Alexithymia and its Effect on the Mental Health Self Reporting of Individuals with Intellectual Disability

RRTC Summit Breakout Group 1

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NIMH RO1 MH108869-01: Development of the Diagnostic Interview for Adolescents and Adults with Intellectual Disability: An interview schedule of mental disorders (DIAAID)

Original DIAAID

- Objective: To develop a self-report mental health interview with clear language, and visual supports, for individuals with intellectual disability ages 14-21.
- Objective: To make an interview that could be given by interviewers with out a clinical background.
- Objective: To develop a parent, caregiver, or service provider interview to allow a care provider the opportunity to report on their experiences with the individual with intellectual disability.

Sanford, et al., 2021; Sinclair et al., 2023

RRTC 1.0 NIDILRR – 90RTHF0002-01-00: Extending the Age-range of the Diagnostic interview Schedule for Adolescents and Adults with Intellectual Disability

- Objective: To further develop the interview for older adults with intellectual disability, ages 14 and above, using a collaborative approach. (Hollway et al., 2025)

Diagnostic Interview for Adolescents and Adults with Intellectual Disability (Sanford et al., 2021)

- DIAAID includes self-report and caregiver/service provider interviews for individuals with intellectual disability ages 14 and above.
- Direct-Report Interview includes 15 mental health concerns from DSM-5
- Care-provider Interview includes 26 mental health concerns from the DSM-5
- Paper including preliminary psychometric findings (Hollway et al., 2025)

Alexithymia "A": What Does It Mean?

- Trouble understanding feelings
- Not able to tell difference between the feelings/thoughts on their mind and their body feelings
- Feelings are unclear, and hard to put into words
- Thinks about what is going on outside rather than what is going on inside their mind
- Emotions are felt, but they are hard to know or explain

Why Check for "A" During the DIAAID Studies?

- DIAAID: Developed with clear language and visual supports for better understanding
- DIAAID questions ask how a person is feeling (i.e., were you sad, nervousness, angry?)
- We wanted to learn if the DIAAID was reliable and valid for use in individuals with intellectual disability
  - Reliable: If you use the interview again you get close to the same results
  - Valid: The interview questions ask about the feelings or behaviors that we want to know about

Why Check for "A" During the DIAAID Studies?

- To check that the clear language and visual supports were understood, we look at how participants respond to the questions.
  - If only a few answers are checked, then perhaps the DIAAID questions are too hard to understand and need to be easier.
  - Or it could be that the person did not have a mental health concern.

- People with "A" have trouble describing feelings.
- We thought that people with "A" would also answer fewer questions about their feelings, so we added the "A" questionnaire.
- We wanted to know if answering fewer questions was due to "A".

Study Procedure

To Participate

- Individuals18 years or older
- Intellectual disability (by WASI-2 and ABAS-3)
- Completed the 15 self-report DIAAID screener items
- Study partner willing to complete the necessary assessments and the 14 items on the "A" questionnaire and who knew participant for 6 months
- Most interviews (95%) were completed virtually via Zoom

Study Recruitment

- Data for this project were collected as part of a larger study looking at how often mental health concerns in adults with intellectual disability.
- Recruited by the National Core Indicators (NCI) project conducted in each of six states (Michigan, North Carolina, Oregon, Rhode Island, Virginia, Ohio).
- Participants were invited to enroll in this project either via mailers or by the NCI interviewer following their participation in the NCI adult in-person survey.

Study Eligibility Measures

Children's Alexithymia Measure (CAM) by study partner(Way, et al., 2010).

- 14 items, scale from 0 to 3 (Max=42; Min=0)
- Asks about the past 3-months

Wechler Abbreviated Scale of Intelligence -FSIQ-2. (Weschler, 2011)

- WASI-2 FSIQ based on two subscales (i.e., Vocabulary; Matrix Reasoning)
- WASI-II FSIQ-2 score between 40 and 75

Study Eligibility Measures

Adaptive Behavior Assessment System – Third Edition (ABAS-3) Harrison & Oakland (2015).

- ABAS-3 completed by study partners prior to administration of the DIAAID.
- General Adaptive Behavior Composite (GAC) scores, or at least one of the Domain Standard scores, must have been 40-75 (Extremely Low or Low).

- The WASI-II and the ABAS-3 together confirmed the diagnosis of mild-to-moderate intellectual disability.

Data Analysis Sample

491 participants enrolled

- 445 participants had a CAM score and answered all 14 questions

- 393 participants completed the 15 DIAAID screener questions

Table 1. *Sample Characteristics of 445 Participants with [a]CAM Scores*

Inclusion Characteristics	**Mean (SD)**
Age	
Mean Age	35.2(13.0)
Intelligence	
[b]WASI FSIQ-2	56.9(10.1)
Min-Max	40,80
Adaptive Behavior - ABAS-3	
[c]GAC	58.9 (7.5)
Conceptual	59.1(6.7)
Social	68.8(10.3)
Practical	58.1 (7.3)
Qualitative Characteristics	**n (%)**
Gender	
Male	242 (55)
Female	193 (44)
Another Gender	2(0.5)
Unknown	8
Race	
[d]AIAN	3(0.7)
Asian	12(2.8)
Black	59(13)
White	1(0.2)
Multiple races	323(76)
Unknown	18
Ethnicity	
Hispanic	30(7.0)
Not Hispanic	406(95)
Unknown	17
Neurodevelopmental Disorders	
[e]ASD	162(40)
Fragile X	4(1.1)
Down Syndrome	71(19)
[f]ADHD (Current and Past)	114(27)
[g]ID (with no other neurodevelopmental disorder)	122(30)
Unknown	37

