

Dual Diagnosis (ID/D-MI): Assessment, Treatment & Service Collaboration

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Outline of Presentation

- **NADD**
- **Concept of Dual Diagnosis**
- **Characteristics of People with ID/MI**
- **Vulnerability Factors**
- **Models of Problem Behavior**
- **Assessment & Diagnostic Procedures**
- **Overview of the DM-ID**
- **Psychotherapy**

WHAT IS NATIONAL ASSOCIATION FOR THE DUALY DIAGNOSED?

NADD

- **NADD is a not-for-profit membership association**
- **Established for professionals, care providers and families**
- **To promote the understanding of and services for individuals who have developmental disabilities and mental health needs**

MISSION STATEMENT

*To advance mental
wellness for persons with
developmental
disabilities through the
promotion of excellence
in mental health care.*

- **Conferences/Trainings**
- **Journals**
- **Webinars**
- **Consultation Services**
- **Book Publisher**
- **Accreditation and Certification**

CONCEPT OF DUAL DIAGNOSIS**Concept Of Dual Diagnosis**

- **Co-Existence of Two Disabilities:
Intellectual Disability and
Mental Illness**
- **Both Intellectual Disability and Mental
Health disorders should be assessed and
diagnosed**
- **All needed treatments and supports should
be available, effective and accessible**

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Terminology

Intellectual Disability
Mental Retardation
Developmental Disability
Intellectual Impairment
Learning Disability (UK)

Dual Diagnosis
Dual Disability
Co-Occurring MI-ID
Co-Existing Disorders

Fletcher, 2008

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Intellectual Disability

Following 3 criteria must be met:

- Deficits in intellectual functioning such as reasoning, problem solving, planning. Abstract thinking, academic learning and learning from experience, confirmed by both clinical assessment and individualized standardized testing;
- Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation and independent living, across multiple environments such as home, school, work and community.
- Onset of intellectual and adaptive deficits during the developmental period.

Specifiers of Mild, Moderate, Severe, Profound

DSM 5, 2013

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Intellectual Disability

Disorder Characteristics: Three Domains

Intellectual Disability involves impairments of general mental abilities that impact adaptive functioning in three domains, or areas. These domains determine how well an individual copes with everyday tasks:

- The Conceptual Domain** includes skills in language, reading, writing, math, reasoning, knowledge and memory.
- The Social Domain** refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities
- The Practical Domain** centers on self-management in areas such as personal care, job, responsibilities, money management, recreation, and organizing school and work tasks.

DSM 5, 2013

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Intellectual Disability

Severity Levels for Intellectual Disability:

Severity	Conceptual	Social	Practical
Mild			
Moderate			
Severe			
Profound			

DSM 5, 2013

IDD Causes

Thousands of Causes

- Chromosomal abnormalities
- Environmental genetic abnormalities
- Infections
- Metabolic
- Nutritional
- Toxic
- Trauma (Prenatal and perinatal)
- Unknown

What Is Mental Illness (MI)?

- MI is a psychiatric condition that disrupts a person's thinking, feeling, mood, ability to relate to others, and can impair daily functioning.
- MI can affect persons of any age, race, religion, income, or level of intelligence.
- The DSM and the DM-ID provide a classification system of diagnoses.



Definition Of Mental Illness In Persons With Intellectual Disability

1. When behavior is abnormal by virtue of quantitative or qualitative differences
2. When behavior cannot be explained on the basis of development delay alone
3. When behavior causes significant impairment in functioning

Adapted from Enfield and Aman 1995

A Summary Of Similarities And Differences Between Intellectual Disability (ID) & Mental Illness (MI)

- | | |
|------------|---|
| <u>ID:</u> | refers to sub-average (IQ) |
| <u>MI:</u> | has nothing to do with IQ |
| <u>ID:</u> | incidence: 1-2% of general population |
| <u>MI:</u> | incidence: 16-20% of general population |
| <u>ID:</u> | present at birth or occurs before age 18 |
| <u>MI:</u> | may have its onset at any age (usually late adolescent) |

Fletcher, 2004

**A Summary Of Similarities And Differences
Between Intellectual Disability (ID) & Mental
Illness (MI)**

- ID:** intellectual impairment is permanent
MI: often temporary and may be reversible and is often cyclic
- ID:** a person can usually be expected to behave rationally at his or her developmental level
MI: a person may vacillate between normal and irrational behavior, displaying degrees of each

Fletcher, 2004

Prevalence of MI in ID

**Two to Four Times
as typical population**

(Corbett 1979)

33% of People with ID have co-occurring MI

(NCI, 2014)

39% of People with ID have co-occurring MI

(Cooper et al, 2007)

Fletcher, 2005

Prevalence



USA

Total U.S. Population:

308,745,538

(U.S. Census Bureau, Census 2010)

Number of People In Total Population With ID:

5,156,050

(1.67% - AAIDD, 2010)

Number of People With ID Who Have MI:

1,701,496


(33% of ID - NADD, 2008)

Fletcher, 2013

**Characteristics of People
with ID/MI**

NADD **Characteristics Of Youth With ID/MI**

- **High Vulnerability to Stress**
 - Often develop mental health problems when confronted with only minimal to moderate stress



Hartley & Maclean, 2009


NADD **Characteristics Of Youth With ID/MI**

- **Extreme Dependency**
 - Often experience themselves as quite helpless, thus requiring massive support from families or care providers to live successfully. When support is threatened, they frequently develop mental health problems

McCleese, 2010

NADD **Characteristics Of People With ID/MI**

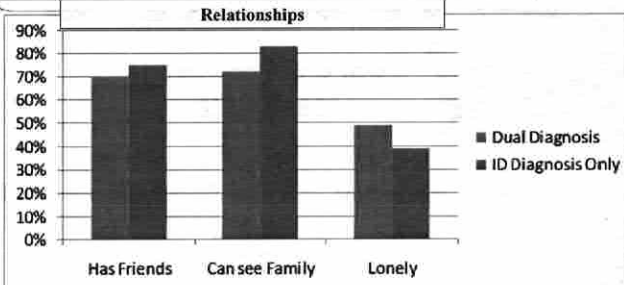
- **Difficulty with Interpersonal Relationships**
 - With some exceptions, people with ID/MI often have great difficulty in developing symmetrical close relationships with others
 - These interpersonal relationship problems can result in disruption in school, home, work, and social environments



McCleese, 2010

NADD **Characteristics Of People With ID/MI**

Relationships

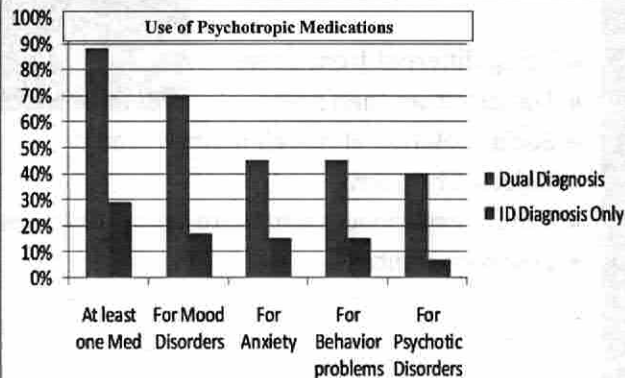


Category	Dual Diagnosis (%)	ID Diagnosis Only (%)
Has Friends	70%	75%
Can see Family	72%	83%
Lonely	49%	39%

Individuals with dual diagnosis were less likely to report having friends (70% vs. 75%) and being able to see family whenever desired (72% vs. 83%) than were those with ID only. On the other hand, they were considerably more likely to report feeling lonely (49%) than were people with diagnosis of only ID (39%).

NCI Survey Report, 2011

Characteristics Of People With ID/MI



NCI Survey Report, 2011

Characteristics Of People With ID/MI

- Individuals with I/DD may learn more slowly
- May have difficulty recalling information- especially newly required information
- Memory issues

NADD, 2013

Characteristics Of People With ID/MI

- May have difficulty focusing, may have shortened attention span
- Difficulty in understanding some abstract concepts
- May have difficulty in considering alternative solutions. For example may see things in "black and white" terms.

Characteristics Of People With ID/MI

- May have difficulty generalizing skills sets
- Developed skill sets may be very task specific
- Passive learning style which may make it difficult for the trainer to know what information is being retained
- Low expectations due to past difficulties. "Self fulfilled prophecy"- the individual believes he/she can not learn, thus preventing learning.

NADD, 2013

Characteristics Of People With ID/MI

- May “perseverate” on some things
- Much harder to focus on things that are too difficult
- Problems with cognitive rigidity
 - Difficulty changing from one task to another
 - Accepting alternative solutions or explanations
 - Shifting focus of attention

NADD, 2013

Characteristics Of People With ID/MI



- Being different from peers
- Losses rather than gains
- Social isolation although mainstreamed
- Rejected by peers
- Failure experiences dominate school histories
- Low social status

Heimen 1998

Characteristics Of People With ID/MI

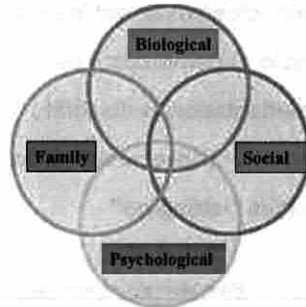
- Outer directed personality orientation
 - look to others rather than selves for problem solution
- Aberrant social styles
 - Too wary or too disinhibited
 - Low expectancy or enjoyment of success

Zigler, 1999

Characteristics Of People With ID/MI

- Low self-esteem
- Distrust of self
- Sadness, depression, dependency & withdrawal
- Helplessness
- Impulsivity

VULNERABILITY FACTORS FOR DEVELOPING PSYCHIATRIC DISORDERS IN PERSONS WITH ID



Vulnerability Factors

Persons with ID are at increased risk of developing psychiatric disorders due to complex interaction of multiple factors:

