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Anxiety Self-Report in Autistic Adolescents with Intellectual Disability: Predictors of Parent-Youth Agreement
--Manuscript Draft--

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Abstract

The use of self-report to assess anxiety in adolescents with intellectual disability (ID) is notably underexplored. This study examined the impact of youth-level factors (i.e., age, verbal and cognitive ability, adaptive skills) on anxiety self-report completion and parent-youth agreement among 72 autistic adolescents with ID. We also examined if parent accommodation behaviors, such as reassurance or routine modification, served as predictors of parent-youth agreement of anxiety. Results showed that 83% of adolescents completed the self-report measure, with verbal, cognitive, and adaptive ability predicting completion. Parental accommodation predicted parent-youth agreement on physical anxiety symptoms, but not global anxiety symptoms. Youth-level factors did not significantly predict agreement. Results highlight the need for expanded assessment approaches for assessing anxiety in youth with ID.

Keywords: Informant Discrepancies, Self-Report, Anxiety Assessment, Intellectual Disability, Autism

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Assessment of Anxiety in Autistic Adolescents with Intellectual Disability

Barriers to Assessment

Anxiety is a predominantly internal experience, including cognitions and physiological responses, and thus often relies on communication of these internal experiences to others for shared understanding. While some aspects of anxiety manifest externally (e.g., physiological symptoms like increased movement, face flushing, muscle tension; behavioral avoidance), being able to understand internal experiences is a key consideration in assessment. The assessment of anxiety in autistic individuals with intellectual disability (ID), therefore, poses significant challenges, due to communication considerations unique to both ID and autism, as well as unique presentations of anxiety in autistic individuals (Kerns et al., 2021). These factors may negatively impact the ability of youth and parents to report on anxiety and develop a shared understanding of anxiety symptoms.

When autistic adolescents with ID are not able to effectively communicate about their anxiety, parent-report on their anxiety may involve a high degree of inference. For example, parents have reported difficulty discerning behaviors attributable to anxiety or autism (e.g., insistence on sameness; repetitive behaviors; Tarver et al., 2021). Understanding adolescent anxiety is also impacted by challenges with self-report assessment instruments; traditional rating scale and interview tools often include inaccessible language or phrasing for youth (Schiltz et al., 2024). Further, measurement tools that have a large proportion of items related to cognitive symptoms often underestimate anxiety in autistic individuals with ID (Appleton et al., 2019).

Current Assessment Practices

Compared to parent-report, self-report has generally been underutilized in both research and practice with autistic individuals with ID (Halvorsen et al., 2023; Schiltz et al., 2024; Stratis & Lecavalier, 2015), despite the importance of including youth's direct perspectives in the assessment of anxiety. This is in part due to historical reliance on proxy-report due to challenges in conducting self-report within this population, and the assumption that differences in parent and self-report are solely due to inaccuracies or biases in youth reporting, rather than diverging perspectives (Schiltz et al., 2024). Within research and clinical practice there is a lack of consistency in the types of self-report measures used (Appleton et al., 2019). Currently, for individuals with ID, there are no measures that have both self-report and parent-report versions of similar items (Flynn et al., 2017; Hermans et al., 2011; Winch et al., 2022), whereas this is a common practice for multi-informant assessment of anxiety in the general population (Spence, 2018).

Assessment tools with quality psychometric properties that can be used with youth with higher support needs are limited (Flynn et al., 2017; Winch et al., 2022). Reviews (Hermans et al., 2011; Winch et al., 2022) have identified the Anxiety, Depression and Mood Scale (ADAMS; Esbensen et al., 2003) and Psychopathology Autism Checklist (PAC; Helverschou et al., 2021) as promising in terms of quality for parent-report, and the Glasgow Anxiety Scale for people with ID (GAS-ID; Mindham & Espie, 2003) for self-report. Both the ADAMS and GAS-ID were designed and validated with youth with ID (Maïano et al., 2023), though not specifically autistic youth with ID. While the PAC was designed to measure mental health for autistic individuals (Helverschou et al., 2021), it has not yet been validated for youth with ID. Interestingly, both parent-report measures are broadband mental health measures with a specific anxiety subscale,

while the GAS-ID is a narrowband anxiety measure. While an anxiety-specific measure, the GAS-ID does not provide distinct anxiety diagnostic subtypes, like other common narrowband anxiety measures.

Studies have shown the strongest psychometric properties for measures specifically designed for use in the ID or autistic population (Halvorsen et al., 2023; Schiltz et al., 2024). Preliminary research with self-report methods indicates that the nature of worries of adolescents with autism or ID may differ from their same age peers, often reflecting common challenges associated with a youth's diagnosis (e.g., making social connections within a new environment or being able to discern if a new person is trustworthy; Hemm et al., 2018; Young et al., 2016). Thus, there is a need for more research utilizing self-report tools that are adapted for use in this population and include strong psychometric properties. As there are yet to be concordant parent and self-report measures for report of anxiety, there is also a need to understand how to best utilize existing measures.

Clinical Utility of Parent-Youth Discrepancies and Agreement

Using self-report in tandem with parent-report can not only support an accurate clinical diagnosis, but also can help indicate treatment readiness for cognitive behavioral therapy (CBT). Research within the general population shows both parent-youth disagreement and agreement in anxiety ratings can be predictive of treatment outcomes, such that higher anxiety ratings from parents than youth are often predictive of worsened treatment outcomes (Becker-Haimes et al., 2018; Ferdinand et al., 2006) and parent-youth agreement of high anxiety is predictive of a need for higher treatment intensity (Makol et al., 2019).

These patterns are likely related to treatment "buy-in", as adolescents who do not identify that anxiety is a salient concern are less likely to engage in treatment. In the general population, this may be particularly relevant for adolescents who are referred by parents, as research suggests treatment effects are primarily driven by adolescents' motivation to learn and apply treatment strategies, and not by parent involvement (Manassis et al., 2014). Over the course of CBT treatment, parent and youth discrepancies are often reduced, specifically for adolescents who report lower levels of anxiety than their parents at the start of treatment (Becker-Haimes et al., 2018), which translates to better treatment outcomes. These findings suggest treatment may increase adolescents' insight and awareness to their anxiety, and "buy-in", as they see learning to cope with anxiety as more relevant to their personal goals.

