

Mental Health Diagnosis in IDD: Bio-psycho-social Approach

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Let's start with an overview

Mental Illness –

- A category of disorders that affect an individual's thinking, mood and/or behavior to a degree that interferes with an individual's ability to function in their typical manner (i.e., living, learning, working, etc.).
- Recovery is possible and generally the focus of treatment.
- 25% of the general population will be diagnosed with a mental illness (US has highest rates in world!)

Overview of DD - Developmental Disability

Developmental Disability means a disability that is manifested before the person reaches twenty-two (22) years of age,

is likely to continue indefinitely,

results in substantial functional limitations,

is attributable to intellectual disability or related conditions which include cerebral palsy, epilepsy, autism or other neurological conditions, and

reflects the individual's need for assistance that is lifelong or extended duration that is individually planned and coordinated.

Developmental Disabilities may include:

Autism Spectrum Disorder

Muscular Dystrophy

Cerebral Palsy

Fetal Alcohol Syndrome

TBI

Some genetic disorders (Down Syndrome, Prader-Willi, Fragile X)

Intellectual Disability

Overview of IDD - Intellectual Disability

Intellectual disability is a disability characterized by significant limitations both in **intellectual functioning** and in **adaptive behavior**, which covers many everyday social and practical skills.

DSM 5 Criteria

1. Deficits in **intellectual functioning**

- Deficits affect reasoning, problem solving, planning, abstract thinking, judgment, academic learning and learning from experience
 - Has to be confirmed by clinical assessment and individualized, standardized intelligence testing
 - Generally an IQ score of 70 or less indicates a limitation in intellectual functioning
 - Four levels of severity –
 - Mild (80%)
 - Moderate (15%)
 - Severe (4%)
 - Profound (1%)

Overview of IDD - Intellectual Disability

DSM 5 Criteria

2. Deficits in **adaptive functioning**

- That results in failure to meet developmental and sociocultural standards for personal independence and social responsibility
 - Without ongoing support the adaptive deficits limit functioning

adaptive behavior includes three skill types:

- Conceptual skills—language and literacy; money, time, and number concepts; and self-direction.
- Social skills—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
- Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

Overview of IDD - Intellectual Disability

DSM 5 Criteria

3. Onset of intellectual and adaptive deficits during the developmental period

Autism Spectrum Disorder

Why is it important to understand?

People with ASD often have co-occurring mental health issues

People with ASD have characteristics that can be misleading during assessment and diagnosing process

Autism Spectrum Disorder

Incidence: 1 in 68 (males 1 in 30)

Cause: current research suggests interaction between genetics environmental factors

Cognition: wide range of intellectual functioning; 60% have IQ above 70.

Why has incidence risen?

- Better diagnosing
- Better early intervention

ASD Characteristics – DSM 5

- **Social Communication/ Social Interaction**
 - Deficits in social-emotional reciprocity
 - Abnormal social approach, failure of normal back-and-forth conversation, reduced sharing of interests, emotions, or affect; failure to initiate or respond to social interactions
 - Deficits nonverbal communicative behaviors used for social integration
 - Limited eye contact and body language, deficits in understanding and use of gestures, decreased facial expressions and non-verbal communication
 - Deficits in developing, maintaining, and understanding relationships
 - Difficulty adjusting behavior to suit various social contexts, difficulty in sharing imaginative play or in making friends, absence of interest in peers

ASD Characteristics – DSM 5

- **Repetitive/restrictive patterns of behavior, interest or activities**
 - Stereotyped or repetitive motor movements, use of objects or speech
 - Simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases
 - Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior
 - extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day
 - Highly restricted, fixated interests that are abnormal in intensity or focus
 - Strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests
 - Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
 - Apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement
- Symptoms present in early developmental period
- Symptoms cause clinically significant impairment in social, occupational, or other areas
- Not better explained by ID

ASD

- **Thinking/Learning**
 - Cognitive inflexibility
 - Focus on details/miss big picture
 - Difficulty integrating information

Executive Function and IDD

Core Deficit in DD

Many studies have shown that people with a developmental disability of any cause have a deficit in **executive functions** – set of mental processes that help us with planning, organization and task management.