Table 2. Shows CAM Items and How Participants Answered

CAM Items	Almost Never n (%)	Sometimes n (%)	Often n (%)	Almost Always n (%)
(1) When asked about how he/she is feeling, instead talks about what he/she has been doing?	176 (41.0)	174 (40.6)	55 (12.8)	24 (5.6)
(2) Has trouble saying he/she looks sad even though he/she looks sad?	138 (32.2)	185 (43.1)	54 (12.6)	52 (12.1)
(3) Talks about unimportant things/topics instead of sharing his/her feelings?	132 (30.8)	160 (37.3)	82 (19.1)	55 (12.8)
(4) Has long periods of little or no emotional expression interrupted by bursts of emotional expression?	258 (60.1)	124 (28.9)	29 (6.8)	18 (4.2)
(5) Has difficulty saying he she is happy even when he/she looks happy?	250 (58.3)	106 (24.7)	44 (10.3)	29 (6.8)
(6) Physically removes self from situations when asked to talk about feelings?	243 (56.6)	140 (32.6)	33 (7.7)	13 (3.0)
(7) Makes up unrelated stories when asked about his/her feelings?	265 (61.8)	106 (24.7)	44 (10.3)	14 (3.3)

Table 2. Shows CAM Items and How Participants Answered

(8) Verbal expressions of feelings do not match non-verbal expressions of feelings?	239 (55.7)	132 (30.8)	39 (9.1)	19 (4.4)
(9) Changes the topic of conversation when asked about his/her feelings?	217 (50.6)	141 (32.9)	45 (10.5)	26 (6.1)
(10) Has difficulty naming his/her positive feelings (such as joy, happiness, excitement)?	192 (44.8)	139 (32.4)	53 (12.4)	45 (10.5)
(11) Says forget it or leave me alone when asked about his/her feelings?	262 (61.1)	127 (29.6)	27 (6.3)	13 (3.0)
(12) Has trouble finding words or getting words out when talking about his/her own feelings?	103 (24.0)	157 (36.6)	86 (20.0)	83 (19.3))
(13) Uses few words (may just say “good” or “bad”) to describe feelings?	104 (24.2)	128 (29.8)	104 (24.2)	93 (21.7)
(14) Says “I don’t know” when asked why he/she is upset?	163 (38.0)	142 (33.1)	74 (17.2)	50 (11.7)

Study CAM Scores, Cronbach's Alpha, and Confidence Intervals (CI)

Sample: Eligible participants with a CAM score (answered all 14 CAM questions) (n=445)

Cronbach's alpha = 0.873

95% CI = (0.855, 0.889)

- Cronbach's Alpha tells us how well the questions on a scale work together. If high, the questions are doing a good job of checking the same thing.
- Researchers have said that a Cronbach's alpha of 0.873 is "good" This means the CAM has good reliability, and that the questions work as a team. They are checking the same thing.
- We look at the CI because we know that scores can change a little depending on who is answering the questions. The CI is a "safe guess". We feel confident that the true alpha score falls somewhere between them.

Table 3. Participant Characteristics Showed Small to Medium Connections with CAM Scores

Characteristic	Pearson Correlation	P-value	Spearman Correlation	P-value
Age	-0.15	0.002	-0.19	<0.001
WASI	-0.06	0.191	-0.08	0.092
ABAS Standard GAC	-0.29	<0.001	-0.29	<0.001
ABAS Standard Conceptual	-0.25	<0.001	-0.28	<0.001
ABAS Standard Social	-0.31	<0.001	-0.30	<0.001
ABAS Standard Practical	-0.25	<0.001	-0.26	<0.001

Table 4. Connection between CAM Scores, Males and Females

Characteristic	**Male** N = 242	**Female** N = 193	**p-value**[1]
CAM Total Score			<0.001
Mean (SD)	13.1 (7.9)	10.4 (7.7)	

[1]Welch Two Sample t-test

Table 5. Connections between CAM Scores and Neurodevelopmental Disorders

Characteristic			
Autism Spectrum Disorder	ASD N=162 M(SD)	No ASD N=221 M(SD)	p-value
	14.1(7.9)	10.4 (7.4)	<0.001[b]
Down Syndrome	DS N=71	No DS N=301	
	11.2 (7.1)	12.1 (8.1)	0.37
Attention Deficit Hyperactivity Disorder (Current)	ADHD Current N=67	No ADHD N=290	
	15.7 (8.8)	10.8 (7.3)	<0.001[c]
Attention Deficit Hyperactivity Disorder (Past)	ADHD (Past) N=47	No ADHD N= 290	
	12.5 (6.3)	10.8 (7.3)	
Cerebral Palsy	CP N=66	No CP N=309	
	12.9 (9.6)	11.7 (7.6)	0.34
Intellectual Disability	ID N= 382	No ID N=26	
	11.9 (8.0)	10.3 (6.7)	0.26
Intellectual Disability and NDDs	ID (alone) N=122	ID + NDD N=260	
	10.2 (7.0)	12.7 (8.3)	0.003

a Children's Alexithymia Measure; bWelch Two Sample t-test; cOne-way analysis of means (not assuming equal variance)