Limited research has focused on examining parent-youth discrepancies over the course of CBT in youth with autism or ID. Treatment "buy-in" may look different for adolescents with autism or ID, where parental involvement is a core component to treatment (Winch et al., 2022), and involves both supporting generalization of adolescents' behavior change, as well as changes in parents' behavior (Blakeley-Smith et al., 2021). Additionally, adolescents with ID may not fully recognize the impairment related to their anxiety or capacity for change, which may affect motivation for treatment. Finally, changes in parent and youth reported anxiety over the course of treatment may reflect greater awareness of anxiety symptoms in addition to changes in these symptoms. For example, treatment studies have found significant changes for parent-report of anxiety, but not child report of anxiety, over the course of CBT treatment in autistic youth without ID (Reaven et al., 2009). Thus, investigating patterns of agreement may be useful for interpretation of treatment outcomes for CBT models within this population.

Predictors of Parent-Youth Agreement

General pooled estimates of parent-youth agreement for internalizing symptoms in youth with autism and/or ID show moderate agreement (r = 0.42; Stratis & Lecavalier, 2015). Study findings are heterogeneous, indicating agreement is largely conditional upon the measures used and population studied. Correlations tend to be lower for dyads with ID. Research on parent-youth agreement is still severely lacking for youth with ID, with only 5 of 50 studies representing youth with ID in recent systematic reviews and meta-analyses in youth with autism or ID (Kim & Lecavalier, 2022; Stratis & Lecavalier, 2015).

Youth-Level Predictors

Studies that have investigated predictors of parent-youth agreement of anxiety in autistic youth have shown higher verbal IQ (Blakeley-Smith et al., 2012; Ooi et al., 2016), meta-cognitive ability (Blakeley-Smith et al., 2012), higher adaptive abilities (Burrows et al., 2018), and lower autism symptoms (Burrows et al., 2018; Kalvin et al., 2020), are related to higher agreement. While these are all youth-level factors, these also may reflect parent-level challenges in reporting. For example, measurement variance studies have shown that age and IQ, were not related to item-level responding for youth with ID (Maïano et al., 2023), nor was autism diagnosis (White et al., 2015). Thus, disagreement may reflect general differences in how parents and youth respond to similar measures of anxiety, which often may relate to differences in perspective and interpretation of anxiety provoking situations.

Parent-Level Predictors

Research on parent-level factors related to agreement has largely focused on parent mental health and emotional states, such as parent psychopathology and parenting stress (Affrunti & Woodruff-Borden, 2015; Ooi et al., 2016). Interestingly, few studies have evaluated how parents'

behaviors related to youth anxiety, termed accommodation behaviors, impact informant discrepancies. Anxiety related avoidance often can extend to involving others in avoiding the feared situation itself, or related thoughts. Within the literature, this has been termed "family accommodation" behaviors, or changes that parents make related to youth anxiety (Lebowitz et al., 2013). These accommodation behaviors occur via two main patterns – 1) modifications to routines, or changes the family makes to their life to avoid the feared situation, and 2) excessive reassurance, or repetitive verbal reassurance that the fear won't come true (which is related to avoidance of thoughts of the feared situation). This pattern is likely even more significant for autistic adolescents with ID, with previous research showing autistic youth show a general delay in utilization of self-regulation strategies, and a prolonged role of parents within co-regulation strategies (Cibralic et al., 2019). Further, autistic adolescents with ID display heightened behavior challenges relative to their non-autistic peers (Baker & Blacher, 2020), which may significantly contribute to their parents' accommodation behaviors as a means of preventing or avoiding aggression and other difficult behavior (O'Nions et al., 2020).

Family accommodation behaviors may influence both parent and youth reporting – such that parents may appraise youth's anxiety levels as higher when inducing behavioral changes to avoid such situations. High levels of accommodation may limit the degree to which youth experience anxiety and impact their reporting of anxiety. Previous research within the general population has shown that level of accommodation moderates parent and youth agreement with lab-based behavioral measures of anxiety. With low levels of family accommodation, both youth and parent reporting of anxiety were related to behavioral measures of anxiety, however, when family accommodation was high, only youth-report of anxiety was correlated with observed anxious

behaviors (Lebowitz, 2017). Thus, parental accommodation behaviors may be a useful factor in understanding differences in parent-youth reporting.

Current Study Aims

The current study aims to address gaps in the literature, which has been relatively limited in terms of investigating patterns of parent-youth agreement on anxiety reporting in adolescents with ID, particularly in determining factors that predict this agreement.

Specifically, the current study aimed to answer the following research questions, and test the following hypotheses:

1) Which adolescent characteristics are related to the ability to complete a self-report measure of anxiety?

    Hypothesis 1: Higher age, cognitive ability, adaptive skills, and verbal ability will significantly predict the ability to complete the GAS-ID, a self-report measure of anxiety.

2) What types of worries and symptoms do autistic adolescents with ID most commonly endorse on a self-report measure of anxiety?

    Hypothesis 2: As this is a descriptive question, specific hypotheses were not made.

3) What is the general level of agreement between parent-report and self-report of anxiety symptoms?

    Hypothesis 3: This is an exploratory aim, due to limited data on these measures and research in this population.

4) What adolescent and parent characteristics predict higher levels of agreement for anxiety ratings?

Hypothesis 4: Higher age, adaptive skills, verbal ability, and lower levels of parent accommodation behaviors will predict greater agreement.

Method

Study Procedure

Parent-adolescent dyads were part of a randomized control trial evaluating the efficacy of a cognitive behavioral therapy program adapted for autistic adolescents with ID, Facing Your Fears – Intellectual and Developmental Disabilities edition (FYF-IDD; Blakeley-Smith et al., 2021). Data used in the current study were collected during a baseline qualification visit, prior to treatment allocation (treatment versus waitlist control). Parents consented to study participation. Adolescents participated in an assent process, which included a plain language statement, adjusted to the adolescent's language level, about the study. The university IRB (COMIRB) approved all study procedures (IRB #20-3142), which were conducted in alignment with the ethical principles set forth in the Declaration of Helenski. To qualify for the study, adolescents needed to meet cut-off scores for autism on the Autism Diagnostic Observation Schedule, 2nd edition (ADOS-2), have adaptive and Abbreviated IQ (ABIQ) scores indicative of ID (below 70), and meet clinical criteria for an anxiety disorder via parent interview (Anxiety Disorders Interview Schedule – Autism Addendum; Kerns et al., 2017; Silverman, 1996) and parent-report (ADAMS).

