Brief Report: Convergence and discrepancy between self- and informant-reported depressive symptoms in young autistic adults

Hannah R. Thomas[a]

Aditi Sirsikar[a]

Inge-Marie Eigsti[a]

[a] Department of Psychological Sciences, University of Connecticut, Storrs, CT, USA

Corresponding Author: Inge-Marie Eigsti
Department of Psychological Sciences, Unit 1020
406 Babbidge Rd
Storrs, CT 06269
Email: inge-marie.eigsti@uconn.edu
Phone number: 860.486.6021

Hannah R. Thomas: https://orcid.org/0000-0003-3003-9363

Aditi Sirsikar**:** https://orcid.org/0000-0002-7901-5023

Inge-Marie Eigsti: https://orcid.org/0000-0001-7898-1898

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Abstract

Purpose: Autistic individuals exhibit elevated rates of depression; however, assessment is complicated by clinical presentations and limited validation in this population. Recent work has demonstrated the utility of the Beck Depression Inventory (BDI-II) in screening for depression in ASD. The current study extends this work by examining the convergence and divergence of self- and informant-reported depression in autistic (n = 258) and non-autistic (n = 255) young adults. **Methods:** Participants completed the BDI-II as a self-report measure of depression; informants completed the Achenbach Adult Behavior Checklist. Analyses probed for between-group differences in rates of depression symptoms, convergence between self- and informant-reported depression, and discrepancy between self- and informant-reported depression. **Results:** Results indicated significantly higher rates of depressive symptoms in the autistic group. Convergence was significant in both groups, with significantly greater agreement in the autistic group. There was differential divergence, with the autistic group reporting significantly lower scores relative to informants, and the non-autistic group reporting significantly higher scores relative to informants. **Conclusions:** Consistent with prior reports, results suggest that depression rates are elevated in autism. Additionally, while the BDI-II may be adequate for screening depressive symptoms in speaking autistic young adults, eliciting information from a close adult informant provides valuable diagnostic information, due to clinically critical concerns about underreporting in this population. Although controlled in analyses, between-group differences in gender, age, race, and informant identity, and a predominantly White and non-Latinx sample, limit the generalizability of these results.

Keywords*:* Depression, Self-report, Informant-report, Convergence, Discrepancy

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Autism spectrum disorder (ASD) is characterized by challenges in social communication and the presence of restrictive and repetitive behaviors (American Psychiatric Association, 2013). Co-occurring psychiatric disorders such as depression are highly prevalent in ASD. Recent estimates suggest that 23-37% of autistic young adults experience depression (Hollocks et al., 2019), compared to 8% of adults in the general population (Brody et al., 2018), though given difficulty assessing depression symptoms in ASD, these rates may reflect over- or under-estimates. Relying on caregiver or informant report is common practice in the assessment of psychiatric symptoms in ASD, due in part to concerns about reduced personal insight and difficulty expressing emotions in this population (Ben Shalom et al., 2006; Bishop & Seltzer, 2012). However, depression in autistic individuals may be less apparent to caregivers or informants (Hurtig et al., 2009), and most depression assessments or screeners for adults are intended as self-report measures. Recent work has demonstrated the utility of the Beck Depression Inventory (Beck et al., 1996), a widely used self-report depressive screener, in autistic individuals (Cassidy et al., 2018; Gotham et al., 2015; Williams et al., 2021). This study tests the convergence of self- and informant-report of depression symptoms in a large sample of autistic and non-autistic adults, to optimize assessment of depression in autistic people.

The accurate and timely diagnosis of depression in ASD is critical as it impacts quality of life and contributes to suicidality (Hirvikoski et al., 2020; Kõlves et al., 2021; Williams et al., 2021), yet several factors interfere with assessment. First, autistic individuals may have a unique presentation of depression, reporting significantly more insomnia, restlessness, and fewer feelings of sadness and worthlessness, compared to non-autistic depressed people (Montazeri et

al., 2020; Moss et al., 2015). Second, there can be difficulty distinguishing features of autism and depression, such as social withdrawal or flat affect (Stewart et al., 2006). Third, existing depression screeners were developed and normed primarily in non-autistic populations, and therefore their efficacy in capturing symptoms in autistic people is unclear (Magnuson & Constantino, 2011).