- Checking Yes CAM to No CAM and Adult and Study Partner

  There were no important differences in the demographic data between participants who had a CAM score and those that did not.
  Yes CAM N=445
  No CAM N=46

- Checking the connection between Adult and Study Partner DIAAID Screener Concerns

  There was a medium but real connection between the adult and the study partner on DIAAID screener concerns

Table 6. Shows the information collected on how many adults with intellectual disability believed they lived with these concerns

Characteristic	**N = 393**[1]
MDD: Depressed	38/392 (9.7%)
MDD: Irritable	25/392 (6.4%)
MDD: Anhedonia	11/391 (2.8%)
Mania: Expansive/Irritable Mood & More Energy	124/382 (32%)
Schizophrenia: Hallucinations	28/375 (7.5%)
Schizophrenia: Delusions	29/375 (7.7%)
Separation Anxiety: Excessive Fear	51/375 (14%)
Specific Phobia: Excessive Fear	145/367 (40%)
Social Phobia: Fear/Anxiety About 1+ Social Situation	139/372 (37%)
Panic Disorder: Unexpected Panic for No Reason	14/371 (3.8%)
GAD: Excessive Worries (2+)	57/364 (16%)
OCD: Recurrent Intrusive Thoughts	34/366 (9.3%)
Eating Disorders: (Anorexia) Weighs Less and Restricts Intake	24/369 (6.5%)
Alcohol Use: Problematic Pattern of Alcohol Use	5/369 (1.4%)
Substance Use: Ever Used Drugs	23/364 (6.3%)

[1]n/N (%)

Figure 1. Relationship between Adult DIAAID Screener Concerns and CAM

Analysis uses participants with a CAM score who have all 15 screener concerns evaluated by AID (n = 345)

