From the DSM-5
To the
DM-ID2

Robert J. Fletcher, DSW, ACSW, LCSW, NADD-CC
Founder & CEO, NADD
Chief Editor, DM-ID2

Pennsylvania Dual Diagnosis Conference
July 20-21, 2017
State College, PA

DM-ID-2 Improves Lives

- Accurate Diagnosis
- Effective Treatment
- Improved Outcomes
- Better Quality Of Life
Outline of Presentation

- Limitations of the DSM System
- Prevalence of MI in IDD
- Description of DM-ID-2
- Structure of the DM-ID-2
- Six Applications of criteria subsets
- Diagnostic specific examples of criteria modification

Limitations of the DSM System

- Psychiatric disorders in persons with IDD are often under or misdiagnosed. (Gustafsona Sonmader, 2004)

- The DSM and ICD are systems designed for use for the general population and are dependent on the individual's ability to participate verbally during the evaluation (DSM-5)
Limitations of the DSM System

- Individuals with IDD may be non verbal or have significant challenges in receptive and expressive language

- Individuals with IDD may not be able to fully participate in the evaluation process through the self-report method

(DM-ID-2, 2016)

Limitations of the DSM System

- Symptoms of psychopathology may not be expressed in the same way in persons with IDD as compared to the general population (Moss, et al, 1998)

- Difficulty with using traditional diagnostic criteria lies in the fact that individuals with IDD may not always be reliable self reporters

(DM-ID-2, 2016)
**Limitations of the DSM System**

- Diagnostic Overshadowing (Reiss, et al, 1982)
- Applicability of established diagnostic systems is increasingly suspect as the severity of IDD increases (Rush & Frances, 2000)
- DSM System relies on self report of signs and symptoms (DSM-5)

**Prevalence of Mental Illness in IDD**

- People with IDD can experience the same psychiatric disorders as the general population
- Studies have indicated that psychiatric disorders in people with IDD are at a higher rate than in the general population
- The research data indicates a wide variance of psychiatric disorders in people with IDD from 30% to 70%.
The Variance of data reflects a number of variables including:

1) Nature of study sample
2) Definitions
3) Classification systems
4) The inclusion or exclusion of “challenging behaviors”
5) The inclusion or exclusion of ASD under the general mantle of psychiatric disorders
6) The training and experience of the clinician
7) Methodological quality of the study
Examples of Three Studies

1) Cooper, Smiley, Morrison, Williamson and Allen (2007)
   - Used multiple measures
   - N= 1,023
   - Comprehensive individualized assessment
   - Point prevalence of mental illness of 40.9% (Clinical diagnosis)
     - 35.2% (DC-LD)
     - 16.6% (ICD-10)
     - 15% (DSM-5)

2) Bailey (2007)
   - Random sample
   - N= 240
   - 57% (DC-ID)
   - 24.8% (ICD-10)
   - 13.2% (DSM-5)
Examples of Three Studies

3) National Core Indicators (2016)
   • Study based on client chart data
   • N= 16,631
   • 49.5% mental illness in IDD

The Publication of the DSM-5 Necessitates Revision of the DM-ID

THE DM-ID-2
Description of DM-ID-2

- Designed to provide state-of-the-art knowledge of mental disorders in persons with IDD
- Corresponds closely to the DSM-5 classification system
- Developed to improve understanding of mental disorders and unique expressions in persons with IDD
Description of DM-ID-2

• Designed to facilitate a more accurate psychiatric diagnosis

• Based on Expert Consensus Model

• Covers all major diagnostic categories as defined in DSM-5

Description of DM-ID-2

• Provides information to help with diagnostic process

• Addresses pathoplastic effect of IDD on psychopathology (how the disorder is manifested in people with IDD)

• Designed with a developmental perspective to help clinicians to recognize symptom profiles in adults and children with IDD
Description of DM-ID-2