Participants

Sixty adolescents out of 72 participating in the larger study provided complete data for the GAS-ID. Factors related to GAS-ID completion were investigated as primary research questions

and are summarized within the results. Adolescents were 12 – 18 years old, with an ABIQ range

of 47 – 79. Additional demographic information for the sample is summarized in Table 1.

Table 1. *Demographics for parents and adolescents in the study (N = 72).*

Adolescent Variable	M (SD) / % (N)	Parent Variable	M (SD) / % (N)
Age	15.2 (2.1)	Relation to Adolescent	
Gender		Biological Mother	80.6% (58)
Female	32.4% (23)	Biological Father	8.3% (6)
Male	64.8% (46)	Adoptive Parent	6.9% (5)
Non-binary	2.8% (2)	Other	4.2% (3)
Race/Ethnicity		Family Income	
American Indian/Alaska Native	5.5% (4)	$15K-$35K	7% (5)
Black/African American	9.7% (7)	$35K-$50K	12.7% (9)
Asian	5.5% (4)	$50-$75K	7% (5)
White	76.4% (55)	$75K-$100K	11.3% (8)
Multiracial	8.3% (6)	$100K+	53.5% (38)
Hispanic/Latino	26.8% (19)	Marital Status	
ABIQ – Stanford Binet	56.0 (9.35)	Married	58% (41)
ABAS General Adaptive Composite (GAC)	60.4 (8.52)		
ADOS Module			
1	5.6% (4)		
2	22.5% (16)		
3	42.3% (30)		
4	29.6% (21)		

Measures

Anxiety Measures

The Glasgow Anxiety Scale for people with an intellectual disability (GAS-ID; Mindham &

Espie, 2003) is a self-report measure of anxiety created for individuals with ID. It has 27 items

related to individual's worries, feared situations, and physiological symptoms, with response

options – "Never", "Sometimes", "Always" (0 – 2). For administration, "practice" items

unrelated to anxiety (e.g., "I like to eat ice cream") are used to help introduce the rater to the

task, with the option of pointing or selecting choice cards, rather than marking an answer. Items were read aloud to adolescents, with additional clarification as needed for comprehending items via examples provided on the GAS-ID or additional verbal clarification. Similar procedures for supporting self-report were used within the original GAS-ID validation studies (Maïano et al., 2023; Mindham & Espie, 2003) and are consistent with best practices in ID.

The GAS-ID has high discriminant and convergent validity in terms of anxiety symptomatology and has been previously validated for use with this age range, and across a range of cognitive functioning (IQ scores = 35 – 70; Maïano et al., 2023). For this study, a "global" anxiety factor was created by summing responses across the 27 items, which has previously been confirmed as a valid "global" construct of anxiety (Maïano et al., 2023). Three subscales can also be constructed for "worries", "situations", and "symptoms", relating to general worries, anxiety provoking situations, and physiological symptoms associated with anxiety. The internal consistency within the current sample for the GAS-ID was high, $\alpha = .84$. Confirmatory factor analyses showed reasonable fit for the factor structure (global and 3 subscale) in this sample (RMSEA = 0.072; original RMSEA = 0.041).

The Anxiety, Depression, and Mood Scale (ADAMS; Esbensen et al., 2003) is a parent-report measure of anxiety. The ADAMS was specifically designed for measuring mental health symptoms in individuals with ID, including adolescents. The general anxiety subscale was used to measure anxiety, which consists of 7 items that the parent rates using a 4-point Likert scale (0 – 3; "Not a problem" – "Severe Problem"). This measure was chosen for its high psychometric properties (internal consistency, re-test reliability, construct validity) and previous use as an outcome measure in mental health treatment trials, as there are no anxiety measures designed for youth with ID with self and proxy report respondent options. The general anxiety subscale

showed good internal consistency within the current sample, $\alpha = .75$. Confirmatory factor analyses also showed reasonable fit for the sample, compared to the original study sample (RMSEA = 0.098; original RMSEA = 0.087).

Predictors

Stanford-Binet Scales of Intelligence-Fifth Edition, Abbreviated Battery (SB-5; Roid & Pomplun, 2012) was used as a measure of cognitive ability for the sample. The abbreviated battery consists of 2 subtests: Object Series/Matrices (Nonverbal), and Vocabulary (Verbal), and results in an abbreviated intelligence quotient (ABIQ), which is a norm-referenced, standard score. The verbal subtest raw score was also used as a measure of verbal ability.

The Adaptive Behavior Assessment System 3rd Edition (ABAS-3; Harrison & Oakland, 2015), General Adaptive Composite (GAC) was used as a measure of adaptive skills and overall developmental level. As floor effects are common with standardized IQ assessments, adaptive skills can often be a better indicator to the level of support needs for individuals with ID. The ABAS-3 is a caregiver-reported, norm-referenced measure, that measures an individual's adaptive skills, or skills required for daily living. This measure focuses on the degree to which an individual can perform a skill independently, requires support to perform a skill, or does not perform the skill.

The Autism Diagnostic Observation Schedule, 2nd edition (ADOS-2; Lord, 2012) module was used in analyses as a proxy of verbal ability (i.e., expressive language), in addition to the SB-5 verbal subscale. The ADOS-2 is a series of semi-structured tasks, that include a series of observational items to help guide autism diagnosis. Tasks vary across modules, which are designed based on an individual's verbal abilities and age. Verbal abilities are as follows: Module

1, pre-verbal to single words; Module 2, phrase speech, Module 3, fluent speech; and Module 4, fluent speech (16 years). See Table 1 for frequency of each module. Those that completed Module 1 or 2 were classified as "Fluent Speech: No" and participants that completed Module 3 or 4 were classified as "Fluent Speech: Yes".

The Family Accommodation Scale – Anxiety (FASA; (Lebowitz et al., 2013) was used to measure parent accommodation of anxiety. The FASA consists of 13 items, which parents rate on a 5-point Likert scale to indicate frequency (Never, 1-3 times a week, 1-2 times a week, 3-6 times a week, Daily). These items comprise 2 different subscales: Participation (e.g., "How often did you reassure your child?"), which includes reassurance, and Routine Modification (e.g., "Have you modified your routine/work schedule/leisure activities because of your child's anxiety?"), which includes avoidance. The FASA has shown good convergent and divergent validity, as well as a validated 2-factor structure (Lebowitz et al., 2013, 2020). FASA subscales showed good internal consistency for the current sample (α's = .78 – .86)

Data Analysis

Data analyses were conducted using R (version 4.3.2), using the psych (Revelle, 2024) and lavaan (Rosseel, 2012) packages to support analyses. To examine group differences on variables of interest, t-tests, and non-parametric tests (Wilcoxon rank sum test) were performed. To examine parent-youth agreement, bivariate correlations were performed.