Executive Function Disorder:

- The greater the EF impairments, the more external structure and supports the person needs
- An individual can have very minimal cognitive deficits but have EF deficits and not function well at all
- This can lead to significant issues – unrealistic expectations, misdiagnosis, etc.
- Important because of the impact on services and supports

IDD and Mental Illness

- 30-40% of all persons with IDD have a psychiatric disorder compared to 27% of the general population
- 10-20% have challenging behavior (self-injury, aggression, destructive behavior) severe enough to impair daily life
- Yet, they are under-diagnosed, not treated, or inappropriately diagnosed
- Symptoms of mental illness often present differently in individuals with intellectual disabilities
- Determining accurate psychiatric diagnosis becomes especially difficult as the level of intellectual functioning declines

Factors that make Psychiatric Diagnosis More Difficult

Cognitive abilities limit understanding of questions and answers

Difficulty with receptive and expressive language

Deficit in ability to articulate abstract concepts as depressed moods

People with IDD have tendency to “please” others some may not answer questions accurately

Atypical presentations suggest incorrect diagnoses

Symptom vs. Sign

- **SYMPTOM**
 - Reported by the individual

SIGN:

- Refers to an observable behavior or state
- There is no implication that an underlying problem necessarily exists or that there is a physical etiology
- It is the simplest level of analyzing a presenting problem

Individuals with IDD have difficulty with reporting as well as with what should be reported

We have to rely on people who know the individual well to help us interpret the signs appropriately

Diagnostic Overshadowing

- Beware of “diagnostic overshadowing” – refers to the process of over-attributing an individual’s symptoms to a particular condition, resulting in key co-morbid conditions being undiagnosed and untreated

Research has shown that comorbid medical conditions are often “overshadowed” by the presence of a prior psychiatric disorder or developmental disability diagnosis

- Ex: A doctor in the hospital assessment unit assumes that the patient with autism is hitting his head due to the DD and doesn’t investigate any further to rule out a medical condition

Baseline Exaggeration

- challenging behavior that exists at a low rate and low intensity may increase dramatically when one has stress or a mental health condition
- For people with ID, the behavior becomes the focus of the referral
- **It is only a symptom**

Intellectual Distortion

- Due to challenges in abstract thinking, receptive and expressive language skills questions will be too complex and answers often meaningless
- To, “Do you ever hear voices when no one is there?” the person with ID responds “Yes” having no concept of a *hallucination*

Psychosocial Masking

Misunderstanding of what may be developmentally appropriate

A delusion of being the chief of police may be mistaken for a harmless fantasy

An imaginary friend may be mistaken for a delusion

Cognitive Disintegration

Due to the lack of cognitive reserve, people with ID may dramatically decompensate under stress and e.g., lose skills, become mute or hallucinate

Have difficulty communicating feelings of stress resulting in anxiety-induced behavior

Can lead to incorrect diagnoses of psychosis, bipolar disorder, or dementia

“Saying someone has a ‘behavior problem’ is like saying they have a fever”

IDD and Behavioral Problems

Mental health and/or behavior problems may be symptoms related to the onset of a medical condition (e.g., ear infection, UTI, diabetes, seizure disorder, thyroid disorder, etc.) or factors related to the environment

In most cases, co-occurring complex behavior problems in individuals with ID are caused or maintained by a combination of factors

Behavioral problems may also arise as a result of past traumatic experiences

Medications can play a major role – too many meds, not the right meds, side effects of medications

High Rate of Antipsychotic Prescribing in IDD

Incorrect diagnosis of bipolar disorder, schizophrenia and psychotic disorders

Medications used for behavioral control when supports are failing

BioPsychoSocial Approach

Takes into account biological, psychological and social factors that may contribute to an individual experiencing a crisis