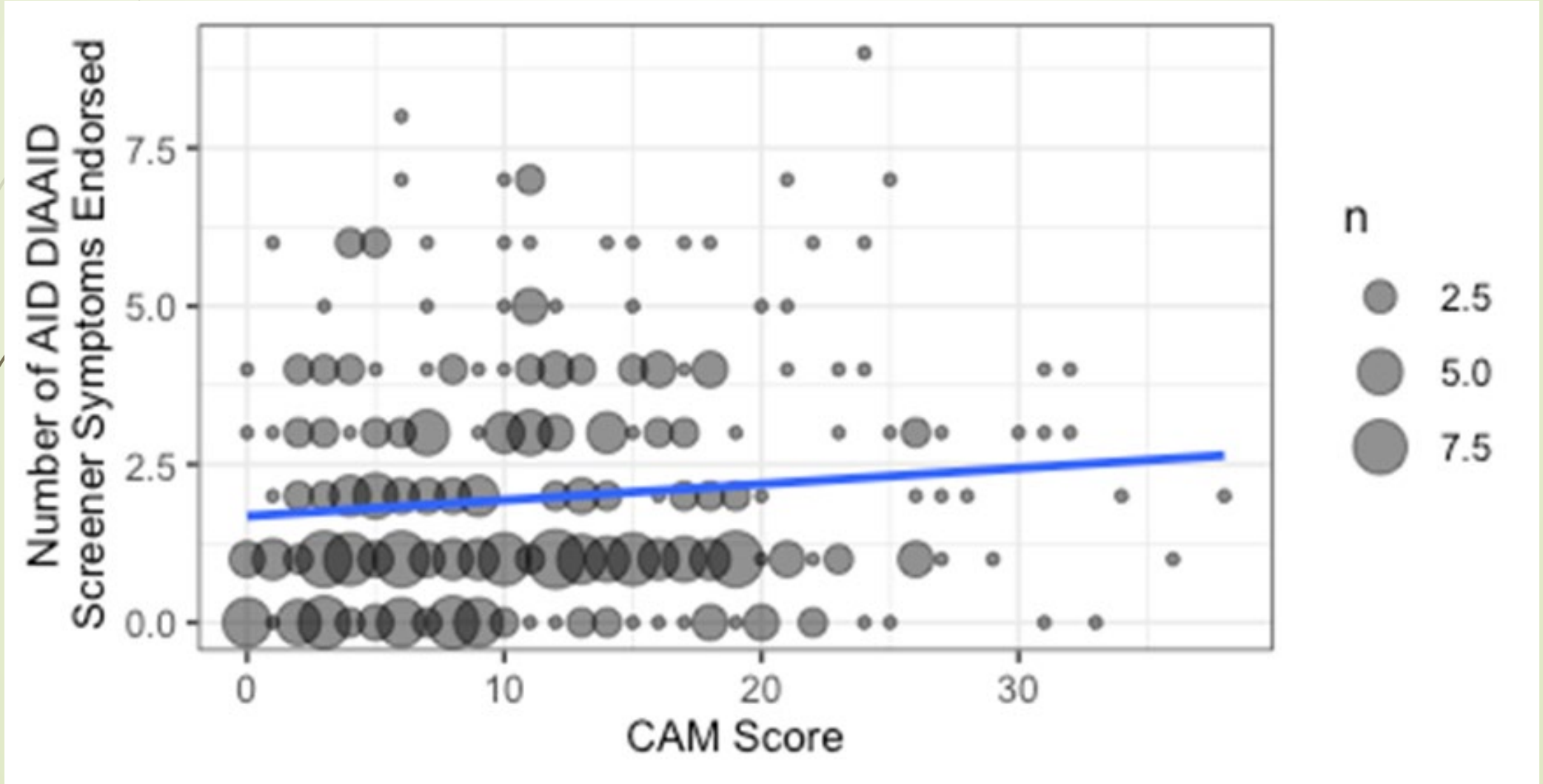


Table 7. Shows the Information Collected on How Many Study Partners Agreed that the Adult with Intellectual Disability Lived with These Concerns

Characteristic	**N = 443**[1]
MDD: Depressed	39/442 (8.8%)
MDD: Irritable	62/442 (14%)
MDD: Anhedonia	59/431 (14%)
Mania: Expansive/Irritable Mood & More Energy	48/442 (11%)
Schizophrenia: Hallucinations	74/442 (17%)
Schizophrenia: Delusions	37/442 (8.4%)
Separation Anxiety: Excessive Fear	178/443 (40%)
Specific Phobia: Excessive Fear	163/442 (37%)
Social Phobia: Fear/Anxiety About 1+ Social Situation	118/443 (27%)
Panic Disorder: Unexpected Panic for No Reason	37/443 (8.4%)
GAD: Excessive Worries (2+)	103/439 (23%)
OCD: Recurrent Intrusive Thoughts	8/441 (1.8%)
Eating Disorders: (Anorexia) Weighs Less and Restricts Intake	0/421 (0%)
Alcohol Use: Problematic Pattern of Alcohol Use	5/443 (1.1%)
Substance Use: Ever Used Drugs	22/443 (5.0%)

[1]n/N (%)

Figure 2. Relationship between SP DIAAID Screener Concerns and CAM

Analysis uses participants with a CAM score who had all 15 screener concerns checked by the SP (n = 402)