- Empirically-based approach to identify specific psychiatric disorders in persons with IDD
- Provides clear examples of how symptom presentations can be interpreted for people with IDD
- Each diagnosis incorporates diagnostic considerations that highlight specific bio-psycho-social factors
- Provides adaptations of criteria, where appropriate

DM-ID-2
Two Special Added-Value Chapters

- Assessment and Diagnostic Procedures
- Behavioral Phenotype of Genetic Disorders
Assessment and Diagnostic Procedures Chapter

• Psychiatric diagnosis is a challenge
• Need to rely on multiple sources for information
• Need to understand the person and their challenges
• Obtain medical information

Assessment and Diagnostic Procedures Chapter

Special Considerations

• Use language that can be understood
• Confirm understanding

Establishing Chief Complaint and History

• Ask client
• Ask other individuals
• Obtain historical information
Historical Information

- Pregnancy, birth
- Early development
- Behavioral adjustment in early school years
- Educational interventions throughout childhood
- Early family relationships, family members
- Behavioral adjustment in adolescence
- Level of education intervention in high school years
- Most recent individual Educational Plan and full assessment
- Friends and community contacts in adolescence-adulthood

(DM-ID-2, 2016)

Historical Information

- Living situations in adulthood
- Occupational history
- Substance abuse history
- Current social connections
- Social history, hobbies, community activities
- History of partners, marriage, or children
- Psychological evaluations
- Intelligence testing (IQ)

(DM-ID-2, 2016)
**Historical Information**

- Adaptive behavior testing
- Medical history (including current and past medications)
- Illnesses in childhood
- Disabilities, visual, hearing, physical
- Seizure disorder (and associated medications)
- Surgical procedures
- Current conditions
- Accidents, especially head trauma

**Behavioral Phenotypes of Neurodevelopmental Disorders Chapter**

- The physical phenotype of a genetic syndrome is:
  - A set of biological characteristics
  - Produced by a genetic abnormality (genotype)
    - Example:
      - Recognized face of a person with Down Syndrome (ie small mouth, upward slant eyes)
      - Diagnosis of genetic syndromes based on physical finding and confirmed by laboratory evaluation
A behavioral phenotype is:

- The specific characteristic behavioral repertoire exhibited by people with a genetic disorder (Flint and Yule, 1994)

- A characteristic pattern of motor, cognitive, linguistic and/or social abnormalities which is consistently associated with a biological disorder (Society of Behavioral Phenotype)

Behavioral Phenotypes of Neurodevelopmental Disorders Chapter

Behavioral Phenotypes of 12 ID Syndromes

- Angelman Syndrome
- Chromosome 15q11-131 Duplication Syndrome
- Down Syndrome
- Fetal Alcohol Syndrome
- Fragile-X Syndrome
- Phenylketonuria
- Prader-Willi Syndrome
- Rubenstein-Taybi Syndrome
- Smith-Magenis Syndrome
- Tuberous Sclerosis Complex
- Velocardiofacial Syndrome
- Williams Syndrome
Behavioral Phenotype of Genetic Disorders Chapter

Phenotype and Behavioral Phenotype for Down Syndrome

<table>
<thead>
<tr>
<th>Phenotype</th>
<th>Behavioral Phenotype</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phenotype</td>
<td>Small head, mouth; upward slant to eyes; epicanthal folds; broad neck; hypothyroidism; hearing loss; visual impairments; cardiac problems; gastro-intestinal; orthopedic, and skin disorders; obesity</td>
</tr>
<tr>
<td>Childhood</td>
<td>Oppositional and defiant; attention-deficit/hyperactivity disorder (ADHD); social, charming personality “stereotype”; self-talk</td>
</tr>
<tr>
<td>Adulthood</td>
<td>Depressive disorders; obsessive-compulsive disorder; other anxiety disorders; dementia of the Alzheimer’s type; mental disorders associated with hypothyroidism; atypical psychoses; self-talk</td>
</tr>
</tbody>
</table>