- Biological
- Psychological
- Social
- Family



Royal College of Psychiatrists, 2001

Vulnerability Factors

Vulnerability factors for psychiatric disorders

Biological

- Brain damage/epilepsy
- Vision/hearing impairments
- Physical illnesses/disabilities
- Genetic/familial conditions
- Drugs/alcohol abuse
- Medication/physical treatments

Royal College of Psychiatrists, 2001

Vulnerability Factors

Vulnerability factors for psychiatric disorders

Psychological

- Rejection/deprivation/abuse
- Life events/separations/losses
- Poor problem-solving/coping strategies
- Social/emotional/sexual vulnerabilities
- Poor self-acceptance/low self-esteem
- Devaluation/disempowerment

Royal College of Psychiatrists, 2001

NADD **Vulnerability Factors**

Vulnerability factors for psychiatric disorders

Social

- Negative attitudes/expectations
- Stigmatization/prejudice/social exclusion
- Poor supports/relationships/networks
- Inappropriate environments/services
- Financial/legal disadvantages

Royal College of Psychiatrists, 2001

NADD **Vulnerability Factors**

Vulnerability factors for psychiatric disorders

Family

- Diagnostic/bereavement issues
- Life-cycle transitions/crises
- Stress/adaptation to disability
- Limited social/community networks
- Difficulties “letting go”

Royal College of Psychiatrists, 2001

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**CONCEPTUAL MODELS RELATED
TO BEHAVIORAL PROBLEMS :
AN INTEGRATED ASSESSMENT
APPROACH**

NADD **Conceptual Models Related to
Behavioral Problems**

I. Five Conceptual Models:

1. Medical Model
2. Communication Model
3. Behavioral Model
4. Psychiatric Model
5. Integrative Model (1-4)

Fletcher, 2012

1. Medical Model

- Problem behaviors are exhibited because of co-existing medical problems
- Assessment of potential medical problems involves conducting a full medical work-up
- Treatment focuses on addressing the underlying medical problem

Fletcher, 2012

2. Communication Model

- Views behavioral problems as reflecting “challenging behaviors” in persons who have deficits in language skills
- Treatment - teach communication skills
- Assessment focuses on evaluation of skills, deficits and communicative intent

Fletcher, 2012

3. Behavioral Model

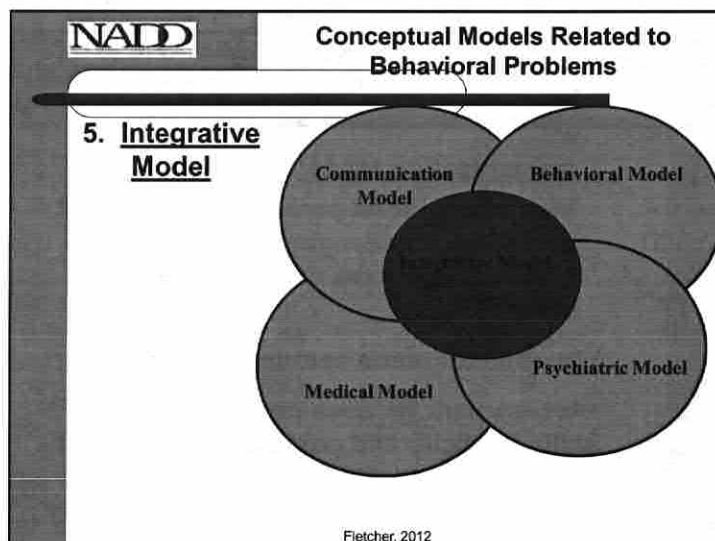
- Problem behaviors are viewed according to learning principles
- Assessment elicits the antecedent and consequences of the problematic behavior
- Treatment focuses on change in behavior through behavioral approaches, i.e., Positive Behavioral Supports

Fletcher, 2012

4. Psychiatric Model

- Views problem behavior as a possible manifestation of a mental disorder
- Presentation of problem behaviors may be associated with a psychiatric disorder
- Assessment based on a bio-psycho-social model
- Treatment focuses on underlying psychiatric disorders

Fletcher, 2012



NADD Conceptual Models Related to Behavioral Problems

Case Vignette: John

- 15-year old male, IQ = 50
- Living with parents
- Becoming angry/hostile at school with other students
- Recent onset of behavioral problems
 - SIB
 - Property Destruction
- Sleep disturbance
- Displays agitation and aggression
- Limited verbal communication skills
- Appetite decreased
- Constipation
- No previous psychiatric history

Fletcher, 2009

NADD The Relationship of Challenging Behavior and Intellectual Disability

Type of Model	Medical	Communication	Behavioral	Psychiatric
Assessment	Medical Evaluation by primary care physician	Standardized administered measure of expressive language	Functional Analysis	DM-ID DSM
Problem Identification	Constipation	Speech and language impairment	Occurrence of problem behavior	Affective disorder, mania
Treatment	Medication for Bowel Movement (Laxative)	Functional communication skill training	Positive behavior support	Medication treatment, psychotherapy

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**BEST PRACTICES
IN
ASSESSMENT AND DIAGNOSTIC
PROCEDURES**

Mental Health Assessment & Managing the Interview

- Obtain records in advance
 - School, medical, development and family
- Become familiar with collateral informants who attend the interview
 - Parents, care provider, service coordinators
- Understand that the assessment interview can be stressful for all involved
 - Interviewer will need to be alert for increased distress on part of the client

Morrison & Gillig, 2012

Mental Health Assessment & Managing the Interview

- Assessment interview will likely take more time than with a neurotypical person
- Examiner needs to use language that correlates with the expressive and receptive language skills of the client
 - Simple language
 - Reflection
 - Stay away from abstract concepts and analogies

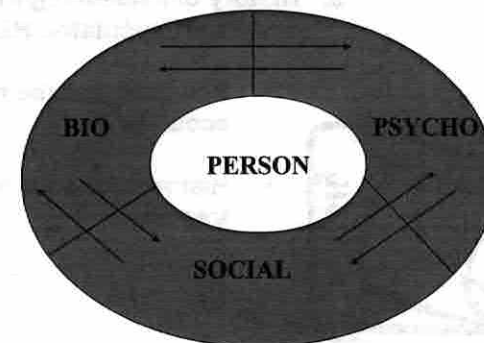
Morrison & Gillig, 2012

Mental Health Assessment & Managing the Interview

- Watch for pleasers
 - People with ID want to please the interviewer and will answer questions in ways that are perceived to please
- Parroting and perseverating habits may interfere with the accuracy of the responses
- Multiple assessment interviews may be needed to obtain a full assessment
 - Attention to detail will wane after about 30 minutes

Morrison & Gillig, 2012

Best Practice Assessment: Bio-psychosocial Model



Fletcher - 2005


NADD Mental Health Assessment

1. Source of Information and Reason for Referral
2. History of Presenting Problem and Past Psychiatric History
3. Family Health History
4. Social and Developmental History

Fletcher, 2009

NADD Mental Health Assessment


1. Source of Information and Reason for Referral
 - Who made the referral?
 - What is different from baseline behavior?
 - Why make the referral now?



Fletcher, 2009

NADD Mental Health Assessment

2. History of Presenting Problem and Past Psychiatric History
 - How long has the problem occurred?
 - History of mental health treatment




Fletcher, 2009

NADD Mental Health Assessment

3. Personal and Family Health History
 - Medical, psychiatric, and substance abuse history
 - Psychotropic medications
 - Medical conditions
 - Genetic disorders
 - Hypo/hyper thyroid condition
 - Constipation
 - Epilepsy
 - Diabetes
 - Gastrointestinal problem

Fletcher, 2009

NADD		Mental Health Assessment
4. Social/Developmental History		
<ul style="list-style-type: none"> • Developmental milestones • Relevant school history • Work/vocational history • Current work/vocational status • Legal issues • Relevant family dynamics • Drug/alcohol history • Abuse history (emotional/physical/sexual) 		
Fletcher, 2009		

NADD		Mental Health Assessment
Behavioral Status Review Reports		
A. Recent Changes		
B. Problem Behavior		
C. Quality of Life Issues		
		
Fletcher, 2009		

NADD		Behavioral Status: Recent Changes: A	
	Yes	No	Comments
1. Moves			
2. Deaths of significant others			
3. Staff or teacher changes			
4. New roommates/classmates			
5. Problems			
6. Loss of friend, pet, family member			
7. Loss of key staff/teacher			
8. Evidence of a delayed grief reaction			
9. Change in employment, program or leisure activities			

NADD		Behavioral Status: Problem Behavior: B			
	C	A	E	N/A	Comments
1. Is aggressive					
2. Is self injurious					
3. Appears anxious					
4. Socially isolates self					
5. Is overactive					
6. Is under-active					
<p><u>C</u>hronic: Person displays behavior on a daily basis, but severity may wax and wane</p> <p><u>A</u>cute: Behavior represents a dramatic change</p> <p><u>E</u>pisodic: Periods of disturbance and periods of normal functioning</p> <p><u>N/A</u>: Non-Applicable</p>					

NADD **Behavioral Status:**
Problem Behavior: B (continued)

	C	A	E	N/A	Comments
7. Engages in ritualistic behavior, compulsions					
8. Has self-stimulatory behavior					
9. Steals					
10. Has tantrums					
11. Is impulsive					
12. OTHER (explain):					

Chronic: Person displays behavior on a daily basis, but severity may wax and wane
Acute: Behavior represents a dramatic change
Episodic: Periods of disturbance and periods of normal functioning
N/A: Non-Applicable

NADD **Behavioral Status: Quality of Life & Person-Centered Issues: C**

Please list and explain the areas that he/she enjoys that promotes quality of life.

