



# **Diagnostic Interview for Adolescents and Adults with Intellectual Disability (DIAAID):**

## **An Interview Schedule of Mental Health Disorders**

**National Institutes of Health, National Institute of Mental  
Health (R01 MH108869-01)**

## Study Personnel & Acknowledgements

- Nisonger Center, The Ohio State University
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- SRI International
  - Christopher Sanford, PhD – PI
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- Key Personnel
  - Cori O’Boyle
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# Mental Health Disorders in the General Population

- Prevalence rates of common mental health disorders (i.e., depression and anxiety) begin to increase in early adolescence (Einfeld, Ellis, & Emerson, 2011; Merikangas et al., 2010).
- Approximately 20 percent of youth experience a mental health problem prior to adulthood (Merikangas et al., 2010).

## Prevalence of Mental Health Disorders Among Individuals with ID

- Prevalence rates of mental disorders for youths with ID can be two to three times higher than for typically developing youths (National Core Indicators, 2016).
- Prevalence rates in persons with ID vary widely, estimates range from 10 to 60% (Einfeld, Ellis, & Emerson, 2011; Koskentausta, Iivanainen, & Almqvist, 2002).



## Issues with Using Existing Methods of Diagnosing Mental Disorders with Individuals with ID

- Self reporting is fraught with bias (e.g., acquiescence and social desirability)
- Items include complex terminology and concepts related to the diagnostic criteria (e.g., hallucinations)
- Proxy reports are good for collecting observational data; however, the validity of it is suspect as it is subjective in nature
- Proxy reports alone do not consider the youth's perspective

# Purpose of Assessment Development Study

- Develop a valid and reliable diagnostic interview specifically designed for assessing mental health disorders in adolescents with mild to moderate ID, ages 14 – 24

# Innovation

## Assessment Concern

## Our Solution

Yes/No



Multiple options & either/or

Complex wording



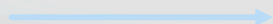
4<sup>th</sup> grade level lexical changes

No scaffolded supports



Visual supports, definitions, and reminders provided

Clinical diagnosis with DSM-5



Clinical diagnosis with DSM-5 & DM-ID 2

Individual reporter



Dual informants with youth and caregiver

# DIAAID Early Development Stages

- Developed a template of example items and response options with visual supports using the major depressive disorder diagnostic criteria
- Conducted item tryouts with a small group of participants to see if we were on the right track (re: wording of the items and use of visual supports)
- Conducted pilot testing to examine:
  - the lexical adaptations of the symptom probes and their cognitive accessibility
  - the response option formats for neutralizing acquiescence bias
  - the time frame and timeline follow-back procedures for assessing past episodes

## DIAAID Current Development Stage

- Conduct a field test of 400 youth/caregiver dyads
  - The caregiver may be a parent, guardian, grandparent, or other primary adult caregiver who has known the youth for at least one year
  - Adolescent and caregiver participants are interviewed separately
    - If an adolescent needs a caregiver in the room during the interview, we ask for the caregiver to sit behind the adolescent and refrain from participating unless helping with a technology issue or reengaging the adolescent.

## DIAAID Current Development Stage

- The assessment covers 25 disorders
  - Adolescents with ID: 15
  - Caregivers: All 25
- Due to issues with administration time:
  - Used screening items at the beginning of each disorder
  - Identified disorders with diagnostic criteria that were primarily externalizing behaviors (marked with a “C” only in the next two slides)

# Organization of the Disorders

Corresponding Disorder	Qualtrics Disorder Codes
<b>Module 1 – Mood Disorders</b>	
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)
<b>Module 2 – Psychotic Disorder</b>	
Schizophrenia	SCHIZ (Y & C)
<b>Module 3 – Anxiety, including Obsessive Compulsive Disorder</b>	
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)
<b>Module 4 – Elimination Disorders</b>	
Elimination Disorders	ELIM (C)

