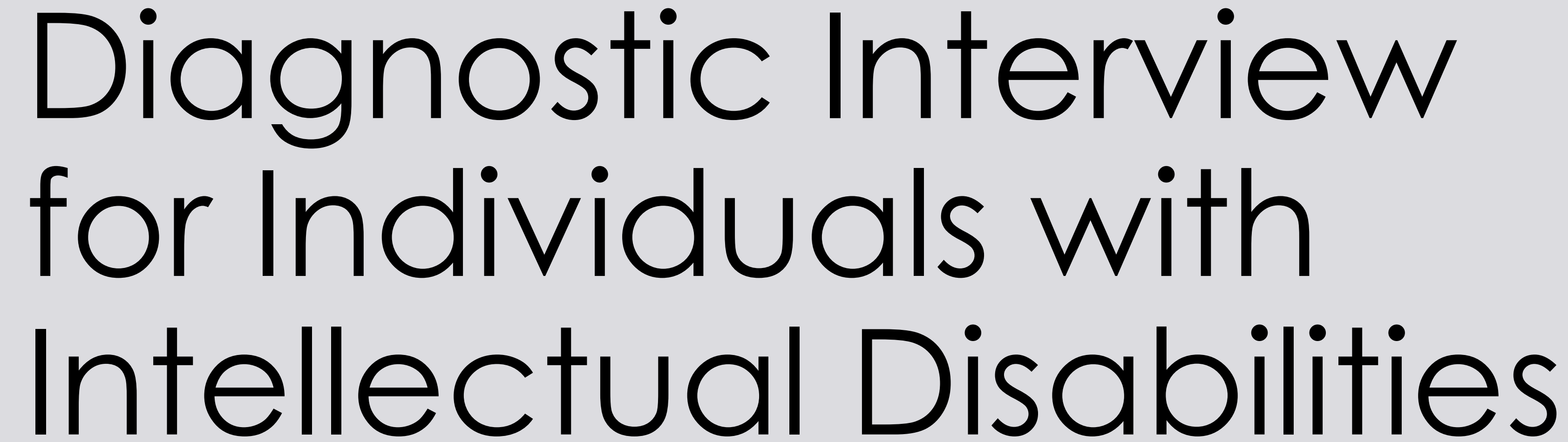

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Study Personnel & Acknowledgements

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- SRI International
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National Institute of Mental Health

Agenda

- Mental health
- Mental health and disability
- Assessment problems
- Current study and design considerations
- Study process and examples
- Considerations for practitioners

The Need:

- Approximately 20 percent of youth will experience some form of threat to their mental health at any given time prior to adulthood (Merikangas et al., 2010).
- Prevalence rates for common mental health disorders (i.e., depression and anxiety) begin to increase as youth age into early adolescence (Einfeld, Ellis, & Emerson, 2011; Merikangas et al., 2010).
- For youth with disabilities, specifically youth with intellectual disabilities, prevalence rates of mental health disorders can be two to three times higher when compared to peers who don't experience an intellectual disability (National Core Indicators, 2016).

Dual Diagnosis

- Typically has been used for individuals who experience both mental illness and substance abuse problems.

- The term dual diagnosis has expanded to include a person with an intellectual disability and a psychiatric disorder (McGilvery & Sweetland, 2011)

The need:

- Despite widespread agreement of the occurrence of mental disorders in people with intellectual disabilities(ID), the epidemiology of psychopathology is poorly understood within this population.
- The fields of medicine and education have given increasing attention to the co-occurrence of ID and mental disorders in recent years (Underwood, McCarthy, & Tsakanikos, 2010).

Prevalence:

- The limited available evidence suggests that individuals with ID may experience psychiatric disorders at higher rates and are more vulnerable to mental illness than individuals without ID (Cooper & van der Speck, 2009; Janssen & Maes, 2013; Tsiouris, 2001)
- However, prevalence rates of psychopathology found in persons with ID have varied widely, with estimates ranging from 10 to 60% (Einfeld, Ellis, & Emerson, 2011; Koskentausta, Iivanainen, & Almqvist, 2002).
- Researchers have begun to examine why differential prevalence rates may impact the population with ID. Findings across multiple studies that examined different risk factors (e.g., socioeconomic status, gender, and severity of ID) were ultimately inconclusive (Austin, Hunter, Gallagher, & Campbell, 2018; Einfeld et al., 2011).