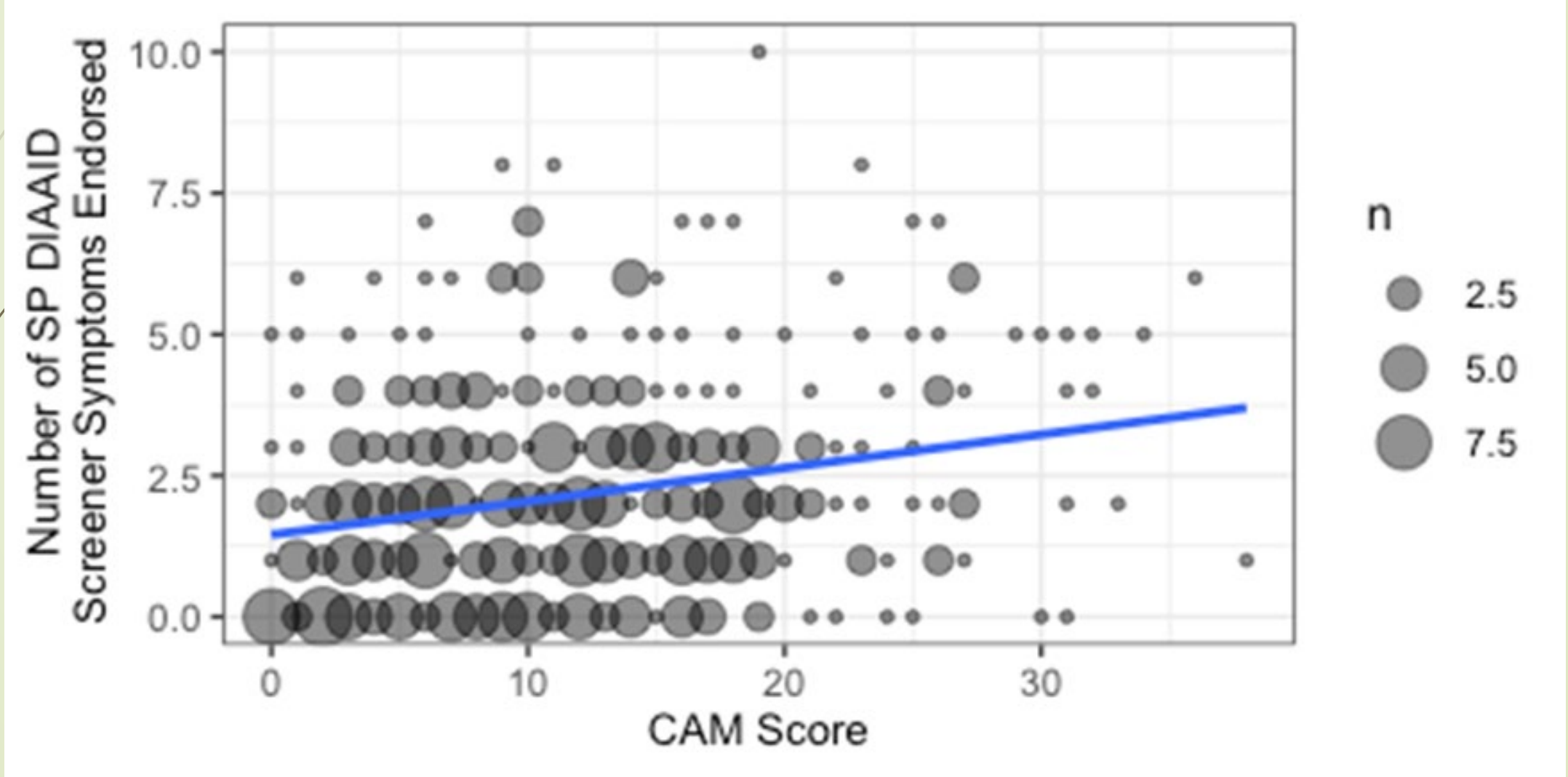


Figure 3. CAM Connection with DIAAID agree/disagree Dyads by both the Adult and the Study Partner

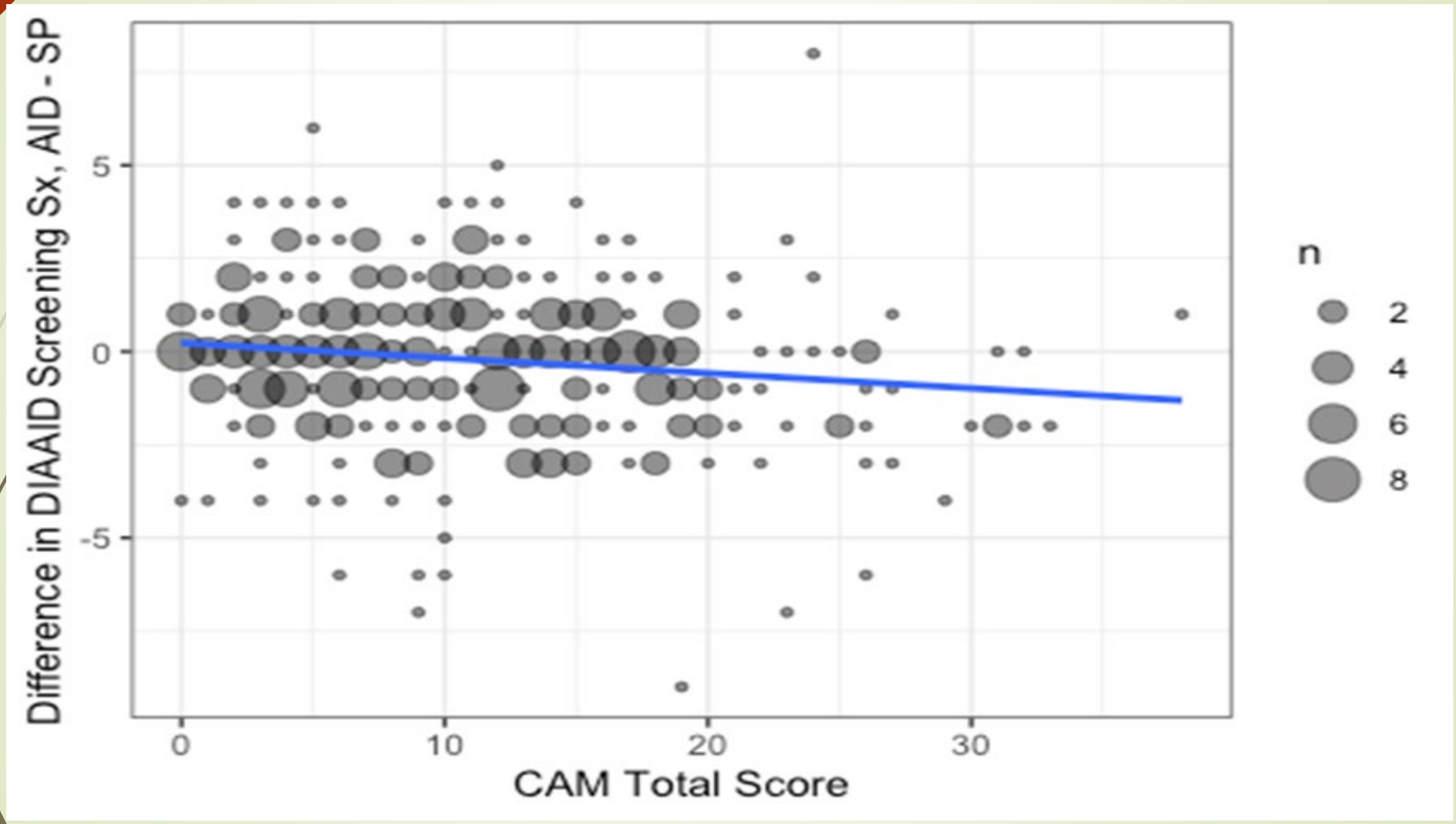


Figure 4.Compare High CAM Score to Low CAM Score
Split at CAM >=17, the 75th Percentile