To examine predictors of agreement, analyses were run using linear regression, with the predictor set as an interaction term (Parent Rating = Adolescent Rating * Predictor). To address issues with adequate power in regression analyses, as a data reduction strategy, we also examined differences in means for the predictor variables between agreement groups (e.g., "agree",

"disagree") using a mean-split strategy with t-tests. Descriptive groups for parent-youth

agreement were based on mean-splits for parent and adolescent anxiety ratings. When examining

agreement patterns across raters, latent profile analysis has been suggested to create groups (De

Los Reyes et al., 2023), however, due to our smaller sample size, this analytic strategy was not

feasible. Mean-split groups are descriptively similar to those created from a latent approach and

are also driven by data characteristics of the sample.

Results

Question 1: Which adolescent characteristics are related to ability to complete a self-report measure of anxiety?

GAS-ID completion was investigated as a function of adaptive skills, cognitive ability, verbal

ability, and age. Adolescents who completed the GAS-ID had significantly higher adaptive skills

scores as measured by the ABAS-3 GAC ($t(14.9) = 4.4$, $p < .001$), higher cognitive abilities (SB-5

ABIQ; $t(61.8) = 6.9$, $p < .001$), and were significantly more likely to have fluent speech (versus

no words to phrase speech; $\chi2 = 18.56$, $p < .001$; Table 2) relative to those who could not complete

the measure. Age did not significantly predict GAS-ID completion ($t(15.7) = 1.6$, $p = 0.12$).

Table 2. *Means and percentages for GAS-ID completion as a function of adaptive skills cognitive ability, age, and use of fluent speech (verbal ability).*

GAS-ID	ABAS GAC Score	SB-5 ABIQ Score	Age (years)	Fluent Speech	
				Yes	No
Completed (n=60)	61.9	57.7	14.4	69%	14%
Not Completed (n=12)	52.1	47.9	15.4	3%	14%

Question 2: What types of worries and symptoms do autistic adolescents with ID most commonly endorse?

Figures 1 – 3 show item level responses across the 3 different subscales. Table 3 provides descriptive statistics for each of the subscales, and the total scale. With the "worries" subscale, most adolescents reported worrying at least sometimes across individual items (range = 59 – 87%). With the "situations" subscale, adolescents tended to rate items with greater variability (21% - 69%) with the most common situations adolescents endorsed including new people (70%), heights (65%), spiders (63%), and busy places (57%). With the "symptoms" subscale, most adolescents endorsed feeling physical symptoms of anxiety at least sometimes (range = 48% - 70%), with less variability than the "worries" or "situations" subscales.

[Figures 1-3]

Question 3: What is the general level of agreement between parent-report and youth self-report of anxiety symptoms?

First, agreement was investigated as a bivariate correlation between the ADAMS General Anxiety Scale, and the GAS-ID Total Scale, as well as the GAS-ID subscales (Table 3). Agreement was generally poor, with all correlations between parent-report and youth-report of anxiety non-significant ($p > 0.05$), and $r < .2$.

Table 3. *Bivariate correlations for ADAMS General Anxiety Scale and the GAS-ID scales (N = 60) and descriptives for the GAS-ID scales*

	GAS-ID Total	Worries	Situations	Symptoms
Correlation ADAMS General Anxiety	0.104	-0.011	0.085	0.180
Mean (SD) GAS-ID Subscales	22.45 (8.45)	9.27 (3.48)	6.83 (3.85)	6.35 (3.54)

Note. * p < 0.05, † p < 0.1.

Second, agreement groups were created based on mean-splits for anxiety ratings. There was a similar number of parent-youth dyads who had high agreement (N = 32) and low agreement (N = 28). Correlations between parent-report and youth-report of anxiety symptoms varied across groups, with a significant positive correlation for the "agree" group, $r(32) = 0.66$, $p < 0.001$; and a significant negative correlation for the "disagree" group, $r(28) = -0.64$, $p < 0.001$.

Question 4: What adolescent and parent characteristics predict higher levels of agreement for anxiety ratings?

Parent-Youth Ratings: Adolescent Global Anxiety

Adaptive skills, verbal abilities, and family accommodation behaviors did not significantly moderate the relationship between parent-report of anxiety and youth-report of global anxiety ($p > 0.05$). Results were similarly nonsignificant when looking at differences on these variables between the "agree" and "disagree" groups ($p > 0.05$).

Parent-Youth Ratings: Adolescent Physical Symptoms

As the correlation between parent-report of anxiety and youth-report was highest for the "symptoms" subscale of the GAS-ID, we repeated moderation analyses to investigate which factors predict greater agreement. Adaptive skills and verbal abilities did not significantly moderate the relationship between parent-report of anxiety and youth-report of physical anxiety symptoms ($p > 0.05$). Parent participation in accommodation behaviors marginally predicted the relationship between parent-report and youth-report of physical symptoms, $F(3, 54) = 5.55$, $p = 0.002$; interaction $\beta = 0.24$, $p = 0.069$. Specifically, when parents reported daily levels of "accommodation" (e.g., score > 18/20), the relationship between parent and youth report was

significant; $\beta = 0.45$, $p < 0.05$. The same pattern did not hold for family changes in routine due to anxiety (i.e., "routine modification"), $F(3,54) = 0.56$, $p = 0.002$; interaction $\beta = .07$; $p = .57$.

Discussion

The study findings highlight both the utility and challenge of including self-report in the assessment of anxiety for autistic adolescents with ID. While most adolescent participants were able to complete the GAS-ID, a well-validated measure of anxiety for ID, completion was dependent on adolescents' adaptive, cognitive, and verbal abilities. Verbal and adaptive skills were not related to parent-youth agreement. While parent accommodation behaviors may be related to agreement, this finding warrants careful interpretation due to its marginal statistical significance and specificity to a specific subscale of adolescent anxiety.