# Organization of the Disorders

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



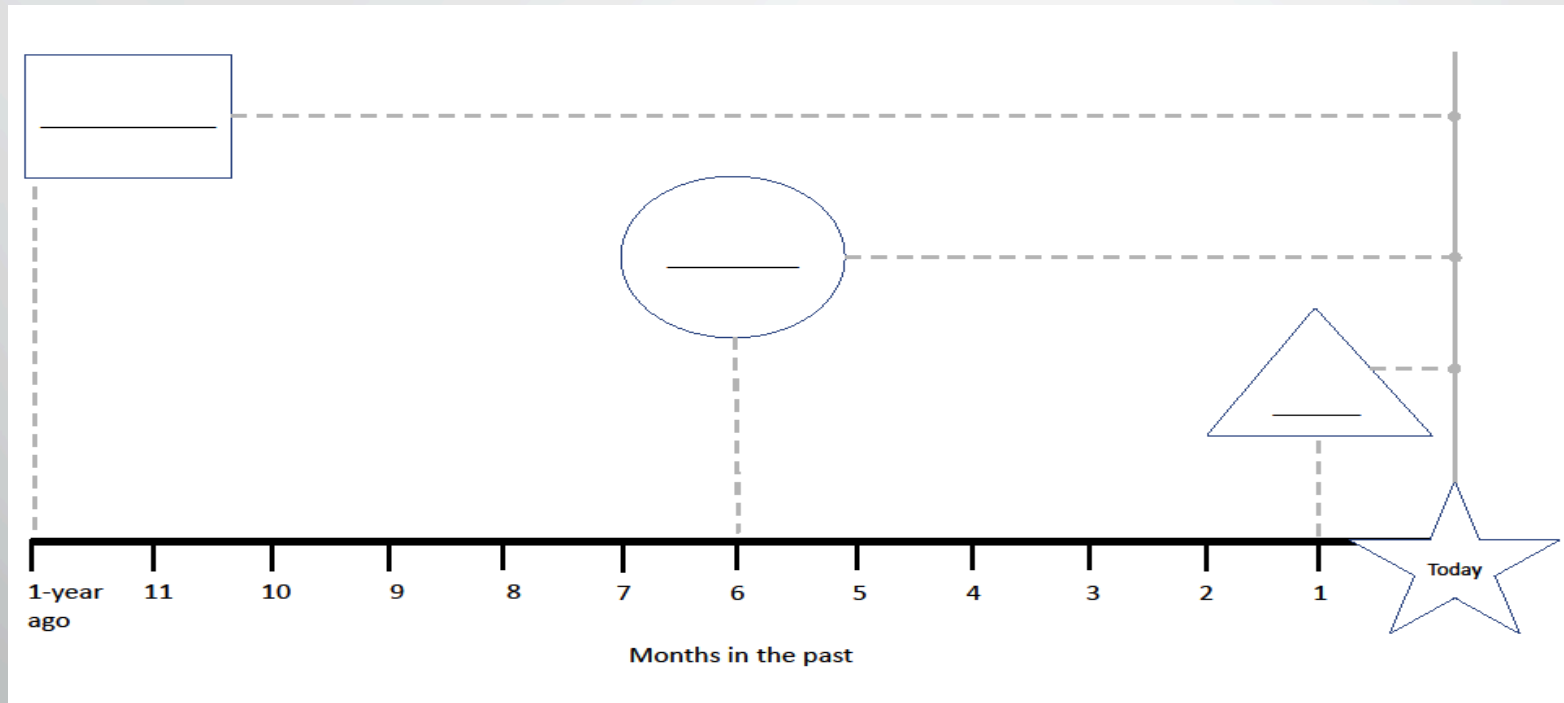
## Field Test Steps: Eligibility

- Interested participants contact us via phone/email
- Determine initial eligibility
  - Adolescent is within the age range
  - Has been diagnosed with Intellectual Disability (e.g., IQ scores, IEP, or caregiver report)
  - Confirm that youth can verbally respond to questions (remote interviews, only)
  - Has a computer with internet access (remote interviews, only)
- Send link to online consent forms and the final screening assessment form (i.e., Caregiver completes the Adaptive Behavior Assessment System, ABAS)