A Guide to Structure of the DM-ID-2

A guideline was developed to structure the diagnostic chapters

- allowing for clarity and uniformity.
- The diagnostic chapters in the DM-ID-2 generally follow this guideline.
- The primary elements of the guideline are listed on the following slides
A Guide to Structure of the DM-ID-2

• Chapter Summary

• Review of diagnostic criteria
  • General description of the disorder
  • Summary of DSM-5 criteria
  • Issues related to diagnosis in persons with ID
    • Development and course
    • Prevalence
    • Differential diagnosis
    • Functional consequences [if relevant]
    • Comorbidity

A Guide to Structure of the DM-ID-2

Application of diagnostic criteria to people with ID

• General considerations
• Methodology
• Review research applying to people with ID
• Adults with mild to moderate intellectual disability
• Adults with severe or profound intellectual disability
• Children and adolescents with intellectual disability
• Limitations in applying DSM-5 criteria to people with ID

(DM-ID-2, 2016)
A Guide to Structure of the DM-ID-2

- Etiology and Pathogenesis
  - Biological Factors
    - Genetic Factors
  - Psychosocial Factors
  - Developmental and Social Factors

- Application of criteria
  - Table of Applied Criteria

- References

The DM-ID-2 encompasses six (6) types of applications of the DSM-5 criteria. Unlike the DSM system, the DM-ID system does not rely on self-report. The DM-ID criteria subsets are principally concerned with observation of behaviors.

<table>
<thead>
<tr>
<th>DSM-5 Criteria</th>
<th>Applying Criteria for Mild and Moderate ID</th>
<th>Applying Criteria for Severe and Profound ID</th>
</tr>
</thead>
</table>

(DM-ID-2, 2016)
The Six (6) Applications 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 change 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

(DM-ID-2, 2016)
## Modification of DSM-5 Criteria
### Change in Count and Symptom Equivalent
#### Major Depressive Disorder

<table>
<thead>
<tr>
<th>DSM-5 Criteria</th>
<th>Applying Criteria for Mild to Profound IDD</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
<td>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.</td>
</tr>
</tbody>
</table>

(DM-ID-2, 2016)

## Modification of DSM-5 Criteria
### Symptom Change in Count
#### Manic Episode

<table>
<thead>
<tr>
<th>DSM-5 Criteria</th>
<th>Applying Criteria for Mild to Profound Intellectual Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>B. During the period of mood disturbance and increased energy or activity, three (or more) of the following symptoms (four if the mood is only irritable) are present to a significant degree and represent a noticeable change from usual behavior.</td>
<td>B. For individuals who have limited expressive language skills, during the period of mood disturbance, adjust criteria to two (or more) of the symptoms listed below if present to a significant degree – three if the mood is only irritable.</td>
</tr>
</tbody>
</table>

(DM-ID-2, 2016)
Modification of DSM-5 Criteria
Addition of Explanatory Note
Manic Episode

<table>
<thead>
<tr>
<th>DSM-5 Criteria</th>
<th>Applying Criteria for Mild to Profound Intellectual Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>B. 1 Inflated self-esteem or grandiosity</td>
<td>B. 1 No adaptations</td>
</tr>
<tr>
<td></td>
<td>Note 1: Observers may report that the individual with intellectual disability expresses: exaggerated claims of skills or accomplishments (based on developmental profile at baseline i.e., individual claims he has a car but does not, claims skills he doesn't have such as ability to drive, states he is the director of the hospital), exaggerates social events (I’m getting married” when not seeing anyone or not engaged), claims a relationship with a famous person,…</td>
</tr>
</tbody>
</table>