Assessment Problems

- Diagnostic overshadowing
  - The tendency to attribute many of the possible symptoms of a psychiatric disorder to the ID (Janssen & Maes, 2013).
  - Example: a youth communicating being upset by acting out could initially be thought of as part behavioral challenges the youth experiences versus a symptom of a psychiatric disorder.

Assessment Problems

- Persons with ID are also known to present atypical mental health symptoms not commonly found in individuals without ID (McGilvery & Sweetland, 2011; Smiley & Cooper, 2003).
  - Example: A youth with an intellectual disability may not express depression through increased sleep or low energy, but may be expressed through anger, agitation, and destructive behaviors.

Assessment Problems

- Limited life experience, or limited control of daily activities may prohibit the expression of behaviors commonly seen in psychiatric disorders.
  - Example: A youth that has no control over their financial situation may not be able to spend money in a state of mania, commonly observed in individuals who have been diagnosed with bi-polar.

Assessment Problems

- Researchers have frequently expressed concerns about the reliability and validity of assessment instruments designed for persons with ID (e.g., Cooper & van der Speck, 2009; Janssen & Maes, 2013; Underwood et al., 2010).
- Example: Acquiescence Bias
  - Individuals with ID are more likely to report “yes” in “Yes/No” questions no matter the content of the question.

Alexithymia

- Defined: Alexithymia is a subclinical phenomenon involving a lack of emotional awareness or, more specifically, difficulty in identifying and describing feelings and in distinguishing feelings from the bodily sensations of emotional arousal (Nemiah et al., 1976).
- The severity of ID can also make it difficult to obtain an accurate diagnosis, as an individual's present level of functioning and communication skills can hinder the ability to explain thoughts, emotions, behaviors, and physical sensations (Janssen & Maes, 2013).

Current Study

- Develop and validate a comprehensive diagnostic interview schedule for persons with ID in order to address the limitations of the current practices and to advance epidemiological research with this population.
- Where did we start?
  - The Diagnostic Interview Schedule for Children (DISC)
    - Problem 1: Potential issues with response formatting due to a limited range of validated response
    - Problem 2: Does not account for differential behavioral representations that may be portrayed in individuals with ID

Design Considerations

- Evidence-Centered Design
    - Supported by US Department of Education as best[practice for assessment design.
    - Primary focus is content validity
- Universal Design for Learning
    - Supported learning for all individuals to access the content being delivered in the interview

Innovation

Assessment Concern		Our Solution
Yes/No	→	Multiple options & either or
Complex wording	→	4th grade level lexical changes
No scaffolded supports	→	Visual supports provided
Clinical diagnosis with DSM-5	→	Clinical diagnosis with DSM-5 & DM-ID 2
Individual reporter	→	Dual informant with youth and caregiver

Our Process

- Phase 1: Item Try Out
- Phase 2: Pilot
- Phase 3: Field Testing

Phase 1 - Item Tryout

- Phase 1 of research focused on an iterative development process with youth who experience intellectual disabilities and their caregivers to provide feedback on the item format and visual supports

Item Tryout Example:

- “**Look at these pictures.”** *Administrator points to each picture.* **“Now, which picture shows someone who has trouble keeping their mind on one thing**.”

A

B

C

Phase 2 – Pilot Study

- Test with youth with intellectual disabilities and their caregivers Mood Disorder and Anxiety modules.
- Keep track of:
  - Administrative issues
  - Youth and Caregiver concerns
  - Ensure all diagnostic criteria are considered
- Make changes accordingly

Interview Development Example: Major Depressive Disorder

- 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

1. Depressed mood most of the day, nearly every day
2. Markedly diminished interest or pleasure in activities
3. Significant weight loss or weight gain
4. Insomnia or hypersomnia
5. Psychomotor agitation or retardation nearly every day
6. Fatigue or loss of energy
7. Feelings of worthlessness or guilt
8. Diminished ability to concentrate
9. Recurrent thoughts of death

DSM-5 Criteria for MDD

Interview Development Example: Major Depressive Disorder

DSM-5

- 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

DM-ID 2

- 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, (2) loss of interest or pleasure, or (3) irritable mood.