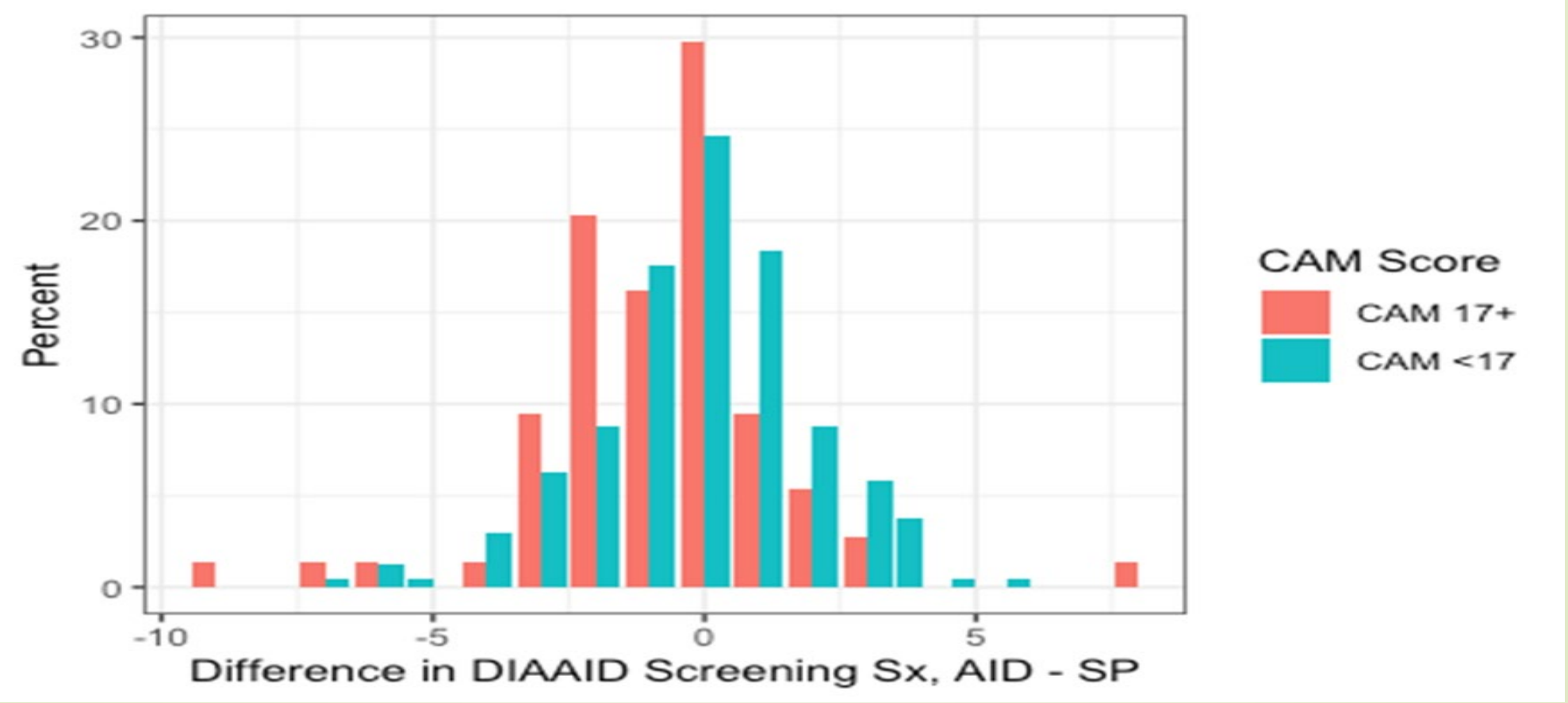


Table 8. Difference in DIAAID Responses, between Adult with Intellectual Disability and its Connection to CAM Scores

Characteristic	**CAM 17+** N = 74[1]	**CAM <17** N = 239[1]	**p-value**[2]
Difference in DIAAID Screening Sx, AID - SP	-0.81 (2.26)	-0.05 (2.06)	0.011

[1]Mean (SD)

[2]Welch Two Sample t-test

- When the Adult had a high CAM score the Adult and study partner did not agree as much
- Adults usually said they had fewer concerns than the Study Partners said
- With a high CAM score, Adults said about one less concern
- With a high CAM score, Adults and study partners mostly agreed