Modification of DSM-5 Criteria
Modification Symptom Duration
Adjustment Disorder

<table>
<thead>
<tr>
<th>DSM-5 Diagnostic Criteria</th>
<th>Applying Criteria for Mild to Moderate ID</th>
<th>Applying Criteria for Severe and Profound ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>E. Once the stressor or its consequences have terminated, the symptoms do not persist for more than an additional six (6) months.</td>
<td>E. An Adjustment Disorder must resolve within six (6) months of the termination of the stressor (or its consequences). However, the symptoms may persist for a prolonged period (i.e. longer than six (6) months) if they occur in response to a chronic stressor (cont.)</td>
<td>E. An Adjustment Disorder must resolve within six (6) months of the termination of the stressor (or its consequences). However, the symptoms may persist for a prolonged period (i.e. longer than six (6) months) if they occur in response to a chronic stressor (cont.)</td>
</tr>
</tbody>
</table>

(DM-ID-2, 2016)
## Modification of DSM-5 Criteria

### Antisocial Personality Disorder

<table>
<thead>
<tr>
<th>DSM-5 Criteria</th>
<th>Applying Criteria for Individuals with IDD</th>
</tr>
</thead>
<tbody>
<tr>
<td>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:</td>
<td>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:</td>
</tr>
<tr>
<td>B. The individual is at least age 18 years</td>
<td>B. The individual is at least age 21 years</td>
</tr>
<tr>
<td>C. There is evidence of Conduct Disorder with the onset before age 15 years</td>
<td>C. There is evidence of Conduct Disorder with onset before age 18 years</td>
</tr>
</tbody>
</table>

(DM-ID-2, 2016)

## Modification of DSM-5 Criteria

### Change in Behavior Equivalent and Symptom Count

### Panic Episode

<table>
<thead>
<tr>
<th>DSM-5 Diagnosis Criteria</th>
<th>Applying Criteria for Mild ID</th>
<th>Applying Criteria for Moderate ID</th>
<th>Applying Criteria for Severe to Profound ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Recurrent unexpected panic attacks. A panic attack is an abrupt surge of intense fear or intense discomfort that reaches a peak within minutes, and during which time four (or more) of the following symptoms occur:</td>
<td>A. No adaptation</td>
<td>A. A panic attack is an abrupt surge of intense fear or intense discomfort, which can be either observed or reported, that reaches a peak within minutes, and during which time 4 or more of the following symptoms occur (then adaptation as for panic attack)</td>
<td>A. A panic attack is an abrupt surge of intense fear or intense discomfort, which can be either observed or reported, that reaches a peak within minutes, and during which time 3 or more of the following symptoms occur (then adaptation as for panic attack)</td>
</tr>
<tr>
<td>Note: The abrupt surge can occur from a calm state or an anxious state</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>1. Palpitations, pounding heart, or accelerated heart rate</td>
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<td></td>
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<tr>
<td>2. Sweating</td>
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<tr>
<td>3. Trembling or shaking</td>
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<td></td>
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</tr>
<tr>
<td>4. Sensations of shortness of breath or smothering</td>
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<tr>
<td>5. Feelings of choking</td>
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<tr>
<td>6. Chest pain or discomfort</td>
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<td></td>
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<tr>
<td>7. Nausea or abdominal distress</td>
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</tr>
</tbody>
</table>

(DM-ID-2, 2016)
**Modification of DSM-5 Criteria**  
**Symptom Equivalent**  
**Reactive Attachment Disorder**

<table>
<thead>
<tr>
<th>DSM-5 Diagnostic Criteria</th>
<th>Applying Criteria for Mild to Moderate ID</th>
<th>Applying Criteria for Severe and Profound ID</th>
</tr>
</thead>
</table>
| A. A consistent pattern of inhibited, emotionally withdrawn behavior toward adult caregivers, manifested by both of the following: | A. Markedly inhibited, emotionally withdrawn behavior toward adult caregivers, manifested by both of the following when compared to children of similar measured intelligence or adaptive skills: | A. Same as criteria for Mild ID.  
**Note:** Attachment behaviors in children with sensory impairments should be compared with those children with similar disabilities. |
| 1. The child rarely or minimally seek comfort when distressed. | 1. The child rarely or minimally seeks comfort when distressed in a developmentally appropriate fashion including agitated, impaired or aggressive behavior with distress. | 1. Same as criteria for Mild ID. |
| 2. The child rarely or minimally responds to comfort when distressed. | 2. The child rarely or minimally responds to comfort when distressed including refusing comforting or becoming agitated, aggressive or destructive with comforting in a maladaptive way. | 2. Same as adaptations for Mild ID. |

