Emerging Best Practices for People with an Intellectual/Developmental Disability Co-Occurring with Serious Mental Illness

Dr. Robert J. Fletcher
Founder & CEO Emeritus, NADD
Lynda Gargan, Ph.D., Moderator
National Federation of Families for Children’s Mental Health
Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services
This webinar was developed [in part] under contract number HHSS283201200021I/HHS28342003T from the Substance Abuse and Mental Health Services Administration (SAMHSA), U.S. Department of Health and Human Services (HHS). The views, policies and opinions expressed are those of the authors and do not necessarily reflect those of SAMHSA or HHS.
Learning Objectives

By the end of this webinar, participants will be able to:

• Describe the major components involved in the assessment process
• Explain why a bio-psycho-social approach is important in the assessment process
• Describe types of criteria modifications outlined in the DM-ID-2
• Articulate modifications/adaptations of psychotherapy practices
• Explain the importance of an inter-systems model of collaboration for people with IDD-MI
Outline of Presentation

• NADD
• Clinical Practices
  • Assessment Practices
  • Diagnostic Practices
  • Adapting Psychotherapy Practices
• Inter-System Model
NADD

• NADD, a not-for-profit membership association established in 1983 for professionals, care providers, and families

• Promotes the understanding of and services for individuals who have IDD and mental health needs

• Designed to promote the exchange of clinical practices, policy initiatives, research, and program development
The mission of NADD is to provide leadership in the expansion of knowledge, training, policy and advocacy for mental health practices that promote a quality life for individuals with dual diagnosis (IDD/MI) in their communities.
NADD’s Goals

• To encourage the exchange of information
• To promote educational and training programs
• To foster the development of resources and services
• To advocate for appropriate governmental policies
• To support research on diagnosis and treatment
• To stimulate public and professional interest
• To establish a vision of mental wellness
NADD

• Conferences/Trainings
• Journals
• Webinars
• Consultation Services
• Book Publisher
• Accreditation and Certification
Prevalence of MI in ID

Three to Four Times More Frequently Than Typical Population
(Corbett 1979)

39% of People with ID have MI
(Cooper et al, 2007)

50% of People with ID have MI
(NCI, 2016)

Fletcher, 2016
Emerging Best Practices in Assessment and Diagnostic Procedures
Assessment Factors

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

• Biological
• Psychological
• Social

Royal College of Psychiatrists, 2001
Assessment 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
Assessment 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/disenfranchisement

Royal College of Psychiatrists, 2001
Assessment 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
Best Practice Assessment: Bio-Psycho-Social Model
Mental Health Assessment

1. Source of information and Reason for Referral
2. History of Presenting Problem and Past Psychiatric History
3. Personal and Family Health and Behavioral Health History
4. Social and Developmental History
1. Source of information and Reason for Referral
   • Who made the referral?
   • What is different from baseline behavior?
   • Why make the referral now?
2. History of Presenting Problem and Past Psychiatric History

- How long has the problem occurred?
- Is there a history of mental health treatment?
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
4. Social/Developmental History
   • 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)
Barriers to Diagnosis: Adequate Assessments

Complicating Diagnostic Factors

1. Diagnostic Overshadowing
2. Medication Masking
3. Communication Deficits
4. Atypical Presentation of Psychiatric Disorders
5. Medical Conditions
6. Acquiescence
7. Aggression and SIB
8. Sensory Impairment
9. Episodic Presentation
10. Lack of Expertise

Adapted from McGilvery & Sweetland, 2012
Diagnostic 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
Diagnostic 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
Medical Problems & Problem Behavior

• Why do medical causes of problem behaviors get missed?
• Why do we have to be....Sherlock Holmes?
Medical Problems & Problem Behavior

• Medical conditions can mask as behavioral problems.

• Medical conditions are often underdiagnosed.

Charlot, 2011
<table>
<thead>
<tr>
<th>Medical Problems &amp; Problem Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DRUG SIDE EFFECTS</strong></td>
</tr>
<tr>
<td>GASTROINTESTINAL ISSUES</td>
</tr>
<tr>
<td>Akathesia, Delirium, Dyskinesia</td>
</tr>
<tr>
<td>Hemorrhoids</td>
</tr>
<tr>
<td>Constipation</td>
</tr>
<tr>
<td>Irritable Bowel Syndrome</td>
</tr>
<tr>
<td>GERD</td>
</tr>
<tr>
<td>GASTROINTESTINAL ISSUES</td>
</tr>
<tr>
<td>Constipation</td>
</tr>
<tr>
<td>Irritable Bowel Syndrome</td>
</tr>
<tr>
<td>GERD</td>
</tr>
<tr>
<td>ENDOCRINOLOGICAL PROBLEMS</td>
</tr>
<tr>
<td>Diabetes</td>
</tr>
<tr>
<td>Thyroid problems</td>
</tr>
<tr>
<td>NEUROLOGICAL PROBLEMS</td>
</tr>
<tr>
<td>Epilepsy</td>
</tr>
<tr>
<td>Other movement problems</td>
</tr>
<tr>
<td>OTHER</td>
</tr>
<tr>
<td>Headaches</td>
</tr>
<tr>
<td>Dental pain</td>
</tr>
<tr>
<td>Back pain</td>
</tr>
<tr>
<td>Hearing and vision problems</td>
</tr>
<tr>
<td>Sleep apnea</td>
</tr>
<tr>
<td>Charlot, 2011</td>
</tr>
</tbody>
</table>
• 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
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, and tooth was extracted
• Mother subsequently reported that hair pulling ceased
From the DSM-5 to the DM-ID-2
Limitations of the 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 System relies on self-report of signs and symptoms (DSM-5, 2013)
DM-ID-2: Two Manuals