Family: _____

Friends: _____

Living Situation: _____

Leisure Activities: _____

Staff Relations: _____

Hobbies: _____

Work: _____

Other: _____

NADD **Minimal Data Collection**

- Physical Health
- 24 Hours Sleep Data (month cycle)
- Medication Changes
- Eating Patterns
- Environmental Changes
- Mood Charting
 - Symptoms and Behavioral Manifestations

Nagy, McNelis 2001

NADD **24-Hour Framework**

Sleep Patterns
Eating Patterns
Mood Patterns

The chart is a circular diagram with 24 radial lines extending from a central point to the outer edge. Each line is labeled with a time in 1-hour increments, starting from 12 p.m. at the top and proceeding clockwise. The lines are grouped into three sections: Sleep Patterns (12 p.m. to 1 a.m.), Eating Patterns (1 a.m. to 6 p.m.), and Mood Patterns (6 p.m. to 11 p.m.).

Myth: Individuals with Intellectual Disability (ID) Cannot Have a Verifiable Mental Health Disorder**PREMISE:**

Maladaptive behaviors are a function of ID

REALITY:

The full range of psychiatric disorders can be represented in persons with ID

DIAGNOSTIC IMPLICATIONS:

Psychiatric diagnosis can be made using the DM-ID, DSM records, service providers, family input, and client interview

Eight Diagnostic Principles For Recognizing Psychiatric Disorders In Persons with ID

1. Persons with Intellectual Disabilities suffer from the full range of psychiatric disorders
2. Psychiatric disorders usually present as maladaptive behavior
3. The origin of psychopathology is multi-determined

Adapted from Sovner 1989

Eight Diagnostic Principles For Recognizing Psychiatric Disorders In Persons with ID (continued)

4. An acute psychiatric disorder may present as an exaggeration of longstanding maladaptive behavior
5. Maladaptive behavior rarely occurs alone
6. The severity of the problem is not diagnostically relevant

Adapted from Sovner 1989

Eight Diagnostic Principles For Recognizing Psychiatric Disorders In Persons with ID (continued)

7. The clinical interview alone is rarely diagnostic
8. It is very difficult to diagnose psychotic disorders in persons with very limited verbal skills

Adapted from Sovner 1989

NADD **Barriers to Diagnosis:
Adequate Assessments**

12 Complicating Diagnostic Factors

1) Diagnostic Overshadowing	7) Acquiescence
2) Medication Masking	8) Learned Behavior
3) Communication Deficits	9) Aggression and SIB
4) Atypical Presentation of Psychiatric Disorders	10) Sensory Impairment
5) Limited Life Experiences	11) Episodic Presentation
6) Medical Conditions	12) Lack of Expertise

Adapted from Mogilvery & Sweetland, 2012

NADD **Barriers to Diagnosis:
Adequate Assessments**

Complicating Diagnostic Factors (1-3)

1) Diagnostic Overshadowing
2) Medication Masking
3) Communication Deficits

NADD **Barriers to Diagnosis:
Adequate Assessments**

Complicating Diagnostic Factors (4-6)

4) Atypical Presentation of Psychiatric Disorders
5) Limited Life Experiences
6) Medical Conditions

NADD **Barriers to Diagnosis:
Adequate Assessments**

Complicating Diagnostic Factors (7-9)

7) Acquiescence
8) Learned Behavior
9) Aggression and SIB

NADD **Barriers to Diagnosis:
Adequate Assessments**

Complicating Diagnostic Factors (10-12)

10) Sensory Impairment
11) Episodic Presentation
12) Lack of Expertise

NADD **Behavioral Patterns in Relationship
to Psychiatric Disorders**

**12 Indications that a Behavioral Pattern
may be the result of a Psychiatric
Condition**

Adapted from McGilvery & Sweetland, 2012

NADD **Assessment Considerations**

**Indications that a behavioral pattern may be the
result of a psychiatric condition**

1. The behavior occurs in all environments; it is not just exhibited in specific settings
2. Behavioral strategies have been largely ineffective
3. The individual doesn't appear to have control over their behavior. They don't appear to be able to start or stop the behavior at will.

Adapted from McGilvery & Sweetland, 2012

NADD **Assessment Considerations**

**Indications that a behavioral pattern may be the
result of a psychiatric condition**

4. There are changes in sleep patterns; increased, decreased or disturbed sleep.
5. The individual is experiencing excessive mood or unusual mood patterns.
6. There are changes in the individual's appearance and a decline in their independent living skills.

Adapted from McGilvery & Sweetland, 2012

Assessment Considerations

Indications that a behavioral pattern may be the result of a psychiatric condition

7. The person may start to engage in purposeful self-harm (cutting, hitting, scratching, pulling out hair).
8. The person may start to show signs of hallucination, such as staring to the side or corners and not appear to track conversations.
9. There may be changes in eating patterns such as eating less or more.

Adapted from McGilvery & Sweetland, 2012

Assessment Considerations

Indications that a behavioral pattern may be the result of a psychiatric condition

10. The individual has a history of a psychiatric disorder that was in remission.
11. There is an acute onset of the behavior. If there is a particularly rapid onset with a significant change in mental status or cognitive functioning, rule out a possible delirium with an underlying medical cause.
12. There is an unusual change in behavior patterns, such as a significant change from baseline behavior

Adapted from McGilvery & Sweetland, 2012

Medical Problems & Problem Behavior

- Why do medical causes of problem behaviors get missed?
- Why do we have to be.....
Sherlock Holmes



Dr. Chariot

Psychiatric Symptoms/Learned Behaviors/Medication Conditions:

A Clinical Challenge

It can be difficult to distinguish whether a behavioral problem is associated with:

- A symptom of a psychiatric disorder
- A learned behavior
- A medical condition



Chariot, 2011

Medical Problems & Problem Behavior

Medical conditions can be present when behavioral problems are exhibited.

Medication effects / reactions can be present when behavioral problems are exhibited.

Medical conditions are often underdiagnosed.

Medical conditions can mask as behavioral problems.

Charlot, 2011

Medical Problems & Problem Behavior

DRUG SIDE EFFECTS

Akathisia, Delirium, Dyskinesia

GASTROINTESTINAL ISSUES

Constipation GERD Hemoroids
Irritable Bowel Syndrome

ENDOCRINOLOGICAL PROBLEMS

Thyroid problems Diabetes

NEUROLOGICAL PROBLEMS

Epilepsy Other movement problems

OTHER

Dental pain Sleep apnea Hearing and vision problems
Back pain Headaches

Charlot, 2011

Medical Problems & Problem Behavior

Medical Problems often under-recognized
Dental Problems often under-recognized

- Medical/Dental problems can cause SIB
- Need to identify if there is an underlying physical problem

Charlot, 2011

Medical Problems & Problem Behavior

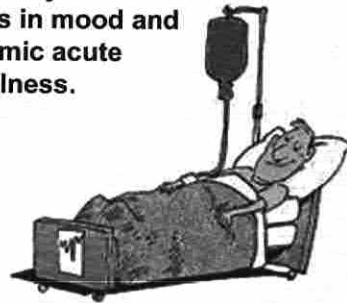
Case Example of Dental Pain & SIB

- 28 year old female with ID referred to dental office for routine exam
- Mother noted that she began pulling out her hair
- Dental exam showed a fractured upper molar tooth, & tooth was extracted
- Mother subsequently reported that hair pulling ceased

Rada, 2013

Medical Problems & Problem Behavior

Medical Problems may cause significant alterations in mood and behavior that mimic acute psychiatric illness.



Charlot, 2011

Medical Problems & Problem Behavior

Symptoms Reported by Informants :

PSYCHIATRIC

- MANIA
 - Irritable, restless, pacing, running back and forth, can't sit still, can't focus, can't get to sleep
- DEPRESSION
 - Crying, won't get out of bed, decreased concentration

MEDICAL

- AKATHISIA
 - Irritable, restless, pacing, running back and forth, can't sit still, can't focus, can't get to sleep
- CONSTIPATION
 - Crying, won't get out of bed, decreased concentration

Charlot, 2011

Medical Problems & Problem Behavior

1. Sleep Pattern

Quality and quantity of sleep can affect physical and mental health

For example:

- a. Poor sleep ⇒ fatigue ⇒ irritability
- b. Depression ⇒ poor sleep ⇒ irritability
- c. Medical problem (discomfort caused by constipation) ⇒ poor sleep ⇒ irritability

Assessment Strategy

Maintain sleep data

Charlot, 2011

Medical Problems & Problem Behavior

2. Appetite Pattern

Changes in appetite can be clues in the assessment of mental health or physical problem

Significant weight change may indicated a medical or mental health problems

Assessment Strategy

Monitor and document a person's weight on a weekly basis

Charlot, 2011

NADD

Medical Problems & Problem Behavior

3. Activity Level

Activity level refers to the things a person usually does during the day. For example:

- going to work
- completing chores
- leisure time pursuits

Assessment Strategy

If a person's activity level changes drastically, it may be an unrecognized medical or mental health problem.