*(DM-ID-2, 2016)*
Modification of DSM-5 Criteria
Symptom Equivalent and Explanatory Note
Posttraumatic Stress Disorder

<table>
<thead>
<tr>
<th>DSM-5 Diagnos tic Criteria</th>
<th>Applying Criteria for Mild to Moderate ID</th>
<th>Applying Criteria for Severe and Profound ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>Note: the following criteria apply to adults, adolescence and children older than 6 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A. Exposure to actual or threatened death, serious injury or sexual violation in one (or more) of the following ways</td>
<td>A. The person has been exposed to a traumatic event they have experienced as being traumatic. This can include exposure to actual or threatened death, serious injury or sexual violation in 1 (or more) of the following ways, but may also be activated by less serious conditions. (See note below)</td>
<td>A. The person has been exposed in a traumatic event they have experienced as being traumatic. This can include exposure to actual or threatened death, serious injury or sexual violation in one (ore more) of the following ways, but may also be activated by less serious events. (See Note for Mild-Moderate ID)</td>
</tr>
<tr>
<td>(DM-ID-2, 2016)</td>
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</tbody>
</table>

Modification of DSM-5 Criteria
Explanatory Note
Posttraumatic Stress Disorder

<table>
<thead>
<tr>
<th>DSM-5 Diagnostic Criteria</th>
<th>Applying Criteria for Mild to Moderate ID</th>
<th>Applying Criteria for Severe and Profound ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Directly experiencing the traumatic event(s) .</td>
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<td></td>
</tr>
<tr>
<td>2. Witnessing in person the event(s) as it occurred to others.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Learning that the traumatic event(s) occurred to a close family member or friend, the event(s) must have been violent or accidental</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Experiencing repeated or extreme exposure to aversive details of the traumatic event(s) (e.g., first responders, collecting human remains, police officers repeatedly exposed to details of child abuse).</td>
<td>No adaptation as to the 4 criteria, but the threshold is often lowered for vulnerability and consequent activation of these conditions. In assessing for traumatic exposure in people with ID, take note that events such as developmental milestones, residential placement, and even adult consensual sexual experiences and ending of romantic relationships have led to posttraumatic reactions in some individuals with ID. It appears that the range of potentially traumatizing events is greater for individuals with a lower developmental age, though no hard data is available that would merit clear-cut distinctions for criteria between Mild-Moderate ID and Severe/Profound ID What composes a traumatic reaction is determined by how the event was interpreted by the individual. Typically the lower the developmental age, the lower the threshold for what qualifies as traumatic.</td>
<td>1-4 Read sections under Modified Criteria for Mild/Moderate ID.</td>
</tr>
<tr>
<td>(DM-ID-2, 2016)</td>
<td></td>
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</tr>
</tbody>
</table>
Modification of DSM-5 Criteria
Addition of Explanatory Note
Schizophrenia

<table>
<thead>
<tr>
<th>DSM-5 Diagnostic Criteria</th>
<th>Applying Criteria for Mild to Moderate ID</th>
<th>Applying Criteria for Severe and Profound ID</th>
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</table>

Please note: A significant change in behavior (for example, increased aggressive, self-injurious, or bizarre behavior) should alert the clinician to the possibility of a psychotic process. Assessment of this criteria might be especially difficult individuals with severe or profound ID.

A. Two or more of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated). At least one of these must be (1), (2), or (3).

1) Delusions
2) Hallucinations
3) Disorganized speech (e.g., frequent derailment or incoherence)
4) Grossly disorganized or catatonic behavior
5) Negative symptoms (i.e., diminished emotional expression or avolition)

A. No adaptation

Note: there may be self-talk, which is common and not necessarily interpreted as an expression of psychotic disorder.