One useful metric of diagnostic efficacy is the agreement (convergence) between self-report and reports from a knowledgeable informant (Ozsivadjian et al., 2014). A previous study found mixed results (weak to moderate correlations) in examining self- and informant-reported depression (Gotham et al., 2015); however, the relatively small sample size (n = 50) and lack of a comparison group limits these findings. It is important to evaluate discrepancies between raters to capture over- or under-reporting (Sandercock et al., 2020). The comparison of convergence *and* discrepancy for autistic and non-autistic young adults in a large sample will provide further evidence of the utility of self-report depression screeners in autism.

The aim of the current study was to investigate the convergence and discrepancy of self- and informant-reported depression symptoms, using the BDI-II for self-reported depression symptoms and the Achenbach Adult Behavior Checklist (ABCL; Achenbach & Rescorla, 2003) for informant-reported depression symptoms. We opted to use the ABCL for informant report for several reasons. First, the BDI-II is used clinically as a self-report measure, and we intended to only utilize measures as clinically implemented. Second, the ABCL and broader Achenbach System of Empirically Based Assessment (ASEBA) tools are widely used as a mental health screener in primary care settings (Lavigne et al., 2016; Simonian, 2006; Warnick et al., 2008) and frequently used in autism research. Third, the ASEBA measures have been found to have high sensitivity, though lower specificity, in capturing depression in autistic samples (Gotham et

al., 2015; Pandolfi et al., 2012). Finally, recent research has employed a similar design and examined associations between the ASEBA system informant report and BDI-II self-report of depression in autistic samples (Gotham et al., 2015; McCauley et al., 2020). We used an online survey to compare rates of depression in autistic versus non-autistic groups and examined convergence and divergence of self- and informant-reported symptoms.

Methods

Participants. Individuals with a confirmed diagnosis of autism spectrum disorder (ASD) were recruited during Fall, 2020, through the Simons Foundation Powering Autism Research (SPARK) database (SPARK, 2018). SPARK has excellent diagnostic validity (98.8%; Fombonne et al., 2022). Inclusion criteria for SPARK participants were: 18-29 years old; fluent English status; and cognitive abilities in the average range (reported FSIQ ≥ 80 in the SPARK database; Feliciano et al., 2018). Of recruited autistic participants, 267 (98% of 273) completed the survey. Participants were asked to nominate an adult informant who could reflect upon their mental health; they were permitted to nominate a preferred informant other than a parent, to accommodate those who live independently and those with more distant relationships with parents or caregivers. We received 119 responses (77 parents; 31 partners or relatives; 11 family friends). Autistic participants and informants received financial compensation. There were differences between participants for whom we did versus did not receive an informant survey; those with informant reports were more likely to be female, $\chi^2(2) = 11.00$, $p = .004$, younger $F(1, 256) = 9.43$, $p = .002$, and to endorse fewer depression symptoms, $F(1, 256) = 8.79$, $p = .003$. Non-autistic participants were recruited from a psychology participant pool and a university listserv during Summer 2019 and Spring 2020. A total of 352 (91% of 388) completed the survey. Participants in either group with self- or parent-reported diagnoses of schizophrenia or

bipolar disorder were excluded from participation. Non-autistic participants were also asked to nominate a knowledgeable informant; we received 52 (13%) informant responses. Participants with informant reports were less likely to identify as Latinx, $\chi^2(2) = 6.12$, $p = .03$. Relative to the non-autistic group, the autistic participants were older, more likely to identify as White, and more likely to be male and non-cis-gender-identifying; see Table 1.

We used G-Power (Faul et al., 2007) to determine sample size. With $f = .3$, $\alpha = .05$, and $(1 - \beta) = .95$, a sample of $n = 110$ was recommended; to account for participants who did not nominate an informant, sample size was set at $n = 290$. The survey included the question "Honestly, how seriously did you take this survey? Your answer will not affect your payment." Response options were "*Not at all*," "*Somewhat*," and "*Seriously*." Only participants who responded "*Seriously*" (258 autistic, 297 non-autistic) were included. More autistic participants responded *Seriously*, $\chi^2(2) = 18.91$, $p < .001$, $V = .182$.