## Field Test Steps: Conduct Interview

- Schedule an interview
- Day of interview: Timeline
- Day of interview: Disorder administration
  - Each participant is interviewed separately
- Types of items
  - Screening items
  - Frequency
  - Intensity/duration
  - Presence

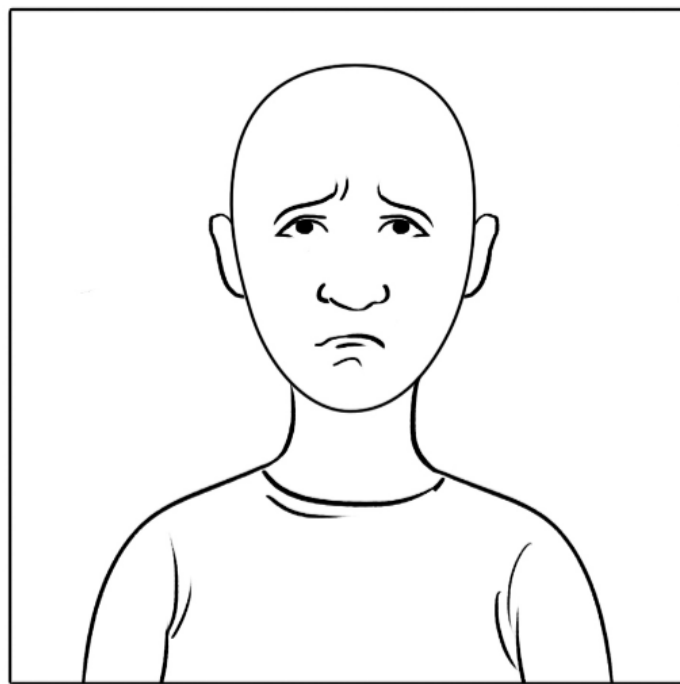
# Timeline



## Timeline Interview

- Adolescent is asked to come up with an event for three different time periods (1-month, 6-months, and 1-year)
- Try to use events identified by the youth
  - Caregiver may assist if the adolescent is unable to remember events on their own
- Use visual representations of events, when possible
- Once events are placed on timeline (using visual supports or words), the adolescent is asked to point to each event on the timeline, in turn.

## Administration Example: Sad (screener)



Administrator says: This person feels sad. Everyone feels sad sometimes.

## Administration Example: Sad (screener)

Sun	Mon	Tue	Wed	Thu	Fri	Sat
X	X	X	X	X	X	
	X	X	X	X	X	X
X	X		X	X	X	X
X		X	X	X	X	X

A

Sun	Mon	Tue	Wed	Thu	Fri	Sat
	X					
			X			
X						

B

Administrator says: Look at these calendars. Someone put Xs on the days he felt sad. This calendar shows that he felt sad a lot of the time (*point to illustration A*). This calendar shows that another person felt sad only a little of the time (*point to illustration B*).

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

Point to or tell me which picture is most like you.

## Administration Example: Sad (frequency)

Sun	Mon	Tue	Wed	Thu	Fri	Sat
X	X		X	X		X
X	X	X	X	X		X
	X	X	X	X		X
		X	X	X		X

A

Sun	Mon	Tue	Wed	Thu	Fri	Sat
X		X			X	X
	X			X		X
X		X	X		X	
X		X			X	

B

Sun	Mon	Tue	Wed	Thu	Fri	Sat
X						
				X		
X						
					X	

C

Administrator says: Look at these calendars. Someone put Xs on the days he felt sad. This calendar shows that he felt sad almost every day for two weeks in a row (*point to illustration A*). This calendar shows that another person felt sad more than half the days for two weeks in a row (*point to illustration B*). This picture shows that another person felt sad only a few days for two weeks in a row (*point to illustration C*).

Since [1-MONTH/6-MONTH EVENT/1-YEAR EVENT], when you were sad, were you sad almost every day for two weeks in a row (*point to illustration A*), were you sad more than half the days for two weeks in a row (*point to illustration B*) or were you sad for only a few days for two weeks in a row (*point to illustration C*)?