Self-Report in Adolescents and ID

Predictors of Self-Report Completion

First, 82% of the sample completed the GAS-ID. In keeping with hypotheses, adolescents with lower adaptive skills, lower cognitive abilities, and those using no words to phrase speech to communicate were less likely to complete the GAS-ID. In contrast to hypotheses, older age was not a significant predictor of successful completion. This finding mirrors previous research indicating measurement invariance across age groups (Maïano et al., 2023), as well as successful use of this tool with youth as young as 5 years old (Gobrial & Raghavan, 2012). This finding also suggests that the GAS-ID was not accessible for adolescents with more limited cognitive and verbal abilities.

Self-Report Descriptive Patterns

The distribution of adolescents' responses on the GAS-ID showed that adolescents generally endorsed feeling worried. Adolescents discriminated between different situational anxiety triggers, as seen by the varied distribution of responses on the "situations" subscale. Adolescents tended to more frequently endorse physiological symptoms that related to external (e.g., hands and legs shake; difficult to sit still) behaviors, which may reflect greater awareness of symptoms that others have pointed out (e.g., observable symptoms).

Common fears endorsed in the "situations" subscale included meeting new people, spiders and new places. Fears of new people and places may be reflective of social anxiety and generalized anxiety symptomatology, which are common in adolescence (Steinsbekk et al., 2022). This supports recent conceptual shifts in research on anxiety in individuals in ID from a primary focus on phobias (Hagopian & Jennett, 2008), which tend to be common across development, to include other types of fears, such as social and generalized anxiety (Kerns et al., 2021; Maïano et al., 2023). Further self-report research may help illuminate if these fears indicate autism-specific fears, as research utilizing parent-report has found a similar rate of autism-specific fears among autistic youth with and without ID (Kerns et al., 2021). For example, fear of new people could include social anxiety that is not driven by fear of negative evaluation, but rather social confusion (Kerns et al., 2017), and that fear of new places may include worries related to unexpected changes.

Parent-Youth Agreement

Limited research on the use of self-report with autistic individuals with ID in part has been driven by challenges in interpreting informant discrepancies (Schiltz et al., 2024). In research with autistic youth without ID, there is generally moderate agreement for internalizing symptoms (Stratis & Lecavalier, 2015). Within our study, there was generally poor agreement between

parent-report and youth-report measures of anxiety. In part, this finding may be explained by the differences in anxiety measures, pointing to the importance of further instrument design. In research investigating agreement in the non-ID autistic population, informant forms often have similar items with parent-youth measures (Blakeley-Smith et al., 2012; Kim & Lecavalier, 2022).

Predictors of Parent-Youth Agreement

Contrasting with previous research in autistic youth (Blakeley-Smith et al., 2012; Burrows et al., 2018; Ooi et al., 2016) and our study hypotheses, verbal abilities and adaptive skills were not predictive of parent-youth agreement. This may be due to the more extreme discrepancy in agreement within our study, which is likely related to the variability in cognitive functioning in our study sample, and differences in parent and youth measures. Within other populations and methods, as agreement tends to be more moderate, these factors may more substantially account for variability. We did see greater agreement between the youth-report "symptoms" subscale and parent-report, which is consistent with previous studies that indicate greater agreement with more "observable" behaviors (Comer & Kendall, 2004; Ooi et al., 2016).

For the correlation between the "symptoms" self-report subscale, and parent-report, we found that parent accommodation behaviors were predictive of agreement. This finding is consistent with previous research in youth without autism or ID, finding parental accommodation behaviors predicted concordance between parent-report of anxiety and lab-based measures (Lebowitz, 2017), however, our findings were in the opposite direction, such that high levels of accommodation behaviors were predictive of agreement. For adolescents with ID, parents' verbal reassurance or avoidance of an anxiety provoking situation, could serve as a "shared language" related to anxiety. Given that the adolescent's anxiety and parent's behaviors both result in behavioral avoidance, these behaviors may serve to foster a shared understanding of anxiety

severity. This also suggests that anxiety measures that focus on physical symptoms and behavioral avoidance may result in higher agreement within this population. For example, the Parent-Rated Anxiety Scale for ASD (PRAS-ASD; Scahill et al., 2019) focuses items on more behavioral manifestations of anxiety. However, replication of this finding would be useful given the marginal range of statistical significance and lack of extension to the other family accommodation subscale (changes in family routines).

Limitations

A major limitation of the study is that parent-youth agreement was assessed using different anxiety measures, reflecting a lack of availability of measures for this population. Naturally, measures included different items and differ in their focus on anxiety, which may have negatively impacted agreement. Response bias, or responding in an overly favorable manner, is also a potential limitation in using self-report among youth with lower cognitive abilities. However, research also shows the procedure used to administer the Glasgow, which includes the ability to paraphrase or expand upon items, helps to reduce response bias among adolescents and adults with ID (Hartley & MacLean, 2006). Additionally, given the heterogeneity of the ID population, it is important to recognize that the generalizability is limited to those with verbal and cognitive abilities similar to this sample. As verbal and cognitive abilities impacted adolescents' ability to complete the youth-report measure, we cannot assume that findings generalize across the full spectrum of ID.

Clinical Implications and Future Directions

This study points to the need for measure development for self-report of anxiety in autistic individuals with ID, specifically that 1) include greater pictorial representations of items to

extend access across all communication abilities of youth with ID and 2) have parent and youth versions. Our findings also suggest focusing on observable physiological symptoms, behavioral avoidance, and situational triggers may enhance agreement, given their increased concordance with parent-report.

Additional research is also needed on parent-youth agreement – including the factors that predict agreement in this population, and how agreement impacts treatment outcomes. In treatment studies, changes in symptom scores could be due to intervention reducing anxiety symptoms or could be due to greater awareness of anxiety symptoms. Using follow-up time points, supplementing patient reported measures with clinician-based measures, or measures of anxiety awareness may support interpretation. Investigating how parent-youth agreement affects treatment outcomes among autistic adolescents with ID is also a pressing question, due to the increased emphasis on parent involvement in CBT adapted for this population. Understanding how to best interpret different parent and youth perspectives on anxiety, particularly among youth with ID, is likely to aid treatment efficacy. Being able to accurately draw conclusions from clinical intervention trials, and to promote positive outcomes, is essential to ensuring that adolescents with ID and their families have equitable access to the supports that will promote overall mental health, well-being, self-determination, and meaningful life experiences.

References

Affrunti, N. W., & Woodruff-Borden, J. (2015). The effect of maternal psychopathology on parent–child agreement of child anxiety symptoms: A hierarchical linear modeling approach. *Journal of Anxiety Disorders*, *32*, 56–65.

