or looking around as if listening to or seeing someone.
- Social withdrawal together with bizarre or disturbed behavior and/or verbal and physical aggression are presenting symptoms of schizophrenia in individuals with ID (DM-ID, p. 146-147).
Schizophrenia and ID:

- In individuals with Mild ID the current DSM-IV-TR diagnostic criteria appear to be reliable and valid, however, with persons with severe and profound ID the diagnosis is much more difficult to make.

Substance abuse??

- Substance abuse must also be considered. Many individuals who live on their own in unsupervised residential settings in the community have access to alcohol and other street drugs that can cause symptoms of a mental disorder (DM-ID, p. 16).

References