## Administration Example: Sad (intensity)

Time	
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	✓

A

Time	
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	

B

Administrator says: Look at these daily schedules. Someone put check marks on the times during the day when he felt sad. This schedule shows that he felt sad most of the day (*point to illustration A*). This schedule shows that another person felt sad for only a little of the day (*point to illustration B*).

Since [1-MONTH/6-MONTH EVENT/1-YEAR EVENT], were you sad most of the day (*point to illustration A*) OR were you sad for only a little of the day (*point to illustration B*)?



## Caregiver and Youth Parallel Screening Items

Youth	Caregiver
Do you feel sad <u>a lot</u> of the time ( <i>point to illustration</i> ) OR do you feel sad <u>only a little</u> of the time ( <i>point to illustration</i> )?	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?

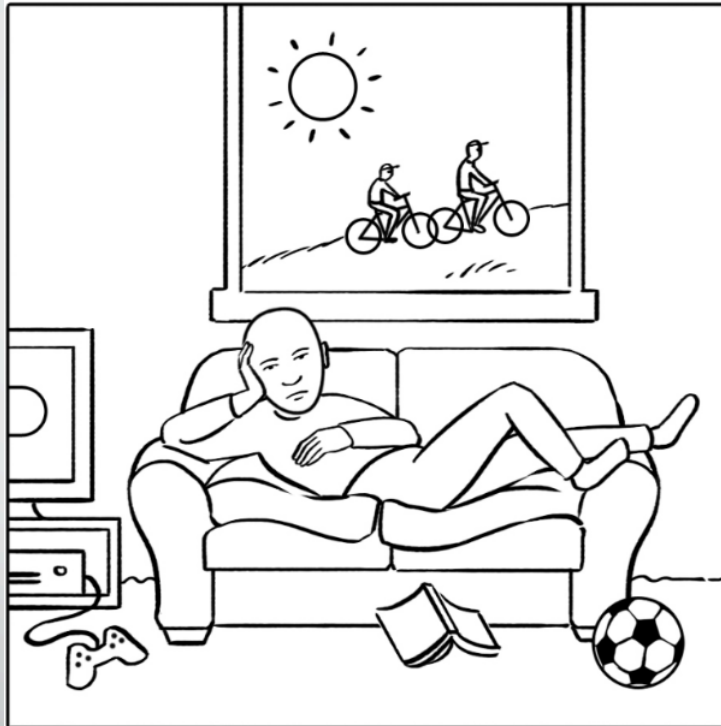
## Example of Varying Supports: Major Depressive Disorder (Core Symptoms)

Symptom (diagnostic criteria)	Embedded Support (based on tryout and pilot test data)
Sad (depressed mood)	This person feels sad ( <i>point to illustration</i> ). Everyone feels sad sometimes.
Grouchy (irritable)	This person feels grouchy ( <i>point to illustration</i> ). Everyone feels grouchy sometimes.
Favorite activities are not very fun (markedly diminished interest or pleasure)	Sometimes people think their favorite activities are not very fun ( <i>point to illustration</i> ). This person usually likes playing video games, riding his bike and being outside. Now he doesn't want to do any of those things.

Grouchy



Favorite activities are not very fun



# COVID-19 Remote Interviewing

Pros	Cons
Continue collecting data during pandemic	Difficult to build rapport
Interviewer and interviewees do not need to leave home (e.g., easier to schedule time, no traffic concerns)	Study participants may not have necessary tech and or there may be connection issues that occur
Participants earn stipends while at home	More difficult to conduct both interviews in one day (e.g., equipment shortage)

## Field Test Reminders

- Currently enrolling
- Participants ages 14 to 24 with Intellectual Disability and their caregiver(s)
- \$50 stipend to the youth
- \$50 stipend for the caregiver participating in the caregiver interview (one stipend per family if more than one caregiver is participating)
- Interested participants should contact Lori Hodge:
  - [lori.hodge@sri.com](mailto:lori.hodge@sri.com), (650) 859-2571
- **Feel free to forward to any individuals or groups you think may be interested. We have administered the assessment to about 50 dyads and need a lot more participants.**

# Questions?

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Thank you!