Table 1. *Participant demographics.*

	Autistic	Non-autistic	X^2/ F	p	Effect size
n (Female:Male:Other)	258 (144:97:17)	255 (191:64:0)	30.3	<.001	V =.172
Age in years	25.3 (3.1) 19-30	19.4 (1.2) 18-23	6.67	<.001	d = 2.51
White	211 (82%)	141 (55%)	94.9	<.001	V = .248
Asian	4 (2%)	49 (19%)			
African American	8 (3%)	0 (0%)			
Multi-racial	30 (12%)	17 (7%)			
Not Reported	5 (2%)	16 (6%)			
Latinx	22 (9%)	33 (13%)	4.66	0.10	V = .067
Not Latinx	231 (90%)	212 (83%)			
Not reported	5 (2%)	10 (4%)			
Autism Quotient, total score	31.4 (8.0)	16.3 (4.8)	2.78	<.001	d = .28

	13-48	7-25			
Informant identity (Parent/Guardian: Other)	77:42	52:0	58.8	<.001	V = .151
BDI-II total raw score	19.1 (14.0) 0-61	12.0 (10.6) 0-53	4.13	.045	η_p^2 = .01
BDI-II z scores	0.13 (0.98)	-0.27 (0.86)	7.42	.005	η_p^2 = .02
BDI-II scores in *moderate* range (20-28; NT) or *Possibly or Likely Depressed Range (ASD)*, by gender (F, M, other)	F: 40 (27%) M: 30 (30%) Other: 6 (35%)	F: 33 (12%) M: 2 (3%) Other: N/A			
BDI-II scores in *severe* range (29-64; NT) or *Very likely or Almost Certainly Depressed* range (ASD) by gender (F, M, other)	F: 61 (42%) M: 19 (23%) Other: 7 (41%)	F: 17 (9%) M: 2 (3%) Other: N/A			
ABCL Depression *T*-score	66.1 (11.9) 50-94	54.4 (9.1) 50-90	15.05	<.001	η_p^2 = .09

Note: Data presented as M(SD); range, or as count and %. BDI-II = Beck Depression Inventory – II; ABCL = Achenbach Adult Behavior Checklist. The autistic sample BDI-II z scores and descriptive categories were obtained from the validated online scoring system from Williams et al., (2020).

Measures

Self-reported depression. Participants completed the Beck Depression Inventory-II (BDI-II; Beck et al., 1996), a depression screener with excellent test-retest reliability (r = .93) (Sprinkle et al., 2002) and a high coefficient alpha (α = .92) (Steer et al., 1998), indicating excellent internal validity in a general population sample. The BDI-II asks respondents to rate the presence of 21 symptoms of depression (autistic coefficient α = 0.95; non-autistic, α = 0.93) during the past two weeks using a four-point scale. Scores of 0-13 suggest "minimal" depression; 14-19 "mild", 20-28 "moderate", and 29-63 "severe." In the autistic sample, the BDI-II was

scored using the validated method from Williams et al. (2020). This method does not yield total scores and rather provides *z*-scores and screen determinations ranging from "unlikely depressed" to "almost certainly depressed." As such, *z*-scores were also computed in the non-autistic sample using BDI-II total scores to allow for group comparisons.

Informant-reported depression. Informants completed the Achenbach Adult Behavior Checklist online (ABCL; Achenbach & Rescorla, 2003). The ABCL generates *T*-scores; the current study examined only the DSM-Oriented Depressive Problems subdmaoin (autistic coefficient $\alpha = 0.90$; non-autistic $\alpha = 0.94$). Respondents are asked to rate items in the past 6 months on a three-point scale as "*not true*", "*sometimes true*", or "*very true*." *T*-scores of 50-64 are "typical", 65-69 are "borderline clinical", and 70-100 suggest "clinical depression."

Traits of autism. Participants completed the Adult Autism Spectrum Quotient (AQ; (Baron-Cohen et al., 2001), a 50-item questionnaire capturing autistic traits. Response choices include "*definitely agree", "slightly agree", "slightly disagree",* and "*definitely disagree".* Responses are summed (range = 0-50); 26 is considered an informative threshold for autism (Woodbury-Smith et al., 2005). We excluded non-autistic participants with AQ ≥ 26 (*n*=42; 11%). Given the strong diagnostic validity of the SPARK sample (Fombonne et al., 2022), we did not include/exclude autistic participants on the basis of AQ scores.