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

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

Edited by
Robert J. Petrich, DSW, ACSW, NADD-CC; Chief Editor
Jami A. Bormuth, MD, DMFA, FAACAP
Sally Ann Cooper, MD, FACP, FAACAP

Substance Abuse and Mental Health Services Administration
Description of the DM-ID-2

- An adaptation to the *DSM-5*
- Designed to facilitate a more accurate psychiatric diagnosis
- Based on Expert Consensus Model
- Covers all major diagnostic categories as defined in *DSM-5*
- Provides state-of-the-art information about mental disorders in persons with ID
- Provides adaptation of criteria, where appropriate
• 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

• Etiology and Pathogenesis
  • Risk Factors
    • Biological factors
    • Psychological factors
    • Genetic syndromes
The Six Modifications of Criteria Subsets

1. Addition of symptom equivalents
   • Observed reports that are equivalent to self-reports as identified in the DSM system

2. Omission of symptoms
   • Symptoms that do not exist or cannot be identified in persons with IDD

3. Changes in symptom count
   • Indicated the frequency of a symptom that is required to meet the diagnostic criteria
4. Modification of symptom duration
   • The length of time a symptom has to be present in order to meet the diagnostic criteria

5. Modification of age requirements
   • Indicates changes in age to take into consideration the developmental perspective of the individual with IDD

6. Addition of explanatory notes
   • Intended to communicate a criterion without an official modification of the criteria subset
Modification Example

**DSM-5 Criteria**

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.

**Applying Criteria for Mild to Profound IDD**

A. **Four** or more symptoms have been present during the same 2-week period and represent a change from previous functioning.

B. AT least one of the symptoms is either (1) depressed mood or (2) loss of interest of pleasure or (3) **irritable mood**.
Adapting Psychotherapy for People with IDD
Myth: Persons with IDD 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 Applications: Psychotherapy approach may be effective but need to be adapted to the expressive and receptive language skills of the person

Fletcher, 2011
Adaptations of Therapy

Top (10) Modifications

1) Language
2) Frequency of Sessions
3) Shorter Sessions
4) Duration of Therapy
5) Utilize a More Structured & Directive Approach
6) Communication with Collaterals
7) Modify Complexity of Interventions
8) Therapist needs to be supportive
9) Therapist needs to be flexible
10) Therapist needs to be part of a team approach

Fletcher, 2011
Inter-Systems Collaboration
Barriers to Service Delivery

The Typical Picture:

• Failure to plan services
• Failure to fund flexible services
• Failure to obtain technical assistance
Barriers to Service Delivery

The Typical Picture:

- MH providers perceive that they do not have the skills to serve adults or children with a dual diagnosis
- IDD providers do not understand the services that the MH sector offers
- MH providers to not understand the services that the IDD sector offers

Moseley, 2004
### Barriers to Service Delivery

<table>
<thead>
<tr>
<th>MH System</th>
<th>IDD System</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Short term episodic treatment</td>
<td>• Services/supports over lifetime</td>
</tr>
<tr>
<td>• Focus on psychiatric needs</td>
<td>• Emphasis on direct support</td>
</tr>
<tr>
<td>• Recovery model</td>
<td>• Self-determination</td>
</tr>
<tr>
<td>• Local authority</td>
<td>• State authority</td>
</tr>
<tr>
<td>• Medication treatment</td>
<td>• Behavioral support (PBS)</td>
</tr>
<tr>
<td>• Consumer/client/patient</td>
<td>• Self-advocate/consumer</td>
</tr>
</tbody>
</table>

**Little Collaboration**
Principles & Practices in Inter-system Service Planning
Co-occurring disorders should be treated as multiple primary disorders, in which each disorder receives specific and appropriate services.

Collaboration of appropriate services and supports must occur as needs are identified.

Services provided to the individual are consistent with what the person wants and what supports are needed.
Dual Diagnosis Planning Principles

- Services are determined on the basis of comprehensive assessment of the needs of each individual.
- Services are based on individual needs and not solely on either MH or IDD diagnosis.
- Emphasize early identification and intervention.
- Involve the person and family as full partners.
- Coordinate at the system and service delivery level.
The system must recognize and value the long-term cost effectiveness of providing best practice services and supports for persons with co-occurring disorders.
Dual Diagnosis Planning Principles

Knowledge of Service System

People with IDD and mental health needs are often served by different programs. Treatment and care is enhanced when knowledge across systems are considered in a person-centered approach. This includes:

- Knowledge about county and state systems and services including education, health care, DD/IDD services, mental health services, the justice system, foster care, youth services, community disability services, transportation and employment
Facilitating Positive and Cooperative Relationships

• Ability to navigate recommendations between systems (e.g., psychiatrists and other health professionals, employment, residential settings)
• Ability to build positive and cooperative relationships with other health and mental health professionals
• Can work positively with multiple systems as a collaborative and cooperative member of the team
• Recognize family members as integral partners in support and gathers input from them
• Demonstrate problem solving and teamwork skills

NADD, n.d.
Inter-Systems Collaboration

Purpose/Function of a Dual Diagnosis Committee

- Gather relevant data/information
- Identify strengths in service delivery systems
- Identify challenges/gaps in service delivery system
- Develop solutions to address challenges and gaps
Stakeholders from other than MH & IDD systems could be included as appropriate. These include, but are not limited to, representatives from:

- Substance Abuse
- Justice
- Health Department
- Social Services
- Parents
- Consumers
- Advocacy Organizations
- Special Education
- Early Intervention
- Child Welfare
- Coordinated Children’s Services
- Service Providers
- Senior Services

Adapted from Moseley, 2010
Dr. Robert Fletcher, NADD
132 Fair Street
Kingston, NY 12401

www.thenadd.org
rfletcher@thenadd.org

(845) 331-4336 (w)
(845) 389-5531 (c)