Provides a person-centered understanding of the individual's history and life experiences

Provides context to explain why a trigger is a trigger for that individual

Medical Factors

People with IDD have higher rates of medical problems

Medical problems are often the source of the chief complaint for individuals with ID

Generally the association of medical conditions with mental disorder is not understood by the individual, caregivers or the clinician assessing

Pain or physical discomfort may act as a “setting event” lowering the threshold for challenging behavior

People with IDD have few ways to express distress and are poor at reporting their internal states

Medical Factors

Medical problems may cause significant changes in mood, behavior and mental states that mimic acute psychiatric illness

Common Medical issues include:

- **Genetic disorders and syndromes**
- **Diabetes**
- **Sleep Irregularities**
- **Constipation**
- **Gastrointestinal problems**
- **Infections**
- **Seizure disorders**
- **Physical pain**
- **Vision/hearing changes**
- **Medication side effects and drug toxicities**

Medical Factors- Study

Non-psychiatric health problems among psychiatric inpatients with Intellectual Disabilities.

Charlot, L., Abend, S., Ravin, P., Mastis, K., Hunt, A., & Deutsch, C. *Journal of Intellectual Disability Research*
doi:10.1111/j.1365-2788.2010.01294.x

MEDICAL PROBLEMS

Medical Diagnoses	N = 50 Consult	N = 198 Inpts
Constipation	64%	60%
GERD*	26%	38%
Seizure D/O	36%	25%
Hypothyroidism	20%	19%
Hypertension	12%	19%
Anemia	16%	18%

Mental Disorder due to a Medical Disorder

For **41%** the medical issue seemed to be the cause of the problem behaviors leading to the admission

Why do these get missed?

- Patients with ID are poor reporters of their own health problems
- Physical problems are often expressed behaviorally
- Developmental features alter the manifestation of psychological and psychiatric symptoms

Psychiatric/Mental Health Factors

Behaviors that may indicate comorbid conditions:

- Self-injurious behaviors, tics, stereotypies, obsessive thoughts and compulsive behaviors, levels of attention, hyperactivity, impulsivity, fears and phobias
- Have to assess whether there have been any changes (increase/decrease in intensity or frequency)
- These same behaviors may be due to side-effects of medications being used/changed to address “problem behaviors”, medical and/or environmental factors

Social/Environmental Factors

Are often over-looked, not considered

These are often the things that act as “triggers”

Common social/environmental factors include:

- **Noise**
- **Temperature**
- **Lighting**
- **Space – too large, too small**
- **Changes in daily routine**
- **Changes or loss of important people**
- **Loneliness, social isolation**
- **Boredom**
- **Lack of Control/Choice**

Frequently Diagnosed Psychiatric Disorders in Individuals with IDD

Mood Disorders

Two types of Mood Disorder – based on whether there has ever been a manic or hypo-manic episode

- Depressive Disorders
- Bipolar Disorders

Issues Related to Diagnosis

- Assessment of mood for individuals with ID is challenging due to the need to access “internal” information
- Self-report is difficult, even for individuals with Mild ID. Have to depend on informant reports
- Externalized behaviors (assaults, property destruction, screaming, severe self-injury) is usually why someone is referred and can overshadow the real issue
- Research has shown that child and adults with ID present with increased rates of conduct problems, social withdrawal and irritable mood when depressed

Mood Disorders

Things to consider before diagnosing a Mood Disorder:

Medical Problems – very important to rule out before diagnosing a Mood Disorder! Unresolved medical problems can indirectly cause mood symptoms in people with IDD

- ***When in doubt, rule out! What else can it be?***
 - Not caused by a chemical imbalance due to medications
 - Behavior done to communicate a need or want?
 - Physical illness or medical conditions which may be observed as manic or depressive episodes?
 - A neurological disorder?
 - Behaviors only occur around certain people or in certain places?
- ***Aggression*** – can be misinterpreted as a symptom of mood disorder
 - “final common pathway” for distress
 - A sign that something is wrong – developmental challenges can limit demonstrations of distress