Statistical analyses. There were no missing data. Assumptions of multicollinearity, linearity, and normality were satisfied. Bootstrapping addressed unmet assumptions of homoscedasticity and normality for BDI-II scores (Roodman et al., 2019). Analyses in SPSS and R included ANCOVAs to compare BDI-II raw and *z*-scores and ABCL *T*-scores between autistic and non-autistic groups. Partial correlations probed self and informant convergence within groups with post-hoc Fisher's *z*-transformations to compare groups. Age, race, and gender were

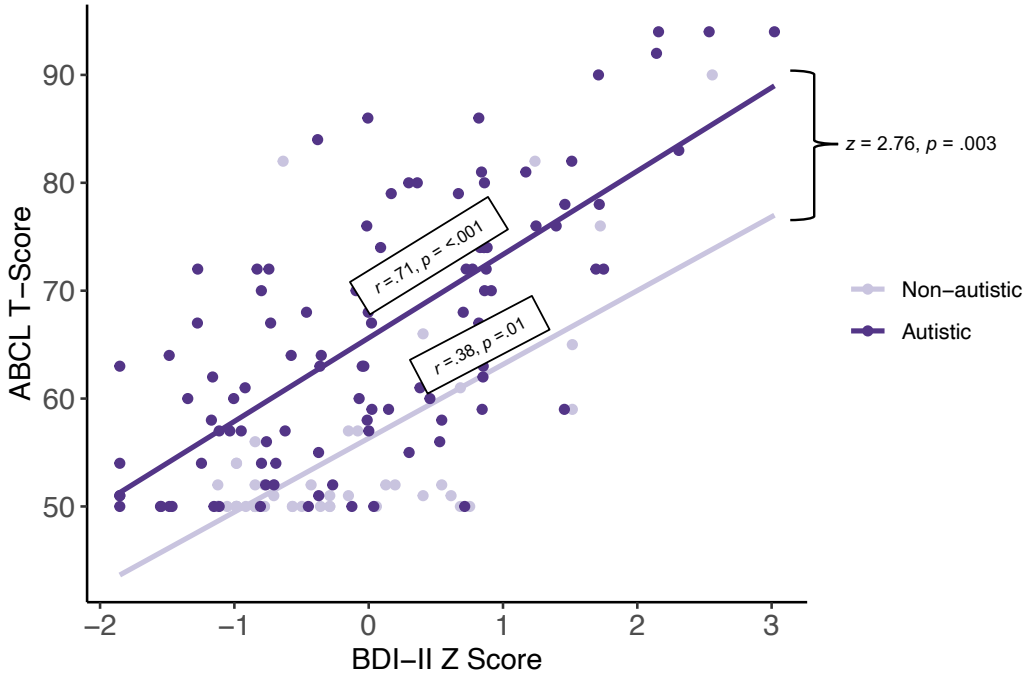
entered as covariates in between-group comparisons. Informant identity (i.e., parent versus not parent) was entered as a covariate for analyses including ABCL scores in the ASD group. In accordance with best practice recommendations for informant discrepancy analyses (De Los Reyes & Kazdin, 2004), ABCL *T*-scores were converted to *z*-scores for within-group paired-samples *t*-test comparisons with the BDI-II z-scores.