Appleton, H., Roberts, J., & Simpson, K. (2019). How is anxiety identified and diagnosed in individuals with autism spectrum disorder and intellectual disability? A scoping review. *Journal of Mental Health Research in Intellectual Disabilities*, *12*(3–4), 152–175.

Baker, B. L., & Blacher, J. (2020). Brief report: Behavior disorders and social skills in adolescents with autism spectrum disorder: Does IQ matter?. *Journal of Autism and Developmental Disorders*, *50*(6), 2226-2233.

Becker-Haimes, E. M., Jensen-Doss, A., Birmaher, B., Kendall, P. C., & Ginsburg, G. S. (2018). Parent–youth informant disagreement: Implications for youth anxiety treatment. *Clinical Child Psychology and Psychiatry*, *23*(1), 42–56.

Blakeley-Smith, A., Meyer, A. T., Boles, R. E., & Reaven, J. (2021). Group cognitive behavioural treatment for anxiety in autistic adolescents with intellectual disability: A pilot and feasibility study. *Journal of Applied Research in Intellectual Disabilities*, *34*(3), 777–788.

Blakeley-Smith, A., Reaven, J., Ridge, K., & Hepburn, S. (2012). Parent–child agreement of anxiety symptoms in youth with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *6*(2), 707–716.

Burrows, C. A., Usher, L. V, Becker-Haimes, E. M., McMahon, C. M., Mundy, P. C., Jensen-Doss, A., & Henderson, H. A. (2018). Profiles and correlates of parent–child agreement on social anxiety symptoms in youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *48*, 2023–2037.

Cibralic, S., Kohlhoff, J., Wallace, N., McMahon, C., & Eapen, V. (2019). A systematic review of emotion regulation in children with Autism Spectrum Disorder. *Research in Autism Spectrum Disorders*, *68*, 101422.

Comer, J. S., & Kendall, P. C. (2004). A symptom-level examination of parent–child agreement in the diagnosis of anxious youths. *Journal of the American Academy of Child & Adolescent Psychiatry*, *43*(7), 878–886.

De Los Reyes, A., Wang, M., Lerner, M. D., Makol, B. A., Fitzpatrick, O. M., & Weisz, J. R. (2023). The operations triad model and youth mental health assessments: Catalyzing a paradigm shift in measurement validation. *Journal of Clinical Child & Adolescent Psychology*, *52*(1), 19–54.

Esbensen, A. J., Rojahn, J., Aman, M. G., & Ruedrich, S. (2003). Reliability and validity of an assessment instrument for anxiety, depression, and mood among individuals with mental retardation. *Journal of Autism and Developmental Disorders*, *33*, 617–629.

Ferdinand, R. F., Van Der Ende, J., & Verhulst, F. C. (2006). Prognostic value of parent–adolescent disagreement in a referred sample. *European Child & Adolescent Psychiatry*, *15*(3), 156–162.

Flynn, S., Vereenooghe, L., Hastings, R. P., Adams, D., Cooper, S.-A., Gore, N., Hatton, C., Hood, K., Jahoda, A., & Langdon, P. E. (2017). Measurement tools for mental health problems and mental well-being in people with severe or profound intellectual disabilities: A systematic review. *Clinical Psychology Review*, *57*, 32–44.

Gobrial, E., & Raghavan, R. (2012). Prevalence of anxiety disorder in children and young people with intellectual disabilities and autism. *Advances in Mental Health and Intellectual Disabilities*, *6*(3), 130–140.

Hagopian, L. P., & Jennett, H. K. (2008). Behavioral assessment and treatment of anxiety in individuals with intellectual disabilities and autism. *Journal of Developmental and Physical Disabilities*, *20*, 467–483.

Halvorsen, M. B., Helverschou, S. B., Axelsdottir, B., Brøndbo, P. H., & Martinussen, M. (2023). General measurement tools for assessing mental health problems among children and adolescents with an intellectual disability: A systematic review. *Journal of Autism and Developmental Disorders*, *53*(1), 132–204.

Harrison, P. L., & Oakland, T. (2015). *Adaptive Behavior Assessment System, Third Edition*. Western Psychological Services.

Hartley, S. L., & MacLean Jr, W. E. (2006). A review of the reliability and validity of Likert-type scales for people with intellectual disability. *Journal of Intellectual Disability Research*, *50*(11), 813-827.

Helverschou, S. B., Ludvigsen, L. B., Hove, O., & Kildahl, A. N. (2021). Psychometric properties of the Psychopathology in Autism Checklist (PAC). *International Journal of Developmental Disabilities*, *67*(5), 318–326.

Hemm, C., Dagnan, D., & Meyer, T. D. (2018). Social anxiety and parental overprotection in young adults with and without intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *31*(3), 360–368.

Hermans, H., van der Pas, F. H., & Evenhuis, H. M. (2011). Instruments assessing anxiety in adults with intellectual disabilities: A systematic review. *Research in Developmental Disabilities*, *32*(3), 861–870.

Kalvin, C. B., Marsh, C. L., Ibrahim, K., Gladstone, T. R., Woodward, D., Grantz, H., Ventola, P., & Sukhodolsky, D. G. (2020). Discrepancies between parent and child ratings of anxiety in children with autism spectrum disorder. *Autism Research*, *13*(1), 93–103.

Kerns, C. M., Renno, P., Kendall, P. C., Wood, J. J., & Storch, E. A. (2017). Anxiety disorders interview schedule–autism addendum: Reliability and validity in children with autism spectrum disorder. *Journal of Clinical Child & Adolescent Psychology*, *46*(1), 88–100.

Kerns, C. M., Winder-Patel, B., Iosif, A. M., Nordahl, C. W., Heath, B., Solomon, M., & Amaral, D. G. (2021). Clinically significant anxiety in children with autism spectrum disorder and varied intellectual functioning. *Journal of Clinical Child & Adolescent Psychology*, *50*(6), 780–795.

Kim, S. Y., & Lecavalier, L. (2022). Evaluating the use of self-reported measures in autistic individuals in the context of psychiatric assessment: A systematic review. *Journal of Autism and Developmental Disorders*, *52*(10), 4355–4374.

Lebowitz, E. R. (2017). Mother and child ratings of child anxiety: Associations with behavioral avoidance and the role of family accommodation. *Parenting*, *17*(2), 124–142.