No adaptations are required for symptom level behaviors, frequency, duration, or intensity

Phase 3 – Field Testing

Corresponding Disorder	Qualtrics Disorder Codes
Module 1 – Mood Disorders	
Major Depressive Disorder	MDD (Y & C)
Persistent Depressive Disorder (Dysthymia)	DYS (Y & C)
Mania-Hypomania	MANH (Y & C)
Disruptive Mood Dysregulation Disorder	DMDD (Y & C)
Module 2 – Psychotic Disorder	
Schizophrenia	SCHIZ (Y & C)
Module 3 – Anxiety, including Obsessive Compulsive Disorder	
Separation Anxiety Disorder	SEP (Y & C)
Specific Phobia	SPEC (Y & C)
Social Phobia	SOC (Y & C)
Panic Disorder	PAN (Y & C)
Agoraphobia	AGOR (Y & C)
Generalized Anxiety Disorder	GAD (Y & C)
Obsessive-Compulsive Disorder	OCD (Y & C)
Trichotillomania	TRICH (C)
Module 4 – Elimination Disorders	
ELIM	Elimination Disorders (C)

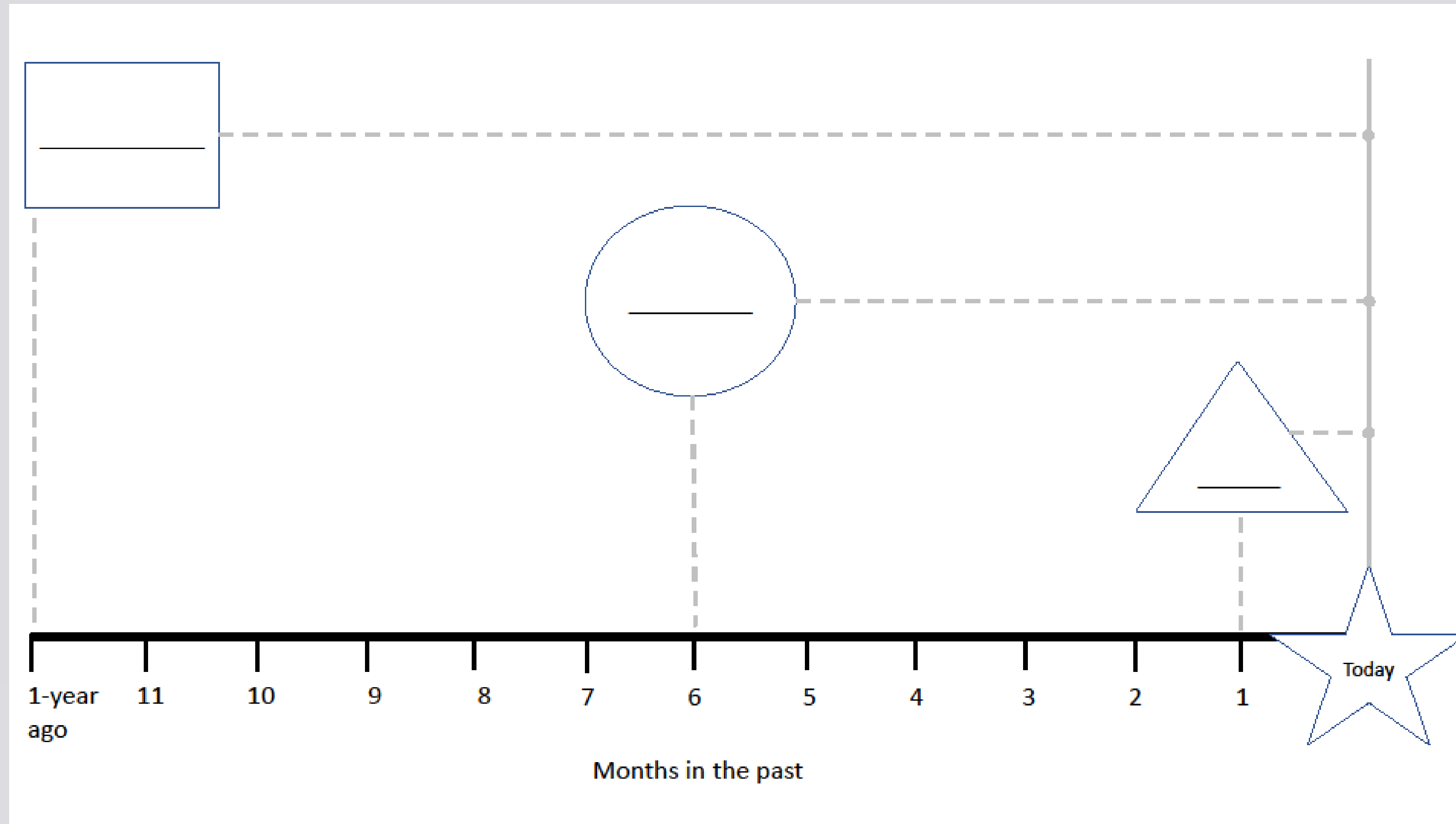
Phase 3 – Field Testing

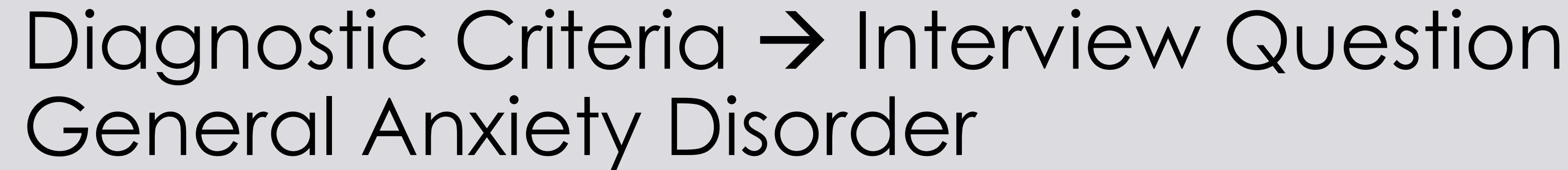
Corresponding Disorder	Qualtrics Disorder Codes
Module 5 – Feeding and Eating Disorders	
Eating Disorders (Binge Eating, Bulimia, Anorexia)	EAT (Y & C)
Pica	PICA (C)
Module 6 –Substance Use Disorders	
Alcohol Use Disorder	ALC (Y & C)
Substance Use Disorder	SUB (Y & C)
Module 7 – Neurodevelopmental Disorders	
Attention-Deficit/Hyperactivity Disorder	ADHD (C)
Autism Spectrum Disorder	ASD (C)
Stereotyped Movement Disorder	SMD (C)
Tic Disorders	TIC (C)
Module 8 – Disruptive Impulse Control Disorders	
Oppositional Defiant Disorder	ODD (C)
Conduct Disorder	CD (C)
Module 9 – Trauma and Stressor-Related Disorder	
PTSD	Posttraumatic Stress Disorder (C)

Phase 3 – Field Testing Supports

Addition Support	When to Utilize Support	Wording Examples
Repeat the item question	Repeat the entire question if the youth seems confused or was not engaged in the interview to fully comprehend the question being asked.	
Repeat the response options	Repeat specific response options if the youth seems confused by the different choices available to answer an interview question.	'Are you very worried about [FEAR(S)] or are you okay?' OR 'This person is very worried. This person is okay.'
Emphasizing differences in response options	Emphasize the differences between response options if the youth is having difficulty differentiating between two or three answers.	'Were you sad a lot of the time or only a little of the time?' 'This calendar shows a lot of the time because it has Xs many days (point to Xs). This calendar shows a little of the time because it has Xs on only a few days (point to Xs'
Repeat calendar descriptions	Repeat calendar descriptions if the youth is having difficulty choosing between two or three answers.	'Someone put Xs on the days he felt sad. This calendar shows he felt sad a lot of the time. This calendar shows he felt sad only a little of the time'
Repeat closest event details as a time frame reminder	Remind and show the youth about the specific event they identified in the timeline interview and the timeframe, if they become confused by questions that include a time frame.	'Since [your birthday 1 year ago] when you had chocolate cake and a big party with all your friends'