Charlot, 2011

NADD


Medical Problems & Problem Behavior

4. Activity Level

Examples:

Arthritis ⇒ decreased activity ⇒ refuses to go to work ⇒ could be viewed as non-compliant

Depression ⇒ decreased activity ⇒ refuses to go to work ⇒ could be viewed as non-compliant



Charlot, 2011

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Mental Health Evaluation

Effects of ID in Clinical Presentation

- The interaction between ID and MI are a result of four factors that reflect the profound biopsychosocial affects of developmental disabilities

1. Intellectual Distortion
2. Psychosocial Masking
3. Cognitive Disintegration
4. Baseline Exaggeration

Sovner, 1986

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Mental Health Evaluation

Four Nonspecific Factors Associated with ID Which Influences the Diagnostic Process

Factor 1: Intellectual Distortion

Definition: Refers to the developmental affects of ID on the person's diminished ability to think abstractly and communicate intelligibly

Clinical Impact: Inability for person to label their own experiences and report them

Example: When asked if he/she "hears voices", the person might respond "yes" without fully comprehending the implication of the question

Sovner, 1986

NADD Mental Health Evaluation

Four Nonspecific Factors Associated with ID Which Influences the Diagnostic Process

Factor 2: Psychosocial Masking

Definition: Impoverished social skills and life experiences can influence the content of psychiatric symptoms

Clinical Impact: The person with ID might present significant symptomology that occurs within the developmental framework

Example: A person with moderate level of ID, might believe he/she can drive a car and this can be a manifestation of grandiosity

Sovner, 1986

NADD Mental Health Evaluation

Four Nonspecific Factors Associated with ID Which Influences the Diagnostic Process

Factor 3: Cognitive Disintegration

Definition: Stress-induced disruption of information processing – Tendency of person with ID to become disorganized under stress

Clinical Impact: Bizarre presentation and psychotic-like state may be misdiagnosed as schizophrenia

Example: Vulnerability to high levels of stress and overload of cognitive functioning may lead to atypical clinical presentation

Sovner, 1986

NADD Mental Health Evaluation

Four Nonspecific Factors Associated with ID Which Influences the Diagnostic Process

Factor 4: Baseline Exaggeration

Definition: Pre-existing maladaptive behaviors, which were not attributed to mental illness, may increase in frequency and intensity with the onset of a psychiatric disorder

Clinical Impact: Creates difficulty in establishing illness features, target symptoms, and outcome measures

Example: SIB or aggression, which occurred infrequently may suddenly increase in severity at onset of a psychiatric disorder

Sovner, 1986

NADD Mental Status Examination (MSE)

- Systemic observation and recording about a person's thinking, emotions, and behavior
- MSE for people with ID needs to be modified
- Useful way to organize and standardize the data of patient observation
- MSE is a snapshot of the mental status at the time of the assessment. The MSE can be used as a tool to note change in the status from one point-in-time to another.
- MSE is a diagnostic measurement. Data from care providers and patient history can be helpful.

- I. General Appearance & Behavior**
- II. Mood and Affect**
- III. Psychomotor Activity and Speech**
- IV. Thought Process and Content**
- V. Cognitive Function**
- VI. Judgment and Insight**

I. General Appearance & Behavior

- Assesses person's attentiveness and effective participation in interview
- Notes person's attitude toward examiner
- Assesses posture and general motor activity
- Notes facial expression
- Notes personal hygiene and grooming
- Assesses weight status

Note : All of the above is based on the cognitive developmental level of the individual with ID.

IA. General Appearance & Behavior

- The clinician may need to rely on collateral information about the person's baseline appearance and behavior
- Baseline for a person with ID may be very different from the neuro-typical person. For example, in a person with ASD, body posturing, self-hugging, and finger flicking may be the typical baseline behavior for a individual on the Spectrum

Note : All of the above is based on the cognitive developmental level of the individual with ID.

II. Mood and Affect

- Describe predominant mood
- Describe affect including range

Note : All of the above is based on the cognitive developmental level of the individual with ID.

IIA. Mood and Affect

- Mood is the prevailing emotional state. Affect is the expression of emotions
- An examiner can draw faces to help the client identify feeling state
 - Ask person to point to face to show how he/she is feeling today

Happy 😊 Sad 😞 Mad 😡 Fearful 😨 Neutral 😐

Note : All of the above is based on the cognitive developmental level of the individual with ID.

III. Psychomotor Activity and Speech

- Assesses psychomotor activity and notes
 - Rate of psychomotor activity (e.g. agitated, slowed)
 - Presence of abnormal movements
- Assesses speech and notes amount, volume, rate, organization of speech

Note : All of the above is based on the cognitive developmental level of the individual with ID.

IIIA. Psychomotor Activity and Speech

- Examiner will need other collateral data in understanding the typical psychomotor activity and speech organization for the person.
- For example, people who have Fragile X often have difficulty with gross motor coordination, which may lead to assessment as abnormal movements in absence of information about the effect of the syndrome.

Note : All of the above is based on the cognitive developmental level of the individual with ID.

IV. Thought Process and Content

- Assess thought abnormalities
- Evaluates the content of thought
- Notes presence of delusions hallucinations (if so, what type of hallucinations)

Note : All of the above is based on the cognitive developmental level of the individual with ID.

IVA. Thought Process and Content

- Clinical challenge in identifying abnormal thoughts and perceptions related to mental illness, compared to behaviors associated with the cognitive / developmental level of the individual
- Similarities between behaviors normal in young children without IDD and adults with IDD (i.e. self talk, imaginary friends, and rich fantasy life)

Note : All of the above is based on the cognitive developmental level of the individual with ID.

V. Cognitive Function

- Assess patient's orientations to time, place, and persons
- Evaluate patient's attention and concentration
- Assess patient's memory
- Assess intellectual functioning

Note : All of the above is based on the cognitive developmental level of the individual with ID.

VA. Cognitive Function

- A person with ID may know what city he or she lives in, but may not know the street address. This should be considered normative, given the person's developmental level.
- Attention & concentration should be evaluated with consideration of the person's developmental level.

Note : All of the above is based on the cognitive developmental level of the individual with ID.

VB. Cognitive Function

- Detailed information and chronology of events need to be considered relative to the person's developmental age. For example, they may remember the names of their siblings and which are older and younger; but may not be able to remember the exact age of each sibling.
- The examiner will need to assess intellectual functioning based on estimating the person's level of functioning.

Note : All of the above is based on the cognitive developmental level of the individual with ID.

VI. Judgment and Insight

- Assess person's judgment in general
- Evaluates person's insight in situation and illness

Note : All of the above is based on the cognitive developmental level of the individual with ID.

VI. Judgment and Insight

- Judgment and insight need to be based on the person's developmental level
- Judgment can be tested by relating the questions to everyday issues. For example "What should you do if there was smoke in your house?"
- Insight into the nature of the problem is likely to be very limited

Note : All of the above is based on the cognitive developmental level of the individual with ID.

DEPRESSION



Depression

- Can significantly disrupt school, work, family relationships, social life, etc.
- Onset tends to be more insidious and changes less dramatic (Deb et al., 2001)
- Increased prevalence in some symptoms as compared to typical population (Matson, 1988)
- Depression is among the most common psychiatric disorders in persons with ID (Lamon & Reiss, 1987)

Hughes, 2006

<div>NADD</div> <div>Depression</div>	
DSM Symptom for Depression	Presentation in Someone with ID
Depressed Mood	<ul style="list-style-type: none"> •Frequent unexplained crying •Decrease in laughter and smiling •General irritability and subsequent aggression or self-injury •Sad facial expression
Loss of Interest in Pleasure	<ul style="list-style-type: none"> •No longer participates in favorite activities •Reinforcers no longer valued •Increased time spent alone •Refusals of most work/social activities

Hughes, 2006

<div>NADD</div> <div>Depression</div>	
DSM Symptom for Depression	Presentation in Someone with ID
Weight Change/ Appetite Change	<ul style="list-style-type: none"> •Measured weight changes •Increased refusals to come to table to eat •Unusually disruptive at meal times •Constant food seeking behaviors
Insomnia	<ul style="list-style-type: none"> •Disruptive at bed time •Repeatedly gets up at night •Difficulty falling asleep •No longer gets up for work/activities •Early morning awakening
Hypersomnia	<ul style="list-style-type: none"> •Over 12 hours of sleep per day •Naps frequently

Hughes, 2006

<div>NADD</div> <div>Depression</div>	
DSM Symptom for Depression	Presentation in Someone with ID
Psychomotor Agitation	<ul style="list-style-type: none"> •Restlessness, Fidgety, Pacing •Increased disruptive behavior
Psychomotor Retardation	<ul style="list-style-type: none"> •Sits for extended periods •Moves slowly •Takes longer than usual to complete activities

Hughes, 2006

<div>NADD</div> <div>Depression</div>	
DSM Symptom for Depression	Presentation in Someone with ID
Fatigue/Loss of Energy	<ul style="list-style-type: none"> •Needs frequent breaks to complete simple activity •Slumped/tired body posture •Does not complete tasks with multiple steps
Feelings of Worthlessness	<ul style="list-style-type: none"> •Statements like "I'm dumb," "I'm retarded," etc. •Seeming to seek punishment •Social isolation

Hughes, 2006

NADD **Depression**

DSM Symptom for Depression	Presentation in Someone with ID
Lack of Concentration/ Diminished Ability to Think	<ul style="list-style-type: none"> • Decreased work output • Does not stay with tasks • Decrease in IQ upon retesting
Thoughts of Death	<ul style="list-style-type: none"> • Preoccupation with family member's death • Talking about committing or attempting suicide • Fascination with violent movies/television shows

Hughes, 2006

NADD **Depression**

Treatment Strategies

A Holistic Model

- Antidepressant medication
- Psychotherapy (individual and/or group)
- Regular exercise
- Regular scheduling of pleasurable activities
- Learning stress management strategies
- Social skill training
- Positive behavioral supports

NADD **Depression**

Case Vignette: Mary

- Mary is a 16 year old female with moderate ID
- Lives at home with mother
- Attends special ed at local public school
- Teacher noticed Mary not participating in class, as she did in the past
- In recent weeks, Mary would yell and scream at teacher when prompted to do her class work
- Mary's performance at school declined
- She became socially isolated from peers
- Referred to school psychologist
- Psychologist suspected depression
- Psychologist referred Mary to psychiatrist

Fletcher, 2009

NADD **Depression**

Case Vignette: Mary

Dx: Major Depression

Tx: Counseling by school psychologist
Antidepressant medication by psychiatrist

Outcome: Gradual lifting of depression
Return to her normal functioning within three (3) months

Fletcher, 2009

BIPOLAR DISORDER



Bipolar Disorder

- Causes mood swings
- Persons with Bipolar Disorder may have periods of mania and periods of depression as well as normal moods
- During manic episode, person will display oversupply of confidence and energy

Bipolar Disorder

DSM Symptoms of Mania

Euphoric, Elevated or Irritable Mood

Presentation in Someone with ID

- Smiling, hugging or being affectionate with people who previously were not favored by the individual
- Boisterousness
- Over-reactivity to small incidents
- Extreme excitement
- Excessive laughing and giggling
- Self-injury associated with irritability
- Enthusiastic greeting of everyone