Lebowitz, E. R., Marin, C. E., & Silverman, W. K. (2020). Measuring family accommodation of childhood anxiety: Confirmatory factor analysis, validity, and reliability of the parent and child family accommodation scale–anxiety. *Journal of Clinical Child & Adolescent Psychology*, *49*(6), 752–760.

Lebowitz, E. R., Woolston, J., Bar-Haim, Y., Calvocoressi, L., Dauser, C., Warnick, E., Scahill, L., Chakir, A. R., Shechner, T., & Hermes, H. (2013). Family accommodation in pediatric anxiety disorders. *Depression and Anxiety*, *30*(1), 47–54.

Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., & Bishop, S. (2012). *Autism Diagnostic Observation Schedule, Second Edition*. Western Psychological Services.

Maïano, C., Morin, A. J. S., Gagnon, C., Olivier, E., Tracey, D., Craven, R. G., & Bouchard, S. (2023). Validation of an adapted version of the Glasgow Anxiety Scale for people with Intellectual Disabilities (GAS-ID). *Journal of Autism and Developmental Disorders*, *53*(4), 1560–1572.

Makol, B. A., De Los Reyes, A., Ostrander, R. S., & Reynolds, E. K. (2019). Parent-youth divergence (and convergence) in reports of youth internalizing problems in psychiatric inpatient care. *Journal of Abnormal Child Psychology*, *47*, 1677–1689.

Manassis, K., Lee, T. C., Bennett, K., Zhao, X. Y., Mendlowitz, S., Duda, S., Saini, M., Wilansky, P., Baer, S., & Barrett, P. (2014). Types of parental involvement in CBT with anxious youth: a preliminary meta-analysis. *Journal of Consulting and Clinical Psychology*, *82*(6), 1163.

Mindham, J., & Espie, C. (2003). Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID): Development and psychometric properties of a new measure for use with people with mild intellectual disability. *Journal of Intellectual Disability Research*, *47*(1), 22–30.

Ooi, Y. P., Weng, S.-J., Magiati, I., Ang, R. P., Goh, T. J., Fung, D. S., & Sung, M. (2016). Factors influencing agreement between parent and child reports of anxiety symptoms among children with high-functioning autism spectrum disorders. *Journal of Developmental and Physical Disabilities*, *28*, 407–424.

O'Nions, E., Ceulemans, E., Happé, F., Benson, P., Evers, K., & Noens, I. (2020). Parenting strategies used by parents of children with ASD: Differential links with child problem behaviour. *Journal of Autism and Developmental Disorders*, *50*, 386-401.

Reaven, J. A., Blakeley-Smith, A., Nichols, S., Dasari, M., Flanigan, E., & Hepburn, S. (2009). Cognitive-behavioral group treatment for anxiety symptoms in children with high-functioning autism spectrum disorders: A pilot study. *Focus on Autism and Other Developmental Disabilities*, *24*(1), 27-37.

Revelle, W. (2024). *psych: Procedures for Psychological, Psychometric, and Personality Research* (R package version 2.4.6). Northwestern University.

Roid, G. H., & Pomplun, M. (2012). *The Stanford-Binet Intelligence Scales, Fifth Edition*. The Guilford Press New York, NY, USA:

Rosseel, Y. (2012). lavaan: An R package for structural equation modeling. *Journal of Statistical Software*, *48*, 1–36.

Schiltz, H. K., Williams, Z. J., Zheng, S., Kaplan-Kahn, E. A., Morton, H. E., Rosenau, K. A., Nicolaidis, C., Sturm, A., Lord, C., & PROMnet, A. (2024). Measurement matters: A commentary on the state of the science on patient reported outcome measures (PROMs) in autism research. *Autism Research*, *17*(4), 690–701.

Silverman, W. K., & Albano, A. M. (1996). *Anxiety disorders interview schedule for DSM-IV.: Parent interview schedule* (Vol. 1). Oxford University Press.

Spence, S. H. (2018). Assessing anxiety disorders in children and adolescents. *Child and Adolescent Mental Health*, *23*(3), 266–282.

Steinsbekk, S., Ranum, B., & Wichstrøm, L. (2022). Prevalence and course of anxiety disorders and symptoms from preschool to adolescence: A 6-wave community study. *Journal of Child Psychology and Psychiatry*, *63*(5), 527–534.

Stratis, E. A., & Lecavalier, L. (2015). Informant agreement for youth with autism spectrum disorder or intellectual disability: A meta-analysis. *Journal of Autism and Developmental Disorders*, *45*, 1026–1041.

Tarver, J., Pearson, E., Edwards, G., Shirazi, A., Potter, L., Malhi, P., & Waite, J. (2021). Anxiety in autistic individuals who speak few or no words: A qualitative study of parental experience and anxiety management. *Autism*, *25*(2), 429–439.

White, S. W., Lerner, M. D., McLeod, B. D., Wood, J. J., Ginsburg, G. S., Kerns, C., Ollendick, T., Kendall, P. C., Piacentini, J., & Walkup, J. (2015). Anxiety in youth with and without autism spectrum disorder: Examination of factorial equivalence. *Behavior Therapy*, *46*(1), 40–53.

Winch, A. T., Klaver, S. J., Simpson, S., Calub, C. A., & Alexander, K. (2022). Identifying and treating anxiety in youth with autism spectrum disorder/intellectual developmental disorder: a review. *Evidence-Based Practice in Child and Adolescent Mental Health*, *7*(1), 160–172.