Limitations and Cross-referencing

The American Psychiatric Association, publisher of the DSM-5, only allows for the reproduction of approximately 50% of criteria subsets. Therefore, the DM-ID-2 was restricted with regards to the number and extent of DSM-5 articulated diagnostic subsets. Thus we had to be selective with which criteria we chose to include in the DM-ID-2. We chose to exclude some criteria on the basis of their extreme similarity with another criteria set; in this case we comment at the bottom of the tables to this effect. Other criteria sets were omitted on the basis of rarity. Throughout several of the DSM-5 chapters, criteria are repeated for the specific mental disorders in question being due to another medical condition, and also for the specific mental disorder in question being induced by a substance/medication. Hence, rather than repeating the full criteria sets in several chapters, we provide them here, and cross-refer the specific chapter to these two tables where they apply.
### DSM-5 Criteria for Mental Disorder Due to Another Medical Condition

<table>
<thead>
<tr>
<th>DSM-5 Criteria</th>
<th>Applying Criteria for Mild and Moderate ID</th>
<th>Applying Criteria for Severe and Profound ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Symptoms/signs as reported in the relevant chapter.</td>
<td>A. Adaptations as reported in the relevant chapter.</td>
<td>A. Adaptations as reported in the relevant chapter.</td>
</tr>
<tr>
<td>B. There is evidence from the history, physical examination, or laboratory findings that the disturbance is the direct physiological consequence of a general medical condition.</td>
<td>B. No adaptation.</td>
<td>B. No adaptation.</td>
</tr>
<tr>
<td>C. The disturbance is not better explained by another mental disorder.</td>
<td>C. No adaptation.</td>
<td>C. No adaptation.</td>
</tr>
<tr>
<td>D. The disturbance does not occur exclusively during the course of a delirium.</td>
<td>D. No adaptation.</td>
<td>D. No adaptation.</td>
</tr>
<tr>
<td>E. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.</td>
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(DM-ID-2, 2016)

### DSM-5 Criteria for Substance/Medication-Induced Mental Disorder

<table>
<thead>
<tr>
<th>DSM-5 Criteria</th>
<th>Applying Criteria for Mild &amp; Moderate ID</th>
<th>Applying Criteria for Severe &amp; Profound ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Symptoms/signs as reported in the relevant chapter.</td>
<td>A. Adaptations as reported in the relevant chapter.</td>
<td>A. Adaptations as reported in the relevant chapter.</td>
</tr>
</tbody>
</table>
| B. There is evidence from the history, physical examination, or laboratory findings of:  
  1. the symptoms in Criterion A developed during, or soon after substance intoxication or withdrawal or after exposure to a medication.  
  2. The involved substance/medication is capable of producing the symptoms in Criterion A. | B. No adaptation.                          | B. No adaptation.                          |
| C. The disturbance is not better explained by a mental disorder that is not substance/medication induced. Such evidence of an independent mental disorder could include the following:  
  The symptoms preceded the onset of the substance/medication use; the symptoms persist for a substantial amount of time (e.g., about 1 month) after the cessation of acute withdrawal or severe intoxication; or there is other evidence of an independent non-substance/medication-induced mental disorder (e.g. history of recurrent non-substance/medication-related episodes). | C. No adaptation.                          | C. No adaptation.                          |
| D. The disturbance does not occur exclusively during the course of a delirium. | D. No adaptation.                          | D. No adaptation.                          |
| E. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning. |                                            |                                            |

(DM-ID-2, 2016)
Summary

- Review of the limitations of existing diagnostic systems
- Assessment practices
- Relevance of behavioral phenotypes
- The structure of the DM-ID-2
- Six (6) modifications to the DSM-5 and how they apply to the DM-ID-2

THANK YOU!

For information

Dr. Robert Fletcher
NADD
rfletcher@thenadd.org
www.thenadd.org
845-331-4336