Depression

- Depression is easily missed in people who have social and communication disabilities, although it is probably more common in people with intellectual disabilities and people with autism than in the general population
- Individuals with ID experience a greater number of psychosocial risk factors that make them vulnerable to mood disorders
- Research has indicated that there is a high correlation with stressful life events and depression for individuals with ID
- Some genetic disorders may predispose an individual to depression
 - Down Syndrome – seem to be particularly vulnerable

Anxiety is frequently part of depressive disorders

In individuals with ID, it can be very difficult to distinguish between the two, either because

- The person complains of both emotions as having equal severity, or because
- There are so few associated symptoms that it's impossible to make an accurate diagnosis

Depression

- Obsessive thoughts and associated compulsive behaviors can appear for the first time in depression
 - *Repetitive behaviors can also worsen during a depressive illness, including SIB*

Developmental effects have to be considered as mood disorders in people with ID often contain features more common in young children

Atypical presentation of depression in people with severe intellectual disability

- In general, behavioral changes, such as screaming, agitation, self-injury, sleep disturbance and reduced communication are common
- Depression is likely to trigger or increase certain kinds of challenging behaviors

Bipolar

Bipolar occurs when a person experiences episodes of depression and mania over a distinct period of time

Individuals with IDD are 2-3 times more likely to be diagnosed with Bipolar Disorder than the general population

Some genetic disorders may predispose individuals for Bipolar

- Fragile X, Prader-Willi, Rubenstein-Taybi

Rule outs – chronic sleep problems, agitated behaviors due to other factors

Manic symptoms may manifest in different ways for people with IDD

- Irritable mood, labile affect, over-activity, and decreased sleep are core clinical features of mania in people with IDD
- 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
- Pressured speech may appear as increased vocalization (rate or volume) or gesturing in individuals with limited expressive language

Sleep Data! Tracking sleep patterns (insomnia vs. hyper-somnia) very important

Anxiety

Anxiety disorders are reported to be as common or more common in people with IDD than in the general population

Subjective elements of diagnosis may not be reported

But objective features of anxiety present in the general population- fear, trembling, flushing, irritability - can be easily observable in individuals with ID

Avoidance of specific situations may not be evident in people with IDD since opportunities for choice may be limited

Presenting symptoms of anxiety may be masked by the sedative effects of psychotropic medications

Anxiety

Anxiety disorders can be diagnosed reliably with few modifications in individuals with Mild-Moderate ID

Genetic disorders that may predispose an individual to anxiety disorders-

- Fragile X – social anxiety
- Cornelia de Lange – compulsive behavior
- Williams Syndrome, Prader-Willi, Down Syndrome

When anxiety cannot be expressed, in those with more severe disability, it may present as a behavior disorder

Behaviors might include constant seeking for reassurance, restlessness, and increased agitation

Screaming and shouting have all been described particularly in individuals with depression and more severe degrees of ID – typically to avoid doing something which the individual is anxious about

Obsessive-Compulsive Disorder

Obsessions – involuntary and seemingly uncontrollable thoughts, images, impulses

Compulsions include:

- Behaviors or rituals one feels driven to act out again and again
- Performed in an attempt to make obsessions go away
- Relief is brief, obsessive thoughts usually come back stronger
- The compulsive behaviors often cause anxiety themselves

OCD is not uncommon with individuals with IDD

Sometimes a person can have symptoms that look like OCD but are characteristics of other disorders such as ***Autism***

Anxiety Disorder vs. Impulse Control Disorder

- Anxiety Disorders are often misdiagnosed as Impulse Control Disorder NOS
- Chances of misdiagnosis increase
 - The more significant the intellectual disability is
 - If the person has limited or no communication

Psychotic Disorders

Schizophrenia

Typically presents with both positive and negative symptoms

Positive symptoms include:

- **Hallucinations –**

- can be varied, auditory are by far most common
- Usually recurrent, persistent and distressing
- Effect of derogatory and command hallucinations are of most concern because they may precipitate unexpected, dangerous behavior

- **Delusions –**

- Usually common and variant in content
- Divided into bizarre and non-bizarre

- **Disordered thoughts –**

- Abnormality of thought is reflected in individuals speech

- **Grossly disorganized or catatonic behavior**

- Negative symptoms – usually persistent, prevent meaningful relationships include:

- **Lack of interest and enthusiasm, apathy, emotional flatness, withdrawal, emotional blunting**

Psychotic Disorders

Research has shown that up to 3% of people who have ID have schizophrenia (compared to about 1% of general population)

It can be difficult to make a diagnosis of psychosis for individuals with IDD, as they might behave in a way that could make others think that they are hearing voices, or experiencing some other symptom of psychosis

Verbal communication is very important for an accurate diagnosis

Psychotic disorders are characterized in general by the presence of psychotic symptoms, which has historically been imprecise in the typical population

Talking to yourself, or talking to imaginary friends, for example, may be developmentally appropriate for someone who has IDD

Affect and communication styles could be due to a syndrome or Autism Spectrum Disorder

- ex: Restricted affect due to Asperger's vs. Psychotic Disorder

Psychotic Disorders

People with IDD sometimes express their thoughts in a way that appears to be jumbled, which could be misattributed to the confused thinking that is a symptom of psychosis

Furthermore, those with IDD are sometimes very concerned about what other people think – often because they have been treated unkindly, rejected or discriminated against in the past

- This could be misinterpreted as paranoid thinking

It is even more difficult to distinguish the symptoms of psychosis in people who have more severe ID and are unable to communicate effectively

Socially inappropriate or disturbed behavior that is out of character could be an early sign of psychosis

It is important to distinguish whether someone's behavior is 'normal' for them, or whether they are acting in a certain way because they are experiencing an episode of psychosis, such as changes in their personality

Psychotic Disorders

- Pseudo-psychotic symptoms and ID
 - Autism: unusual thinking, sensory sensitivities, behaviors
 - Monologue: talks to self out loud
 - Fantasy: daydreaming, fantasy in play
 - Imaginary Friends: always there, understands you, likes you
 - Confabulation: spontaneous narrative report of events that never happened.
- Overlap of sx of ASD and psychotic disorders make diagnosis very difficult
- Autism Spectrum Disorder – until 1980 revision of DSM, autism was a psychotic diagnosis

Sources of Misdiagnosis for Psychotic Disorder and ASD and IDD

General Population

- ⦿ Hallucinations
- ⦿ Delusions
- ⦿ Disordered speech
- ⦿ Disorganized behavior
- ⦿ Negative symptoms

ASD and IDD

- ⦿ Sensory sensitivities
- ⦿ Unusual beliefs, preoccupations, fears
- ⦿ Language delay, poor pragmatics
- ⦿ Stereotypies
- ⦿ Severe/profound ID: aloof, preoccupied

Trauma in IDD

Estimated 80% or more of individuals with IDD have experienced trauma

Individuals with disabilities are 4-10 times more likely to be sexually abused

Sexual abuse is rarely reported

Involvement in the service system increases the risk for abuse

More likely to experience negative life events

Life losses may result in complicated or traumatic grief

“Little Ts” – much more significant for this population

Trauma in IDD

People with IDD may also experience:

- Cognitive and processing delays that interfere with understanding what is happening in abusive situations
- Feelings of isolation and withdrawal, leaving individual more vulnerable to manipulation

Trauma in IDD

Trauma has an impact on the maturation of biological as well as psychological processes.