Hughes, 2006

Bipolar Disorder

DSM Symptoms of Mania

Decreased Need for Sleep

Presentation in Someone with ID

- Behavioral challenges when prompted to go to bed
- Constantly getting up at night
- Seems rested after not sleeping (i.e., not irritable due to lack of sleep as is common in depression)

Hughes, 2006

<div>NADD</div> <div>Bipolar Disorder</div>	
DSM Symptoms of Mania	Presentation in Someone with ID
Inflated Self-esteem/ Grandiosity	<ul style="list-style-type: none"> • Making improbable claims (e.g., is a staff member, has mastered all necessary skills, etc.) • Wearing excessive make-up • Dressing provocatively • Demanding rewards
Flight of Ideas	<ul style="list-style-type: none"> • Disorganized speech • Thoughts not connected • Quickly changing subjects

Hughes, 2006

<div>NADD</div> <div>Bipolar Disorder</div>	
DSM Symptoms of Mania	Presentation in Someone with ID
More Talkative/ Pressured Speech	<ul style="list-style-type: none"> • Increased singing • Increased swearing • Perseverative speech • Screaming • Intruding in order to say something • Non-verbal communication increases • Increase in vocalizations

Hughes, 2006

<div>NADD</div> <div>Bipolar Disorder</div>	
DSM Symptoms of Mania	Presentation in Someone with ID
Distractibility	<ul style="list-style-type: none"> • Decrease in work/task performance • Leaving tasks uncompleted • Inability to sit through activities (e.g., favorite TV show)

Hughes, 2006

<div>NADD</div> <div>Bipolar Disorder</div>	
DSM Symptoms of Mania	Presentation in Someone with ID
Agitation/Increase in Goal Directed Behavior	<ul style="list-style-type: none"> • Pacing • Negativism • Working on many activities at once • Fidgeting • Aggression • Rarely sits
Excessive Pleasurable Activities	<ul style="list-style-type: none"> • Increase in masturbation • Giving away/spending money

Hughes, 2006

Treatment Strategies

- Mood stabilizing and antidepressant medication
- Psychotherapy with a focus on understanding and managing the disorder
- Environmental and social modification (i.e. increase supervision to insure safety)
- Positive Behavioral Supports

Case Vignette: Bob

- Bob is a 20 year old male with severe ID
- Mother reported sleep disturbance
- At school he began hitting other peers
- Mother reported weight loss
- Teacher reported increased agitation (i.e., rarely sits, fidgety, angry outbursts)
- Mother referred Bob to family physician
- Dx: Bi-Polar Disorder
- Tx: Mood stabilizing medication
- Outcome: After eight (8) weeks, Bob's behavior began to improve. At twelve (12) weeks, he was able to return to his normal daily routine without disruption

Fletcher, 2010

Behavioral Phenotype of Genetic Disorders

Genetics & IDD

- 283 Causes of ID identified in 1994
- 1200 + Genetic Causes of ID in 2013
- Prenatal causes dominated diagnosis

Phenotype and Genotypes

Definition of Phenotype:

The phenotype of a genetic syndrome is the set of physical characteristics produced by a genetic abnormality or genotype. (DM-ID, 2009)

Definition of Behavioral Phenotype:

The specific and characteristic repertoire exhibited by people with a genetic disorder (Flint & Yale, 1994)

Fletcher, 2013

Fragile X Phenotype



Long face, prominent ears, high arched palate, flat feet, soft skin, other connected tissue abnormalities (DM-ID 2007)



Behavioral Phenotypes in Youth with Fragile X Syndrome



- Social anxiety, shyness, gaze aversion, perseveration, autism/PDD, inattention, hyperactivity, sadness or depression (primarily females), Attention Deficit Disorder

Dykens, 2000

Phenotype: Williams Syndrome



Full lips, puffy cheeks, small jaw, short stature, spinal curvature, slumped posture (DM-ID, 2007)



Behavioral Phenotypes in Youth with Williams Syndrome



- Anxiety, fears, phobias, inattention, hyperactivity, social disinhibiting, overly friendly, indiscriminate relating, Attention Deficit Disorder



Dykens 2000

Prader-Willi Phenotype



Hyperphagia, obesity, small hands and feet, dysmorphic facial features (DM-ID, 2007)



Behavioral Phenotypes in Youth with Prader-Willi

- Prader-Willi



- Hyperphagia, non-food obsessions & compulsions, skin-picking, temper tantrums, perseveration, stubbornness, under activity, OCD, Affective Disorders



Dykens, 2000

Down Syndrome Phenotype



Small head, upward slant eyes, broad neck, hearing loss, obesity, gastrointestinal problems (DM-ID, 2007)

Behavioral Phenotypes in Youth with Down Syndrome



- Noncompliance, stubbornness, inattention, over activity, argumentative, withdrawn (depression and dementia among adults), ADHD



Behavioral Phenotypes

- Behavioral phenotypes
 - Are not set in stone
 - Look at syndromes rather than set diagnoses
 - Behavioral manifestations arise from the interaction of genes and environment
 - Present a wide range of symptoms
 - Used as clues not as expectations

NADD, 2013

Overview of the Diagnostic Manual for Persons with Intellectual Disabilities DM-ID

Limitations of DSM System

- **Diagnostic Overshadowing** (Reiss, et al, 1982)
- **Applicability of established diagnostic systems is increasingly suspect as the severity of ID increases** (Rush, 2000)
- **DSM and ICD Systems rely on self report of signs and symptoms**

Fletcher, 2008

NADD **DM-ID**
Diagnostic Manual – Intellectual Disabilities


Developed By
National Association for the Dually Diagnosed
(NADD)

In association with
American Psychiatric Association
(APA)


Partial Funding from the Joseph P. Kennedy, Jr. Foundation
Published by the NADD Press, 2007

NADD **DM-ID: Two Manuals**

Diagnostic Manual – Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability



DM-ID



Diagnostic Manual – Intellectual Disability: A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability

NADD **Description of DM-ID**

- An adaptation to the *DSM-IV-TR*
- Designed to facilitate a more accurate psychiatric diagnosis
- Based on Expert Consensus Model
- Covers all major diagnostic categories as defined in *DSM-IV-TR*

Fletcher, 2008

NADD **Description of DM-ID**
(continued)

- Provides information to help with diagnostic process
- Addresses pathoplastic effect of ID on psychopathology (expression disorder)
- Designed with a developmental perspective to help clinicians to recognize symptom profiles in adults and children with ID

Fletcher, 2008

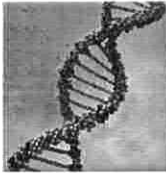
NADD **Description of DM-ID** (continued)

- Provides state-of-the-art information about mental disorders in persons with ID
- Provides adaptations of criteria, where appropriate

Fletcher, 2008

NADD **Two Special Added-Value Chapters**

- Assessment and Diagnostic Procedures
- Behavioral Phenotype of Genetic Disorders



NADD **Assessment and Diagnostic Procedures: Chapter 2**

Special Consideration

Language That Is Understandable

- Use simple language
- Create short sentences
- Check back with person for understanding
- Use of examples

Hurley, et al., 2007

NADD **Assessment and Diagnostic Procedures: Chapter 2**

➤ **Assessment of Medical Conditions**

- ➤ Constipation → distress
- ➤ Hypothyroidism → depressive symptoms
- ➤ Hyperthyroidism → manic episode
- ➤ Diabetes → behavioral side effects

Hurley, et al., 2007

NADD **Behavioral Phenotype of Genetic Disorders: Chapter 3**

Angelman Syndrome	Prader-Willi Syndrome
Cri-du-Chat (5p-) Syndrome	Rubenstein-Taybi Syndrome
Down Syndrome	Smith-Magenis Syndrome
Fetal Alcohol Syndrome	Tuberous Sclerosis Complex
Fragile-X Syndrome	Velocardiofacial Syndrome
Phenylketonuria	Williams Syndrome

Levitas, et al, 2007

NADD **Behavioral Phenotype of Genetic Disorders: Chapter 3**

Phenotype and Proposed Behavioral Phenotype for Down Syndrome

Phenotype	Small head, mouth; upward slant to eyes; epicanthal folds; broad neck; hypothyroidism; hearing loss; visual impairments; cardiac problems; gastrointestinal; orthopedic, and skin disorders; obesity	
Behavioral Phenotype	Childhood	Oppositional and defiant; Attention-Deficit/Hyperactivity Disorder (ADHD); social, charming personality "stereotype"
	Adulthood	Depressive disorders; Obsessive-Compulsive Disorder; other anxiety disorders; dementia of the Alzheimer's Type; mental disorders associated with hypothyroidism

Levitas, et al, 2007

NADD **DM-ID Diagnostic Chapter Structure**

- Review of Diagnostic Criteria
 - General description of the disorder
 - Summary of *DSM-IV-TR* criteria
- Issues related to diagnosis in people with ID
- Review of Literature/Research
 - Evaluating level of evidence

Fletcher, 2007

NADD **DM-ID**

- Application of Diagnostic Criteria to People with ID
 - General considerations
 - Adults with Mild to Moderate ID
 - Adults with Severe or Profound ID
 - Children and adolescents with ID

Fletcher, 2007

NADD

DM-ID
(continued)

- Etiology and Pathogenesis
 - Risk Factors
 - Biological Factors
 - Psychological Factors
 - Genetic Syndromes

Fletcher, 2007

NADD

DM-ID
(continued)

Diagnostic Criteria

DSM-IV-TR Criteria	Adapted Criteria Mild-Moderate ID	Adapted Criteria Severe-Profound ID

Fletcher, 2007

NADD

DM-ID
(continued)

Adaptation of the DSM-IV-TR Criteria

- Addition of symptom equivalents
- Omission of symptoms
- Changes in symptom count
- Modification of symptom duration

Fletcher, 2007

NADD

DM-ID
(continued)

Adaptation of the DSM-IV-TR Criteria

- Modification of age requirements
- Addition of explanatory notes
- Criteria Sets that do not apply

Fletcher, 2007

Adaptation of DSM-IV-TR Criteria
Change in Count and Symptom Equivalent

Major Depressive Episode

DSM-IV-TR Criteria	Adapted Criteria for Mild to Profound ID
A. Five or more of the following symptoms have been present during the same 2 week period and represent a change from previous functioning. At least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.	A. Four or more symptoms have been present during the same 2 week period and represent a change from previous functioning. At least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure or (3) irritable mood .