Figure 5. CAM Connection with MDD Concern Count From Adult Self-Report

- CAM Score for each number of named MDD Concerns

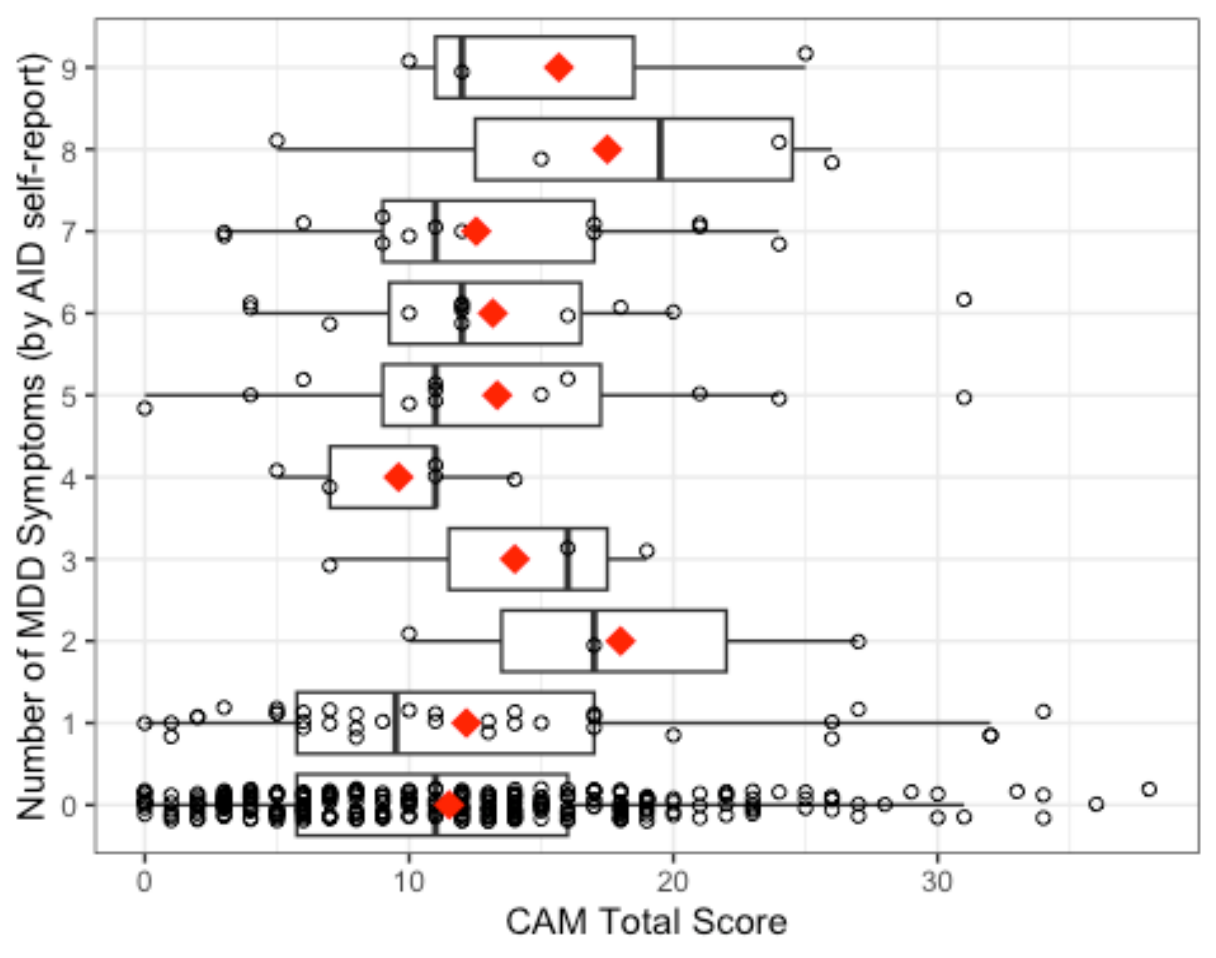
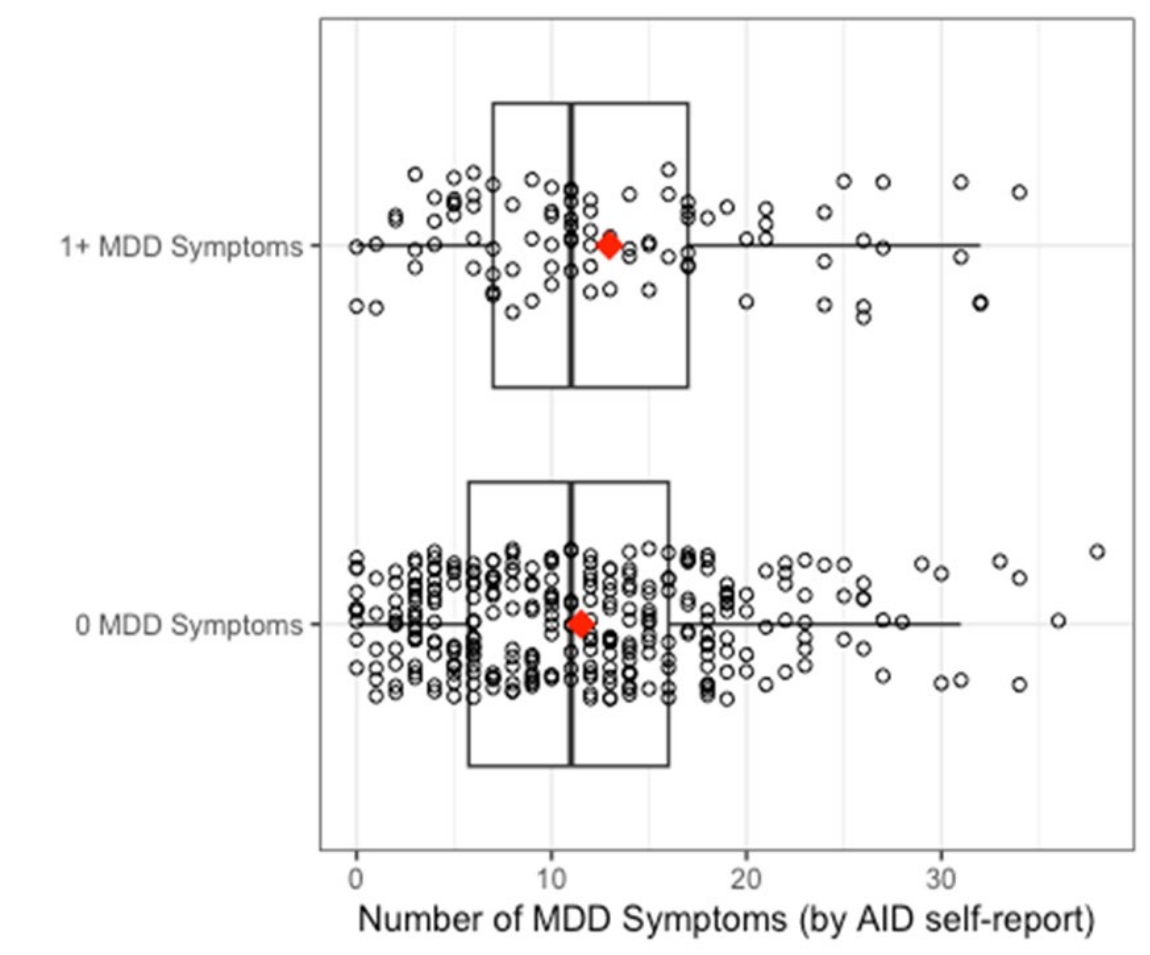