Traumatic exposure disrupts the development of self-regulatory processes, leading to chronic affect dysregulation, destructive behavior toward self and others, learning disabilities, dissociative problems somatization, and distortions in concepts of self and others

The brain responds differently after trauma – less executive functioning and more “fight or flight”

Trauma in IDD

Reviewing the issues related to trauma and developmental level suggests that people with ID might be more vulnerable than the general population to the disruptive effects of trauma

Research indicates that the high level of self-injurious behavior among individuals with ID may be a function of exposure to trauma at lower developmental levels, regardless of chronological age

Other symptoms which can appear to be the result of ID, might be the function of, or made worse, by traumatic exposure

- Symptoms such as “acting out” rather than “think through” when distressed
- Difficulty describing emotional states
- Difficulty in understanding causality, including the role of one’s own behavior
- Distorted self-concept

PTSD??

Alarming, one of the most frequent diagnoses preceding an accurate diagnosis of PTSD in individuals with IDD is either *no diagnosis or schizophrenia*

“The state becomes a trait”

Rather than recognizing a fear-based brain state, or attempt to manage or prevent fear, a person may be diagnosed incorrectly with:

- Obsessive Compulsive Disorder
- Psychotic Disorder
- Bipolar Disorder
- Borderline Personality Disorder
- Intermittent Explosive Disorder
- Oppositional Defiant Disorder
- Disruptive Behavior Disorder

Post Traumatic Stress Disorder

- PTSD is an anxiety disorder involving an individual's exposure, either as a victim or as a witness, to a traumatic event associated with perceived threat of bodily injury or death and resulting in the experience of fear or horror
- In the general adult population, the most common symptoms reported include nightmares, trouble sleeping and jumpiness
- The traumatic event can compromise functioning at every level: biological, social and spiritual (Van de Kolk & MacFarlane, 1996)
- Research of general population indicates a history of at least one other psychiatric diagnosis – Major Depressive Disorder, Substance Use disorders, and other Anxiety Disorders, particularly Social Phobia & Agoraphobia

PTSD and IDD

The diagnosis of PTSD in the population of IDD is complex

- Intellectual and communication deficits may interfere with the individual's capacity to give a coherent and reliable narrative disclosing trauma experience
- Thus, the burden typically falls upon others to recognize significant departures from baseline behavior which may signal traumatic response, particularly in individuals who are non-verbal or minimally verbal
- Traumatic events for individuals with developmental disabilities often include multiple residential placements involving multiple caregivers, institutionalization, or hospitalizations
- Common referral problems such as noncompliance, self-injury, aggression, outbursts of anger and irritability can be manifestations of PTSD

PTSD and IDD

An individual may be misdiagnosed when symptoms of extreme stress reaction are mistaken for "behavioral problems" or other psychiatric disorders

- *Flashbacks may be mistaken for hallucinations*
- *Re-experiencing for individuals at lower developmental levels may experience frightening dreams with unclear content*
- *Re-enactment behaviors can look bizarre and be mistaken for brief episodes of psychosis*
- *Lack of motivation or confusion is associated with the negative symptoms of psychosis*
- *Emotional numbing, a common trauma response, may be confused with depression*
- *Other ways individuals can re-experience trauma is through self-injury (skin picking, head-banging) or acting out towards others (physical attacks/aggression towards others)*
- *"Noncompliance" might represent persistent avoidance of stimuli associated with trauma*

PTSD and IDD

Bruce Perry -

Persistent trauma leads to a “dysregulated” brain stem – which manifests with symptoms such as impaired cardiovascular regulation, extreme affective lability, and poor impulse control.

People who are aroused from fear cannot take in cognitive information. They are too busy watching for threatening gestures, and not able to listen to what is being said.

More Common: Mood Disorders, Anxiety Disorders,
Trauma and Stressor Related Disorders

Less Common: Psychotic Disorders



The best treatment plans are derived from a comprehensive multidisciplinary diagnosis and assessment which includes:

Understanding the core deficits of IDD

Consideration of Bio-Psycho-Social factors

Consideration of diagnostic overshadowing, intellectual distortion, psychosocial masking, cognitive disintegration, baseline exaggeration

Recognizing the impact of trauma

Considering the impact of health issues and medication side effects