Timeline Interview





Diagnostic Criteria → Interview Question General Anxiety Disorder

Diagnostic Criteria

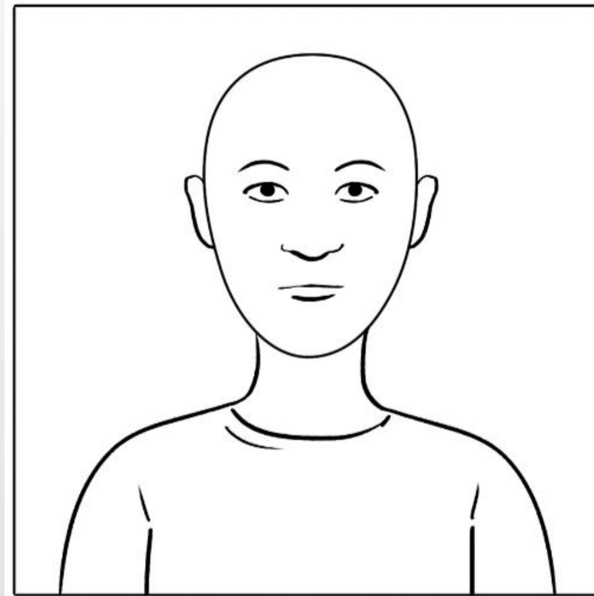
- Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least 6 months, about a number of events or activities (such as work or school performance)

Interview Question

- This person is feeling worried about many different things (*point to illustration*) He is worried about taking a test, playing a game, making small mistakes or about being sick.
- This person is okay. He has very few worries.
- Do you feel worried about many different things OR are you okay?

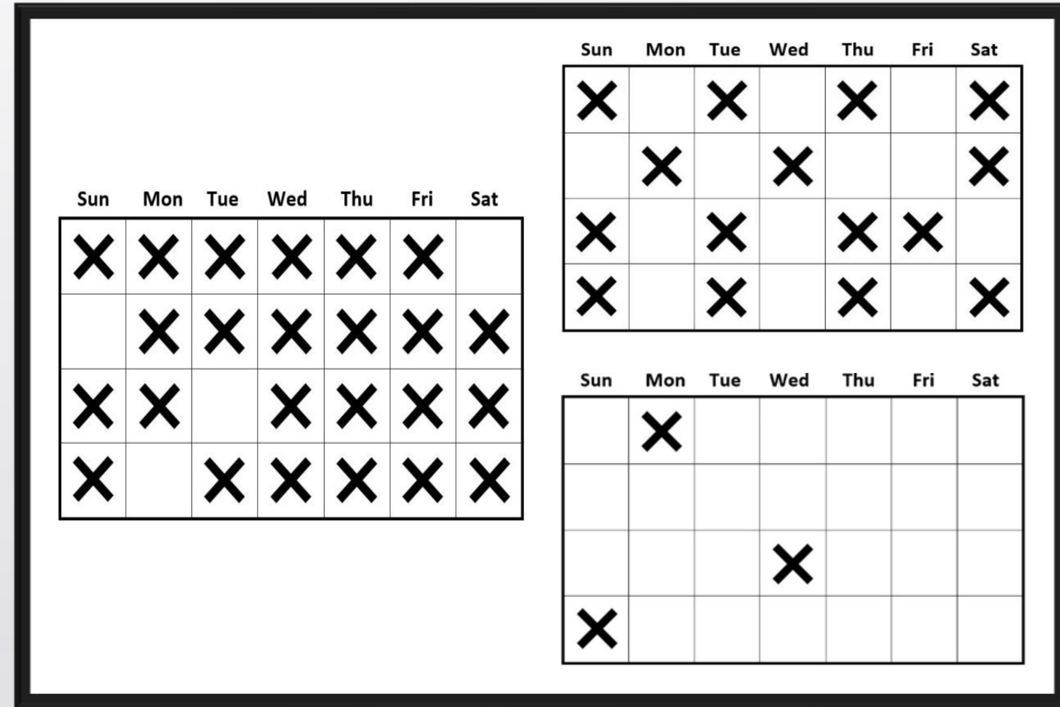
Visual Supports – Acquiescence Bias

- *"This person is really sad. This person is okay. Point to or tell me which picture is most like you?"*