Young, R., Dagnan, D., & Jahoda, A. (2016). Leaving school: a comparison of the worries held by adolescents with and without intellectual disabilities. *Journal of Intellectual Disability Research*, *60*(1), 9–21.
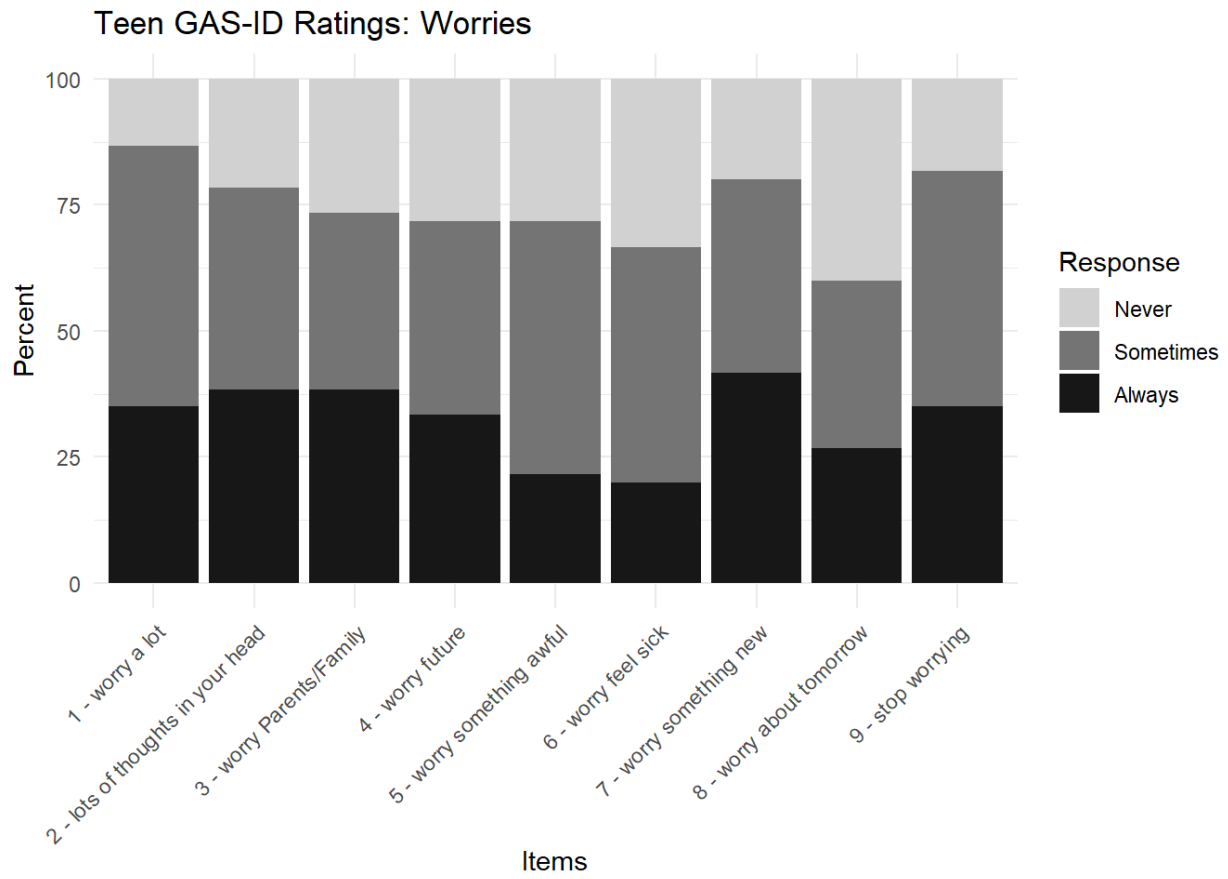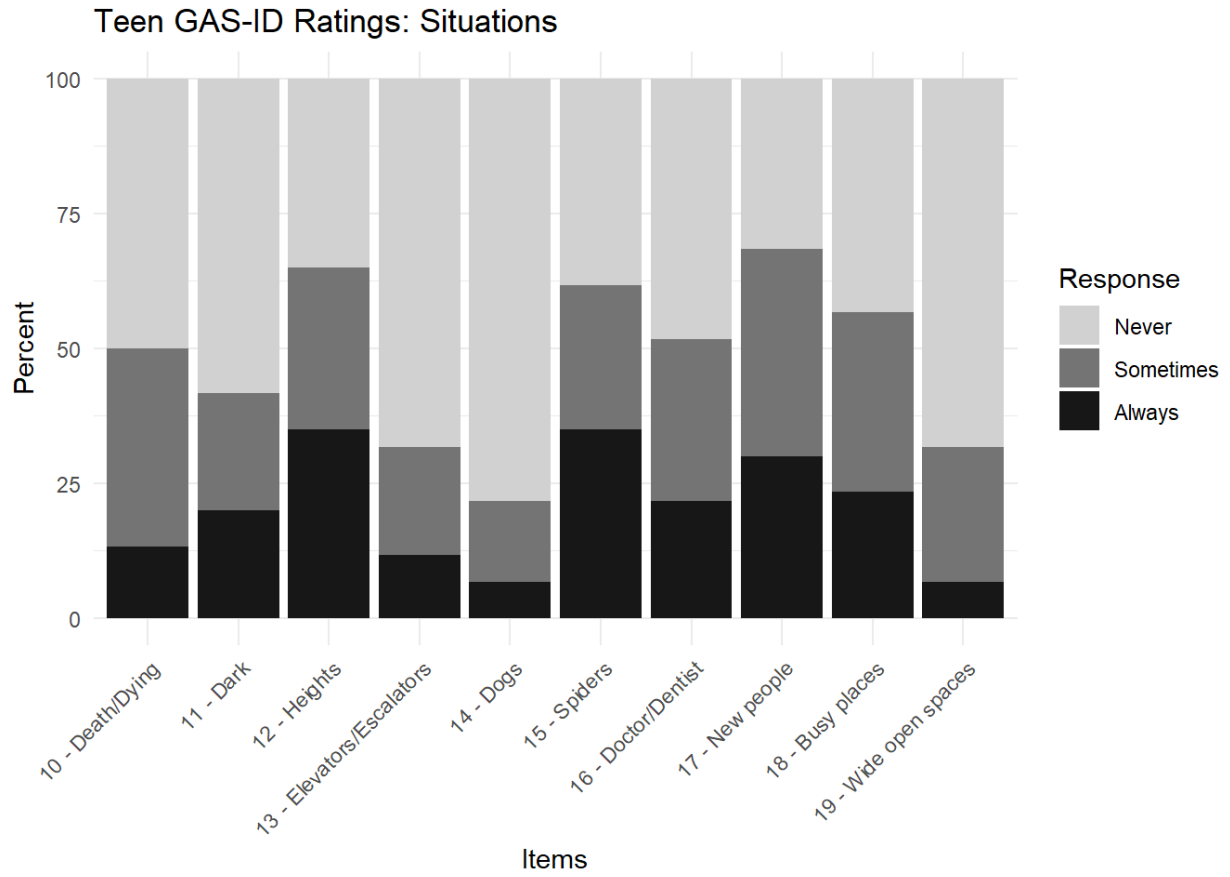
Figure 1

Teen GAS-ID Ratings: Worries

Figure 2

Teen GAS-ID Ratings: Situations

Figure 3

Teen GAS-ID Ratings: Symptoms