Adaptation of DSM-IV-TR Criteria

Modification of Symptom Duration

Intermittent Explosive Disorder

DSM-IV-TR Criteria	Adapted Criteria for ID (Mild to Profound)
A. Several discrete episodes of failure to resist aggressive impulses that result in serious assaultive acts or destruction of property.	A. Frequent episodes that last for at least two months of failure to resist aggressive impulses that result in serious assaultive acts or destruction of property.

Adaptation of DSM-IV-TR Criteria

Modification of Age

Antisocial Personality Disorder

DSM-IV-TR Criteria	Adapted Criteria for Individuals with ID
A. There is a pervasive pattern of disregard for and violation of the rights of others occurring since age 15 years, as indicated by three (or more) of the following:	A. There is a pervasive pattern of disregard for and violation of the rights of others occurring since age 18 years, as indicated by three (or more) of the following:
B. The individual is at least age 18 years	B. The individual is at least age 21 years
C. There is evidence of Conduct Disorder with the onset before age 15 years	C. There is evidence of Conduct Disorder with onset before age 18 years

Lindsay, et al, 2007

Adaptation of DSM-IV-TR Criteria

Addition of Explanatory Note

Manic Episode

DSM-IV-TR Criteria	Adapted Criteria for Mild to Profound ID
A. A distinct period of abnormally persistently elevated, expansive or irritable mood, lasting at least 1 week (or any duration if hospitalization is necessary)	A. No adaptation. Note: Observers may report that the individual with ID; has loud inappropriate laughing or singing, is excessively giddy or silly; is intrusive, getting into other's space; and smiles excessively and in ways that are not appropriate to the social context. Elated mood may be alternating with irritable mood

Field Study of the Clinical Usefulness of the DM-ID			
Table 1: Clinician Impressions by Level of Intellectual Disability (%YES)			
Item	Level of Intellectual Disability		
	Mild N=305	Moderate N=237	Severe/ Profound N=285
Was the DM-ID easy to use (user friendly)?	72.4	68.6	62.6
Did you find the DM-ID clinically useful in the diagnosis of this patient?	74.9	67.8	66.0
Did DM-ID allow you to arrive at an appropriate psychiatric diagnosis for this patient?	85.6	83.3	80.2
Did DM-ID allow you to come up with a more specific diagnosis than you would have with the DSM-IV-TR?	36.1	38.0	35.9
Did DM-ID help you avoid using the NOS category?	63.2	63.3	54.9


Fletcher, et al. 2008

The Future DM-ID 2 In Development

Edited By:

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Jarrett Barnhill, M.D., DFAPA, FAACAP
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Implications of Psychotherapy for People with a Dual Diagnosis



Myth: Persons with ID Are Not Appropriate for Psychotherapy

Premise: Impairments in cognitive abilities and language skills make psychotherapy ineffective.

Reality: level of intelligence is not a sole indicator for appropriateness of therapy.

Treatment implications: Psychotherapy approaches need to be adapted to the expressive and receptive language skills of the person.

Fletcher, 2000

Psychotherapy/ Counseling

- Relationship between a client and a therapist/counselor
- Engaged in a therapeutic relationship
- To achieve a change in emotions, thoughts or behavior



Robert Fletcher, DSW, ACSW, 2004

Counseling & Psychotherapy: Who Is Appropriate for Therapy? A Developmental Perspective

WITHOUT ID	WITH ID
6-7 Years old	6-7 Years Old cognitive level
	Mild ID
	Borderline ID

Strohmer & Prout, 1994

General Similarities Between Life Issues Faced by Adolescents without ID and Adults with ID

- Both usually dependent on others
- Both tend to be in supervised settings
- Both have cognitive limitations in terms of:
 - Problem solving
 - Impulse control
 - Concrete thought

Strohmer & Prout, 1994

General Similarities Between Life Issues Faced by Adolescents without ID and Adults with ID

- Both struggle with issues of:
 - Independence
 - Peer group
 - Identity choices
 - Vocational
 - Sexual identity
 - Authority issues
- Both referred to therapy by others


Strohmer & Prout, 1994

NADD Problems that Clients with ID Want to Address in Therapy	
Interpersonal Concerns	22%
General Psychological Functioning	18%
Work	12%
Sexuality	6%
Family	5%
Residential Living & Adjustment	5%
Behavior	4%
Financial & Material Resources	4%
Accepting & Coping with Disability	4%
Dealing with Authority Figures	4%
Other	16%

Wittman, Strohmer & Prout, 1989

NADD Principles for Achieving a Therapeutic Relationship
<ul style="list-style-type: none"> • Empathetic understanding • Respect and acceptance of client • Concreteness • Be consistent • Confidentiality • Draw the client out • Express genuine interest in your client • Be aware of your own feelings

Robert Fletcher, DSW, ACSW, 2004

NADD Confidentiality
<ul style="list-style-type: none"> • Nothing discussed in therapy will be released without the person's permission • With the client's permission, the therapist will work collaboratively with other care providers


Robert Fletcher, DSW, ACSW, 2004

NADD Therapy Techniques for Promoting Mental Wellness
<p>Help People Better Cope With Problems</p> <ol style="list-style-type: none"> 1. Listen 2. Reflect 3. Probe 4. Support 5. Facilitate problem solving 6. Evaluate outcome

YAI

Active Listening



- Attentive
- Interested

YAI

Reflect

- Repeat a few words
- Reflection demonstrates active listening



YAI

Probe

- Ask direct questions
- Avoid interrogation
- *How* and *what* questions are usually easier to answer than *why* questions



YAI

Support

- Supportive statements indicate understanding
- Express that you care
- Acknowledge having been in a similar situation




YAI

NADD

Therapy Techniques for Promoting Mental Wellness

Facilitate problem solving

- Explore alternative options
- Support acceptable solutions




YAI

NADD

Therapy Techniques for Promoting Mental Wellness


Evaluate outcome

- Was outcome acceptable?
- Was it positive?
- What was learned?



YAI

NADD



OK -
We took our
clothes off
and
I got on top...
When does it
start feeling
good?


I don't know
but I already
have a
headache!

NADD

Therapy Techniques for Promoting Mental Wellness

Guiding Principles:

- Use language that promotes hope
- Raise expectations of what people are capable of accomplishing
- Stay focused on strengths



Fletcher, 2009

Therapy Techniques for Promoting Mental Wellness

- Build everyone's hope
- Instill a source of hope whenever possible
- Feeling a sense of hope for the future can be transformative



Fletcher, 2009

Therapy Techniques for Promoting Mental Wellness

- Celebrate accomplishments
- Find ways to listen to our consumers



Fletcher, 2009

STRESS & PSYCHIATRIC DISORDER

- Stressful events may exacerbate or trigger acute psychiatric problems



- People tend to underestimate the impact of stressful life events in people with DD

Dr. Charlot

Types of Stress Experienced by Persons with Intellectual Challenges

- I. Ordinary situations which are not typically stressful to the general population
 - a. social interactions
 - b. meeting new people
 - c. going to public places
- II. Stress from difficult to manage situations for all people, even more stress for people with disabilities
 - a. Major changes in one's life
 1. job
 2. death in family
 3. home relocation
 - b. Adult expectations
 1. sexuality issues: dating, sex,
 2. money management
 3. living independently
 4. employment

Duetsch, 1989

NADD


RECOGNITION EXPOSURE TO STRESS

- Greater exposure to negative life events
- Peer rejection (Philips)
- Residential transfers (Berkson, Heller)
- Negative self-image (Edgerton)
- Transition (Rusch & Chadsey-Rusch)
- Sexual abuse (Ryan)
- Communication of needs (Carr)

Reiss, 2009

NADD

BERRY'S WORLD



"I'M AFRAID THAT YOU'RE SIMPLY GOING TO HAVE TO GIVE UP STRESS."

Robert Fletcher, DSW, ACSW, 2004

NADD

Predictable Crisis and Prevention

Implication for Therapy


There are a number of transitional stages that an individual with ID and his or her family experience throughout the life course. Each one of these transitional stages can contribute to increased stress on the individual and family.

Each one of these transitional stages can result in a crisis situation. If we can identify these stages before they occur, and if we can provide supportive therapy, then we can work toward avoiding a crisis.

NADD

Predictable Crisis and Prevention

- Confirmation/realization of diagnosis of ID
- Birth of siblings
- Starting school
- Puberty and adolescence



Levitas and Gilson, 1989

Predictable Crisis and Prevention

- Sex and dating
- Being surpassed by younger siblings
- Emancipation of siblings
- End of education



Levitas and Gilson, 1989

Predictable Crisis and Prevention

- Out-of-home placement and/or residential moves
- Staff/client relationships
- Loss of peers, friends & parents
- Medical illness & Psychiatric Illness



Levitas and Gilson, 1989



Considerations in Therapy with Persons Who Have Mental Illness and ID

Special Considerations

- Watch for pleasers
- Slow progress
- Multiplicity of problems
- Reliability of reporting
- Difficulty relating to analogies
- Problems with terminating

Jackson & Gentile, 2012

Psychotherapy Adaptations

1. **Flexible sessions**
2. **Adjust language**
3. **Augment interventions with activities**
4. **Involve caregivers**
5. **Increased length of care**
6. **Express hope for the future**
7. **Story Telling**
8. **Use of Reflection**

Fletcher, 2013

Psychotherapy Adaptations**1. Flexible Sessions**

Length of therapy sessions should match the individual's attention span. For some people, this may be no longer than 30 minutes.