Figure 6. Comparing 0 Adult MDD Concerns to 1 or more Adult MDD Concerns

Characteristic	0 MDD Concerns N=300	1+ MDD Concerns N=91	p-value
CAM Total Score	11.5 (7.6)	13.0 (8.2)	0.14



List of Study Results

- There was a small but real positive connection between the adult screener concerns and CAM scores. We can report that in our study sample "A" was not an important problem.
- There was a small but real connection between the study partner screener concerns and CAM scores (although a bit larger than the adults).
- There was a medium but real (significant) connection between the number of screener concerns checked between the adult and the study partner
- Cronbach's alpha for the CAM was "good"
- There were weak but real connections between participant demographics (age, IQ, ABAS scores)
- There was an important difference between men and women on CAM scores (i.e., men had higher CAM scores)
- There were important differences in CAM scores for specific NDDs
- There were no important differences between CAM and no CAM scores
- There was no important difference between 0 MDD Concerns and 1+ MDD concerns
- There was a small but real negative connection between agree/disagree dyads
- On average, the agree/no agree dyads who had high CAM scores showed a slightly bigger difference between the Adult and study partners reports of concerns compared to those with lower CAM scores. Adults reported less concerns on average than partners

Next Steps in Paper Writing

- We had decided to write a brief report about our main finding that CAM scores were only weakly connected to DIAAID screener question answers. Do we still want to move forward in this manner?
- Providing a rationale for why we added the "A" questionnaire to the DIAAID development studies will be important. Do we utilize the findings on the connection found between NDDs and CAM scores (i.e., DS and CP ns and ADHD and ASD ss) or could we just state the differences between ID alone and ID + NDD and CAM scores?
- Or instead do we write a second paper stating the connections between demographics/NDDs and CAM scores highlighting the differences in CAM scores by NDD etc. and discuss the need for caution when engaging in instrument development research (or does it even matter since our main result is practically nil?)
- How should we report the results of the CAM connection with the agree/disagree dyad information?
- Which tables and figures do we include or not?

These are just some of my questions. I am sure that I will produce more questions as the writing process moves forward.

DEEP Authorship Ideas

- Writing assignments
- Reviewing and editing
- Researching articles
- Sharing relevant disability real life experience examples for the discussion sections
- Helping with data tables
- Other ideas to discuss?

Journals to Consider for Publishing

American Journal on Intellectual and Developmental Disabilities (AJIDD)
AJIDD is a multidisciplinary, peer reviewed journal that publishes high-quality research on intellectual disability, including causes, treatment, and prevention. It is widely read by researchers, clinicians, and policymakers in the field of disabilities, neuroscience, and behavioral sciences, making it suitable for studies on psychological constructs like alexithymia in individuals with intellectual disabilities (AAIDD). Impact Factor 1.9

Journal of Intellectual Disability Research (JIDR): JIDR publishes research on all aspects of intellectual disability, including psychological and emotional functioning. It is widely recognized in the field and suitable for studies examining alexithymia, emotional regulation, and related constructs (Disabled World). Impact Factor – 2.47

Journal of Intellectual Disabilities(American): JID aims to provide a peer-reviewed medium for the exchange of best practice of knowledge and research between academic and professional disciplines, from education, social and health settings. JID aims to bring about the advancement of services for people with intellectual disabilities. Impact factor 1.4 (5 years – 1.8)

Journals to Consider for Publishing

Journal of Intellectual and Developmental Disability (Australian): JIDD is an international, multidisciplinary journal in the field of intellectual and developmental disability. JIDD publishes substantive original research articles that address the situation and concerns of people with intellectual disabilities. JIDD accepts research into commonly associated developmental and neurodevelopmental disabilities only when these are in conjunction with intellectual disability. JIDD welcomes qualitative, quantitative and mixed method research. Impact factor 1.9 =(5 years – 3.2)

Global Journal of Intellectual and Developmental Disabilities (GJIDD): GJIDD is an open-access, peer-reviewed journal that publishes research on the origin, prevention, and treatment of intellectual disabilities. It is suitable for studies exploring psychological and behavioral aspects, including alexithymia (Juniper Publishers). Impact – 0.080

DIAAID References

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