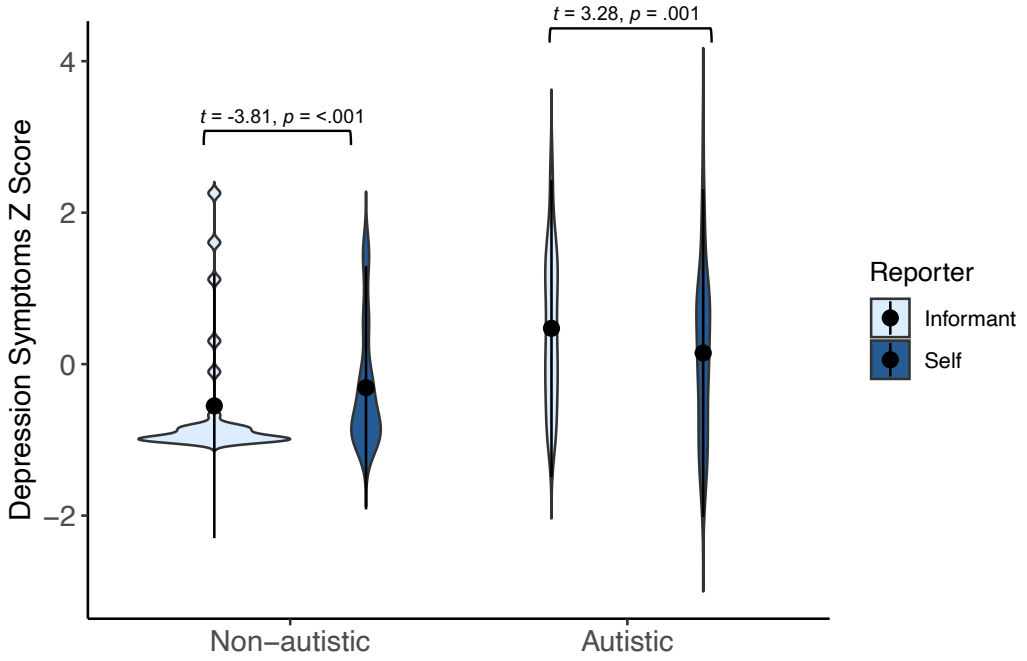
Results

Assessing Depression. BDI-II *z*-scores were elevated, with a small effect size, in autistic adults, *M*(*SD*) = 0.13 (0.98), compared to non-autistic adults, *M*(*SD*) = -0.27 (0.86), above and beyond age, gender, and race; $F(1, 513) = 7.42$, $p = .005$, $\eta_p^2 = .02$; see Table 1. Results were similar using the raw scores $F(1, 513) = 4.13$, $p = .045$, $\eta_p^2 = .01$. Similarly, ABCL scores differed by group, controlling for age, gender, race, and informant identity, with a medium effect size, $F(1, 158) = 15.05$, $p < .001$, $\eta_p^2 = .09$; average scores were higher and in the borderline clinical range for autistic adults, *M*(*SD*) = 66.1 (11.9), compared to non-autistic adults, *M*(*SD*) = 54.4 (9.1).

*Self and informant convergence***.** Self-reported (BDI-II z) and informant-reported (ABCL *T*) depression symptoms were significantly correlated in *both* the autistic group, $r(104) = .71$, $p < .001$, and the non-autistic group, $r(50) = .65$, $p = .01$, controlling for age, gender, race, and (in the ASD group) informant identity; see Figure 1. A comparison of correlations found that convergence was significantly greater in the autistic group, $z = 2.76$, $p = .003$.

Figure 1. *Convergence (top) and divergence (bottom) of self (BDI) and informant (ABCL) reports.*


ABCL T−Score
BDI−II Z Score
r = .71, p = <.001
r = .38, p = .01
z = 2.76, p = .003
Non−autistic
Autistic


Depression Symptoms Z Score
t = -3.81, p = <.001
t = 3.28, p = .001
Non−autistic
Autistic
Reporter
Informant
Self

193

194

195

Self and informant discrepancy. Self-reported (BDI-II *z*-score) and informant-reported (ABCL *z*-score) depression symptoms were significantly discrepant in *both* autistic and non-autistic groups; Fig. 2. In the autistic group, self-reported scores were significantly *lower* than informant-reported scores, with a large effect size, $t(105) = 3.28$, $p = .001$, $d = 0.79$, whereas in the non-autistic group, self-reported scores were significantly *higher* than informant-reported scores, with medium effect size, $t(51) = -3.81$, $p < .001$, $d = 0.49$. That is, reports were discrepant in opposite directions. Exploratory analyses utilized ANCOVA to control for age, race, gender, and (for ASD group only) informant identity; non-autistic self-reported scores remained significantly higher than informant scores, with a medium effect size, $F(1, 96) = 6.88$, $p = .01$, $\eta_p^2 = .07$, whereas autistic self- and informant-report was no longer significantly discrepant, $F(1, 186) = 0.425$, $p = .515$, $\eta_p^2 = .005$.

Discussion

The current study examined the convergence and discrepancy between self- and informant-reported depressive symptoms in autistic and non-autistic young adults. Given the high rates of co-occurring depression (Hollocks et al., 2019), associated functional impairments (Kõlves et al., 2021; Magnuson & Constantino, 2011), and challenges with timely and accurate diagnosis (Montazeri et al., 2020; Stewart et al., 2006), optimizing the assessment of depressive symptoms in ASD is critical. We built on previous work (Cassidy et al., 2018; Gotham et al., 2015; Williams et al., 2021) reporting that the BDI-II was effective in assessing depression in autistic individuals.