Jackson & Gentile, 2012

Psychotherapy Adaptations**2. Adjust language**

Reduce level of vocabulary, sentence structure and length of thought to match the cognitive abilities of the patient.

Jackson & Gentile, 2012

Psychotherapy Adaptations**3. Augment interventions with activities**

Use of activities can help deepen change and learning and may include the use of drawing, therapeutic games, role play and homework assignments.

Jackson & Gentile, 2012

Psychotherapy Adaptations

4. Involve caregivers

Important source of collateral information necessary to ascertain progress between sessions.

Jackson & Gentile, 2012

Psychotherapy Adaptations

5. Increased length of care

Most research indicates that a longer length of treatment (1-2 years) is a best practice with this population. This allows the psychotherapy to move at a slower pace so that the clinician can spend additional time on each intervention utilized, ensuring that the skills being taught are internalized. It also allows for the inclusion of additional treatment stages that may be necessary.

Jackson & Gentile, 2012

Psychotherapy Adaptations

6. Therapy can express interest in the client and hope for the future. This in and of itself can be very therapeutic by:

- Increasing self esteem
- Instill sense of hope
- Helps to counter-act feelings of distrust, fear and aloneness
- Hope is transformative for the future

Fletcher, 2010

Psychotherapy Adaptations

7. Story Telling

- Encourage client to tell his/her story
- Therapist to listen carefully to story
- Therapist to respect the need for client to "open up" in their own time and way

Drucker, 2010

8. Use of Reflection

- Therapist should reflect back what he/she thinks the client is saying
- Client should also reflect back what he/she thinks the dialogue is about
- Important to insure clear communications using reflection and clarification

Drucker, 2010

**Group Psychotherapy for
People with ID/MH****13 Benefits**

1. Fosters meaningful relationships
2. Increases relationship skills
3. Promotes problem solving skills
4. Enables learning through observation

Fletcher, 1984

13 Benefits

5. Helps decrease feelings of: inadequacy, isolation and defeat
6. Promotes peer support
7. Fosters a sense of security
8. Promotes group cohesiveness
9. Establishes sense of trust

Fletcher, 1984

13 Benefits

10. Promotes sense of belonging – shared experiences
11. Instills sense of hope - optimism
12. Facilitates altruism – helping others
13. Promotes self understanding

Fletcher, 1984

- I. Problem Solving
- II. Identification & Expression of Feelings
- III. Social Skills
- IV. Human Sexuality
- V. Interpersonal Relationships
- VI. Grief & Loss

I. Problem Solving

- Lack of problem solving skills is common
- Poor coping strategies
- Lack of experience and opportunities to cope with problems effectively
- Group therapy can be useful to help group members develop a range of coping skills

Fletcher & Duffy, 1993

I. Problem Solving

- Group therapy offers a safe environment to learn and “talkout” problem solving strategies
- Group members observe and learn from other group members (role modeling)
- Problem solving skills learned in group can then be generalized outside of the group

Fletcher & Duffy, 1993

NADD Common Clinical Themes in Group Therapy

II. Identification and Expression of Feelings

- Learn to identify feeling states in group (i.e., angry, happy, scared)
- This particularly important for people at the lower end of intellectual range
- Feeling pictures can be useful
- People learn this by observing others in the group

Fletcher & Duffy, 1993

NADD Common Clinical Themes in Group Therapy

II. Identification and Expression of Feelings

- Expression of feelings is a very important part of group therapy
- Participants learn how to express themselves in socially appropriate ways
- Participants express feelings rather than act out in inappropriate ways
- Group offers opportunity to learn appropriate expression of feelings in a safe environment

Fletcher & Duffy, 1993

NADD Common Clinical Themes in Group Therapy

III. Social Skills

- Group can be a viable approach to teach and learn social skills
- Social skills are important to success in community-based living
- Social skills training can be part of group therapy
- Discussion on wanting to be as independent as possible
 - Will need certain social skills to live independently

Fletcher & Duffy, 1993

NADD Common Clinical Themes in Group Therapy

IV. Human Sexuality

- Teaching boundaries
 - Circle concept
 - Closeness relative to proximity
- Teaching dating skills
- Teaching anatomy and physiology of sexuality

Fletcher & Duffy, 1993

IV. Human Sexuality

- In group, close interpersonal relationships can be addressed
- As group progresses, the members work on higher level of intimacy skills
- Therapist often in dual role of teacher and therapist

Fletcher & Duffy, 1993

V. Interpersonal Relationship

- Many people who have ID/MI feel isolated, defeated and alone
- Little opportunity to develop meaningful relationships
- Group offers an avenue to learn how to make friends and engage in meaningful interpersonal relationships

Fletcher & Duffy, 1993

V. Interpersonal Relationship

- Group offers opportunity for giving and receiving interpersonal transactions which helps to:
 - Break down social fears and barriers
 - Learn interpersonal relationship skills
 - Engage in meaningful relationships
 - Make new friends

Fletcher & Duffy, 1993

VI. Loss and Grief

- Loss can result from:
 - Death of friend or family
 - Roommate is moving
 - Staff turn-over
 - Death of pet

Fletcher & Duffy, 1993

VI. Loss and Grief

- The group can help a member:
 - To accept the reality of the loss
 - To experience the pain of grief
 - To adjust to an environment in which the other person is missing
 - Reinvent energy, after time, in new relationships

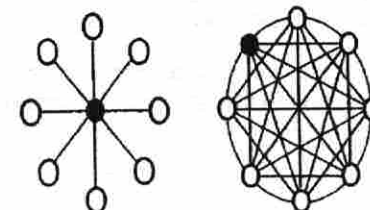
Fletcher & Duffy, 1993

- What a person reveals in group must not be disclosed outside the group
- Confidentiality must be a ground rule
- Members can and should talk about themes/topics with significant others, but members must preserve anonymity

Fletcher, 2006

- **Facilitates Interactions**
 - Encourages Interaction
- **Active Leader**
 - Establishes Ground Rules
- **Accepting Individual**
 - Warming, Caring
- **Facilitate interaction concerning members**
- **Two Facilitators are the Ideal**
 - One Male/One Female

Fletcher, 2006



Typical Model

Interactive Model

Tomasulo, 1998

Barriers to Service Delivery for People with ID/MI

- States and communities are struggling to provide care for people with co-occurring ID and MI.
- These people are often described as the most expensive and difficult population to serve.
- Unmet needs in childhood ultimately rest on the doorsteps of adult agencies, family caregivers and service organizations.

SAMHSA, 2006

- Co-occurring ID and MI are far more common than generally recognized.
- These individuals are at elevated risk for out of home placement, incarceration, referral to child welfare and eventual homelessness.
- Necessary comprehensive services and supports are very difficult to access in most communities.

SAMHSA, 2006

- The fragmented and categorical structure of services is a major barrier.
- The impact of our societal failure to provide adequate care can be life-long and devastating for the individuals and their families.

SAMHSA, 2006

NADD People with Co-occurring
ID and MI

- Many parents experience long and painful searches for appropriate assessments, evaluations or treatment, commonly unavailable or inadequate.
- People may be turned away from one public agency after another because their children have the "wrong" diagnosis or the wrong IQ (either too high or too low)

SAMHSA, 2006

NADD Complex needs do not match our funding streams
and narrowly defined programs.

Categorical Financing Limits

- States have made only limited use of Medicaid waivers for people with co-occurring disorders.
- Cost-benefit data shows that comprehensive community-based services cost far less than residential care, yet financing mechanisms and community needs are not in alignment.
- Categorical financing leads to a fragmented service structure and problems with eligibility.

SAMHSA, 2006

NADD Complex needs do not match our funding streams
and narrowly defined programs.

Fragmented Service Structure

- School systems, juvenile justice and child welfare agencies are generally not integrated with developmental disabilities and mental health.
- Adult and child systems are generally segregated, which sets up problems as teenagers transition to adult services.
- Cultural differences among agencies, historic turf issues and competition for diminishing funds complicate the problem.

SAMHSA, 2006

NADD Complex needs do not match our funding streams
and narrowly defined programs.

Inadequate array of community services

- This fragmentation contributes to gaps in essential community services such as
 - after school, summer camps and respite care,
 - crisis prevention planning and training for local providers including police
 - supports for parents coping with stress or other special needs,
 - services for adolescents who are not in school
 - services for adults

SAMHSA, 2006

Inadequate array of community services

- This fragmentation contributes to gaps in essential community services such as
 - substance abuse programs that will accept individuals with intellectual disorders,
 - trauma-focused intervention for people who have been abused
 - socialization programs to prevent isolation and to address social skill deficits
 - appropriate programs for people with autism spectrum disorders

SAMHSA, 2006

Restricted access and eligibility

- In spite of its importance for people with complex needs, continuity of care is particularly difficult to achieve at the transition points between early intervention and school aged services and again at transition to adult services.
- Private insurance companies shift costs to the government through restrictive eligibility and reimbursement practices.
- Organization of services by diagnosis rather than a need-based leads to inadequate and fragmented care.

SAMHSA, 2006

Workforce

- Few professionals have the specialized training necessary to recognize co-occurring disorders and to treat people appropriately with evidence-based practices.
- Few professionals are willing to see these people and fewer still are within the public system.
- Few professional training programs include information on mental health needs of individuals with developmental problems.

SAMHSA, 2006

Workforce

- Paraprofessionals are a key part of the workforce but their work conditions and pay are often inadequate. A stable workforce requires adequate pay and training so that people can feel effective in their work.
- Parents currently comprise a vast and unpaid workforce. Their expertise should be supported with opportunities for formal training and adequate pay.