Visual Supports - Frequency

- *" Look at these calendars. Someone put an X on the days when he was sad. This person was sad almost everyday, this person was sad more than half the days and this person was sad only a few days. Since Christmas one month ago today, how often were you sad?" Almost everyday? More than half of the days? Or only a few days?"*



Visual Supports - Duration

- *"This daily schedule shows that someone was sad for most of the day. This schedule shows that someone was sad for only a little of the day. Since Christmas one month ago today were you sad most of the day or only a little of the day?"*

Time	Mood
6 am	
7 am	
8 am	
9 am	
10 am	
11 am	
12 pm	
1 pm	
2 pm	
3 pm	
4 pm	
5 pm	
6 pm	
7 pm	
8 pm	
9 pm	

Time	Mood
6 am	
7 am	
8 am	
9 am	
10 am	
11 am	
12 pm	
1 pm	
2 pm	
3 pm	
4 pm	
5 pm	
6 pm	
7 pm	
8 pm	
9 pm	

Caregiver and Youth Parallel Items

Caregiver

- Was there ever a time when [YOUTH] said [he/she] was sad or when you noticed that [he/she] appeared sad, blue, or tearful for several days in a row?

Youth

- Do you feel sad a lot of the time *(point to illustration)* OR do you feel sad only a little of the time *(point to illustration)*?

Caregiver and Youth Parallel Items

Caregiver

- During that/those times when [YOUTH] lost interest in [review favorite activities from timeline interview], how long did it/they usually last?

Youth

- Since [1-MONTH/6-MONTH EVENT/1-YEAR EVENT] did you think [YOUTH's favorite activities] were not very fun almost every day for two weeks in a row *(point to illustration),* more than half the days for two weeks in a row *(point to illustration)* OR for only a few days for two weeks in a row *(point to illustration)*?

Considerations for Practitioners

Considerations for Practitioners:

- When working with youth with intellectual disabilities who have expressive language difficulties:
  1. Be a good listener
  2. Summarize the message you heard to ensure accuracy
  3. Be patient and provide time for expression of concerns or feelings
  4. Don’t answer before the individual is finished to ensure you capture the individuals full thoughts
  5. Focus on feelings
  6. Acknowledge any accompanying behaviors as well as verbal expression

(McGilvery & Sweetland, 2011)

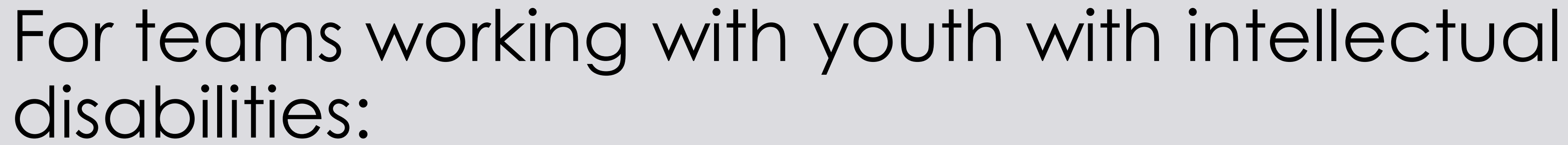
Depression

Typical Presentation	Presentation Common for Persons with Intellectual Disabilities
Sad mood	Agitated or irritable mood
Low energy and motivation	High energy exhibited with anger and agitation
Poor concentration	Poor concentration and low frustration tolerance
Change in eating habits, eating less or more	Change in eating habits, eating less or more
Change in sleeping habits, sleeping less or more	Change in sleeping habits, with sleeping less more typical than sleeping more
Loss of pleasure in activities	Loss of pleasure in activities
Thoughts of harming self	Actions that harm self, expressed wish to be dead

(McGilvery & Sweetland, 2011)

Anxiety

- Favilla & Mucci (2000) found similar characteristics for the diagnosis of general anxiety disorder for individuals with and without intellectual disabilities.
  - Individuals with ID
    - Maybe restless, pace or have difficulty sitting still.
    - May repeat the same concern over and over because they are excessively worrying
    - May have somatic complaints and issues with sleep