Consistent with previous reports, current results suggested elevated depression in autistic individuals according to both self- and informant-report; this interpretation is supported by findings that the BDI-II (Gotham et al., 2015; Williams et al., 2021) and the ASEBA measures

(Gotham et al., 2015; Pandolfi et al., 2012) have good sensitivity in measuring depression in this population. This might reflect the social isolation and loneliness that are frequent in autism (Burrows et al., 2017; Hollocks et al., 2019), potentially exacerbated by cognitive inflexibility or a tendency to ruminate. These results highlight the need to improve our assessment of depression in autism.

Results also indicated significant convergence between the reports of participants and their informants, controlling for informant identity, with the autistic dyads being significantly more correlated. This is consistent with prior work assessing self- and informant-report convergence in a wider range of functional outcomes (e.g., daily living skills, quality of life, ASD symptoms; (Sandercock et al., 2020) and strengthens the small-to-moderate convergence demonstrated in a smaller previous study (Gotham et al., 2015). These results are particularly compelling given that self- and informant-reports utilized different measures, which would typically serve to amplify differences in results.

These results are consistent with the possibility that parents, caretakers, or other informants can provide clinically relevant information that may be an informative supplement to self-report during assessment. Of course, the current findings must be replicated; studies comparing informant-report, self-report, and, crucially, formal clinical diagnoses of depression in autistic populations will be particularly valuable in determining the accuracy of informant-report. Additionally, although informant identity was included as a predictor in analyses, future work should obtain more detailed information on the participant/informant relationships, such as living arrangements, closeness of the relationship, etc. Notably, findings suggest that speaking autistic young adults have some insight into their own depressive symptoms; their perspectives and experiences should be included in mental health evaluations to augment informant report.

An important caveat to these results is that self- and informant-report *discrepancy* was significant in both groups. Autistic individuals were more likely to report *lower* scores relative to their informants (though no longer significant after controlling for demographic factors), suggesting either reduced insight, difficulty communicating emotions (Ben Shalom et al., 2006; White et al., 2012), or inaccurate perceptions by informants (Magnuson & Constantino, 2011). These results do not reveal who is the more accurate reporter, of course, but suggest that a multi-informant approach may best capture depressive symptoms in autistic young adults, particularly in situations where sensitivity (e.g., detecting the presence of depression) is more clinically urgent than specificity (e.g., excluding cases of depression). If replicated, results suggest that clinical cutoffs on depression screeners might be lowered (i.e., improving sensitivity) for autistic adults. In this sample, non-autistic individuals reported *higher* rates of symptoms compared to their informants, likely reflecting in part that this sample comprised college students who live independently.

Limitations. This study did not include a formal clinical evaluation of depression, which limits our interpretation of the use of the BDI-II as a depression screener. A second significant limitation is the difference between informant- versus self-report measures. The BDI-II captures depression symptoms in the last two weeks, whereas the ABCL captures symptoms in the last six months. Despite recent research comparing these measures and demonstrating that they are both sensitive to depression in autistic samples, we cannot be certain that the discrepancy analyses truly reflect differences in reporter versus differences in measures. The groups differed in how many informant reports were received, and in informant identity. Although we controlled for the latter in analyses, we did not assess where adult participants lived or reported closeness with the informant, limiting our ability to estimate how knowledgeable a given informant was.

Additionally, the stronger self- and informant-report convergence found in the autistic group may be partially due to the larger sample size compared to the non-autistic group. The groups differed on gender, age, race, and informant identity (e.g., parents versus other knowledgeable adults), limiting interpretability of results. In both autistic and non-autistic groups, most participants identified as White, and given that participation required access to the internet, they were likely from well-resourced families, further limiting generalizability. Most importantly, the study included speaking individuals with age-appropriate cognitive abilities; work examining depression in non-speaking autistic individuals is urgently needed.

Conclusions. These results support previous evidence that the BDI-II can provide useful and informative information for speaking autistic young adults. Self- and informant-report agreement suggests that autistic adults have the insight to report on their depressive symptoms, however, discrepancies between raters suggest that caretaker insight may be an important addition to mental health evaluations and that autistic individuals may report lower rates of symptoms relative to their informants. Further research is needed to determine best practices for assessing depression in autism, with careful attention towards the degree of underreporting in this population.

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