SAMHSA, 2006

Recommendations for Redesigning Services

SAMHSA, 2006

Recommendations for Redesigning Services

Make Services More Accessible and Responsive

- Families should be involved in all clinical decisions and at all levels.
- Non-clinical supports such as respite care, home-based services and after school programming should be greatly increased.

SAMHSA, 2006

Recommendations for Redesigning Services

Make Services More Accessible and Responsive

- Provide easier access to services, so that there is "no wrong door" and the services are fully networked. Co-location of services can be helpful.
- Each person should have a single service plan developed by a multidisciplinary team that integrates all needed services based on needs rather than diagnosis.

Recommendations for Redesigning Services

Increase Capacity in the Field

- Integrate developmental disability and mental health services within the schools and adult services
- Systematically address the gaps that exist in community services.
- Increase understanding and awareness of this population among primary care providers.
- Increase skill level among providers, special educators, professionals and the paraprofessionals who work with them.

SAMHSA, 2006

Increase Capacity in the Field

- Recruit child psychiatrists, psychologists, and other professionals and paraprofessionals and train them. Consider scholarships and student loan relief to attract more professionals to the field.
- Infuse expertise among existing providers through ongoing consultation with a multidisciplinary team of experts. Promote multi-disciplinary cross-training programs for staff working with this population.

SAMHSA, 2006

- Effective and respectful services for individuals with complex needs require person-centered, culturally competent and family-driven planning.
- Sometimes the most important intervention is to assure that an individual with a development disorder has meaningful days and meaningful relationships, as well as a feeling of belonging.

National Technical Assistance Center for Children's Mental Health

- A multidisciplinary clinical team of experts in co-occurring developmental and psychiatric disorders is critical. The assessment and treatment of this population requires a different skill set than needed for the general population.
- Intensive care coordination is critical as well to provide linkages among agencies, integrated care planning, assistance to all family members and crisis prevention planning and support.

National Technical Assistance Center for Children's Mental Health

- Mobile crisis outreach and emergency respite care are needed for psychiatric hospital diversion
- Crisis prevention planning is central. Staff and families need emergency supports to call during crisis, and also training in preventing and de-escalating challenging behavior.

National Technical Assistance Center for Children's Mental Health

**Facilitate Interagency Collaboration at the Local,
State and Federal Level**

- The System of Care approach provides a framework for community-based collaboration that is both culturally competent and family-driven.
- It has proven effective for complex multi-system children including those with co-occurring developmental and emotional disorders.

SAMHSA, 2006

**Facilitate Interagency Collaboration at the Local,
State and Federal Level**

- Promote interagency collaboration
- Increase collaboration and coordination across agencies and programs at the federal, state and local levels to bring regulations, eligibility, and financing into alignment with the needs of this population.

SAMHSA, 2006

- Conduct focus groups with parents and providers from mental health, developmental disabilities and other systems to better understand the local issues and to build a shared understanding of the urgency of needs. Identify service gaps, recommendations, barriers to integrated services.
- Set up an interagency planning and advisory committee including representatives from providers, MH, IDD, education, clinical justice systems and family members.

Fletcher, 2015

- Identify local resources. Study gaps in service, additional supports needed, and create a list of available resources and services.
- Obtain existing data at state and local levels to understand baseline rates, services used, baseline costs, service gaps, hospitalization, juvenile justice, child welfare, homelessness.

Fletcher, 2015

- **Set up cross- system case conferences to support interagency planning. Present de-identified individuals who require many expensive services from several systems but whose needs are not well addressed.**
- **Develop a call to action for the state or locality. Parent advocates are often the most effective in driving needed changes.**

Fletcher, 2015

- **Locate or develop a multidisciplinary clinical diagnostic and consultation team of specialists in co-occurring disorders.**
- **Local resources are not available, focus on infusing expertise among local providers through consultation and training.**

Fletcher, 2015

- **Use the interagency planning and advisory body that includes community agencies and family stakeholders to monitor the implementation and management of the Call to Action, with primary attention on maintaining services integration.**
- **Set up cross-system training for providers and other stakeholders.**
- **Maximize use of existing data systems to support quality improvement.**

Fletcher, 2015

- **Crisis prevention planning is central.**
- **Identify classes of individuals likely to be at high risk (prior history of violence or disruptive behavior, multiple medications, unstable home or school situation, prior trauma experiences, etc.) and focus on prevention of crises.**

Fletcher, 2015



Using Data to Drive Services & Document Cost-Benefits

- Data collection needs to be thoughtfully planned to provide ongoing feedback for quality improvement.
- Data is critical for sustained funding support
- Data needs to include
 - Careful analysis of costs and service utilization
 - Satisfaction surveys
 - Objective assessment of progress toward goals

Fletcher, 2015



NADD Accreditation/Certification Programs



Standards for Quality IDD/MH

4 Separate but Interrelated Competency-Based Quality Standards Programs:

1. Competency-Based Certification for Clinicians
2. Competency-Based Certification for Direct Support Professionals
3. Competency-Based Certification for Specialists
4. Accreditation for Programs



Partner

The Accreditation and Certification Programs
were developed by NADD in association with the

National Association of State Directors of
Developmental Disability Services (NASDDDS)





Purpose of Program

- Provide a workforce and system with a demonstrated level of expertise
- Assure that public and private healthcare dollars are purchasing effective services
- Assist families/advocates to make informed choices about services



Purpose of Program

- Promote & advance the field of DD/ID & MH by establishing standards and competencies to promote the highest standard of care
- Recognize programs, clinicians, and support staff that achieve certification through the NADD review process (NADD Seal of Approval)



Competency-Based Clinical Certification in Dual Diagnosis



Purpose of Clinical Certification

- To recognize clinical persons who have documented quality care and treatment for persons with ID and MI
- To create an awareness of quality services.
- To promote excellence in clinical support for persons with ID/MI



Stages of Clinical Certification Process

- Application & clinical portfolio
- Submission of work sample
- Interview/Exam
- Response to case vignette provided by NADD



Possible Content for Work Sample

- Diagnosis
- Substance Abuse
- Positive Supports
- Modification of the Environment
- Therapy
- Psychopharmacology
- Lifespan issues



Receiving Clinical Certification

If an applicant completes all stages successfully,
NADD Competency-Based Clinical Certification
is granted.

NADD-CC



**Competency-Based
Direct Support Professional
(DSP) Certification
in Dual Diagnosis**

Purpose of DSP Certification

- Identify competencies to evaluate the DSP's knowledge, values, skill, and ability working with people with IDD/MI
- Increase the capacity of DSPs to work with individuals with IDD/MI
- Acknowledge the importance of DSP work

DSP Application Process

- Application and fee: \$60
- Summary of experience
- Summary of continuing education experience
- Letter of recommendation from supervisor and from a person supported or the person's representative
- 1,000 hours experience
- NADD member / Organization member

Competency Standards in Five Areas

1. Assessment and Observation
2. Behavior Supports
3. Crisis Prevention and Intervention
4. Health and Wellness
5. Community Collaboration and Teamwork

Examination

- Online – multiple choice
- Scenario questions focus on competence in knowledge, values and ethics in overlapping competency areas
- Questions elicit knowledge of key indicators
- Passing 80% overall, 60% minimum in each area



Receiving DSP Certification

If an applicant completes all stages successfully,
NADD Competency-Based DSP Certification
is granted.

NADD-DSP



The NADD Competency- Based Specialist Certification Program in Dual Diagnosis



Purpose of Specialist Certification

- Improve the quality and effectiveness of services provided to individuals with a dual diagnosis
- Raise the bar in service delivery for individuals with MI/DD
- Improve and advance knowledge on the field
- To acknowledge the skills, values and attributes of staff providing services for people with a dual diagnosis



Who is Eligible?

- People who
 - Deliver
 - Manage
 - Train
 - Supervise

Stages of DDS Certification Process

- **Application & Portfolio**
- **Submission of work sample**
- **Interview / Exam**

6 Competency Areas for Specialist

1. **Multi-Modal/bio-psycho-social approach**
2. **Application of emerging best practices**
3. **Knowledge of therapeutic constructs**
4. **Respectful and effective communication**
5. **Knowledge of dual role service delivery & fiduciary responsibilities**
6. **Ability to apply administrative critical thinking**

Receiving DSP Certification

**If an applicant completes all stages successfully,
NADD Competency-Based Specialist Certification is
granted.**

NADD-DDS

NADD Accreditation Program

Purpose of Program Accreditation

- Provide recognition to programs who meet and exceed NADD best practice standards
- Provide NADD expert consultation services aimed at quality improvement during the course of the survey

Four Components of The Survey Process

- 1) Interview Format
- 2) Clinical Chart Review
- 3) Policy Review
- 4) Consultation Service

18 Module Competency Areas and Scoring

	Competency Areas	Score
I	Medication Evaluation /Reconciliation	
II	Holistic approach	
III	Database/outcomes	
IV	Protocols for assessment	
V	Treatment plans	
VI	Basic health care	
VII	Treatment team members	
VIII	Staff/family/consumer training	
IX	Crisis/emergency services	

18 Module Competency Areas and Scoring (cont)

X	Cultural competency/family values	Score
XI	Trauma	
XII	QI /incident management	
XIII	Evidenced-based treatment practices	
XIV	Ethics, Rights, Responsibilities	
XV	Interagency & cross agency collaboration	
XVI	Long term living/service coordination	
XVII	Advocacy & rights	
XVIII	Informatics & technology	



NADD Certification Decisions

Three Years – The agency has demonstrated excellent services in supporting people with (ID/MI)

Two Years – The agency has demonstrated quality services but needs improvement in certain areas

Provisional - Time limited 1 year accreditation for programs who score below NADD Accreditation standards, or who are recently established and/or have limited experience and resources, but show potential in providing services and supports for person's with (ID/MI)



Receiving NADD Accreditation

If an applicant completes all stages successfully, NADD Accreditation is granted.



NO QUICK FIX



Robert Fletcher, DSW, ACSW, 2004



THANK YOU

For more information, please contact

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