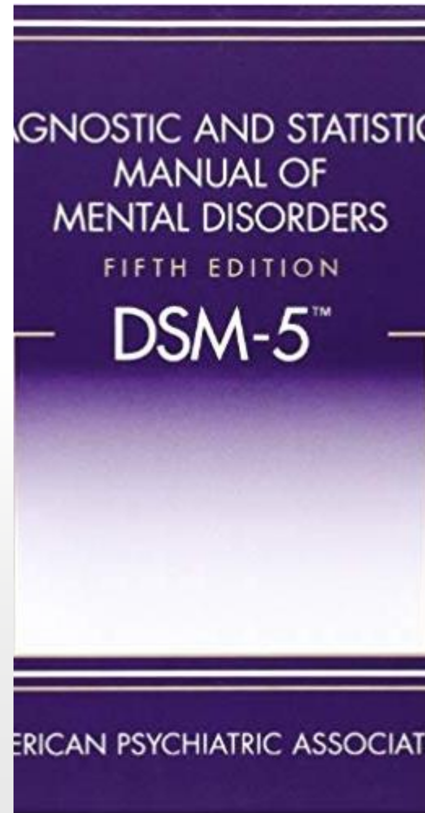


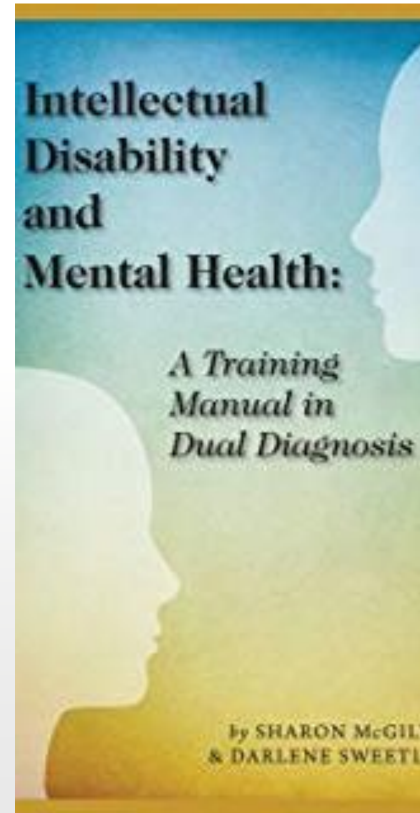
For teams working with youth with intellectual disabilities:

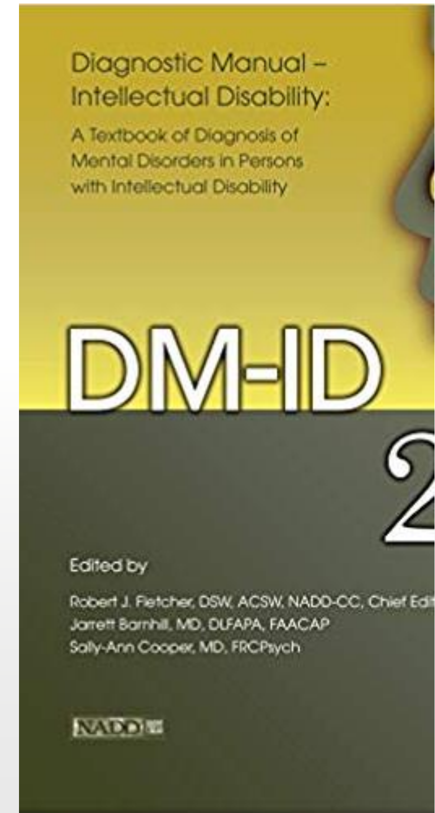
1. Discuss as a team **ALL OF THE POSSIBLE REASONS** for the person's challenges. Make sure that medical and psychological supports are used to rule in, rule out, or defer each possible reason.
2. Consider the person's **developmental level** and goals and achievements appropriate to that person's developmental needs.
3. Consider the person's **emotional development** and how the person's experiences and history may impact current relationships and awareness of how the individual's interactions are impacting others
4. Make sure **accommodations** are made to reduce the emphasis on using cognitive processes that are inherently difficult.

(McGilvery & Sweetland, 2011)

Additional Resources







Questions or Additional Information

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