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### IMPACT OF RESPONDENTS ON SIS-A

Impact of Different Pairings of Respondents on Scores on the Supports Intensity Scale -

Adult Version (SIS-A)

### Abstract

This secondary analysis examined the impact of respondent-level factors on scores on the Supports Intensity Scale–Adult Version (SIS-A) to determine if there were patterns of differences in SIS-A scores based on the number of respondents and the pairings of respondents that were included in SIS-A interviews. Results indicated that having fewer respondents led to a greater variability in SIS-A scores while having more respondents led to higher mean, overall support need scores. When respondents included an adult with intellectual disability (ID) the mean score was significantly lower. However, there were complex influences of pairing an adult with ID with either a professional or family member on SIS-A scores. Implications for administering and using the SIS-A are discussed.

*Key Words*: the Supports Intensity Scale – Adult Version (SIS-A), respondent-level factors, secondary analysis

# Impact of Different Pairings of Respondents on Scores on the Supports Intensity Scale – Adult Version (SIS-A)

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is a human rights treaty that recognizes the fundamental right of people with disabilities, including those with intellectual disability (ID), to participate fully in all facets of life including education, employment, and community living (United Nations, 2006). The treaty is another indication of how the conceptualization of ID has shifted from a deficit model of disability to a social-ecological model of disability (Thompson et al., 2017; World Health Organization, 2007) in recent years. A social-ecological model emphasizes understanding disability from a strengths-based perspective where efforts are made to identify and provide supports that enable people to function successfully in community environments (Wehmeyer et al., 2018). As such, the role of supports to minimize discrepancies between personal competencies and the demands of community environments to promote the full participation of people with ID in all life activities and domains is prominent (Shogren et al., 2018; Wehmeyer et al., 2017).

A social-ecological model of disability gives rise to a focus on the supports needed for people with ID to fully participate in community environments, as well as ensuring that supports provided align with each person's preferences, strengths, and values (Thompson et al., 2017). Support needs is "a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning" (Thompson et al., 2009, p. 135). Supports are "resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning" (Schalock et al., 2010, p. 18). As such, supports must be in place to address people's support needs, and these supports must be selected based on assessed support

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needs as well as an understanding of what will enable people with intellectual disability to participate in activities and environments in ways that match their preferences and values (Hagiwara, Shogren, & Lockman Turner, 2019; Shogren & Broussard, 2011).

Contextual factors influence access to supports as well as the preferences and values for supports and participation that are held by people with ID and those that support them. Context is defined as "a concept that integrates the totality of circumstances that comprise the milieu of human life and human functioning" (Shogren, Luckasson, et al., 2014; Shogren et al., in press) and encompasses both (a) independent variables, including personal and environmental factors that usually are not manipulated (e.g., age, gender, race/ethnicity, culture, family) and (b) intervening variables, including organization and system policies and practices that can be manipulated to enhance human functioning. In seeking to understand both independent and intervening variables, context can serve as an integrative concept to organize personal and environmental factors that influence human functioning, informing planning for systems of supports (Schalock et al., 2020; Shogren et al., in press). For example, planning for services and supports to align with a person's goals, preferences, and support needs and providing opportunities for increased community access and participation are considered to be influential contextual factors that impact human functioning and quality of life outcomes (Schalock et al., 2020; Shogren et al., in press).

Societal expectations toward people with ID are also part of context, and can serve as intervening variables, influencing outcomes (Hagiwara, Shogren, & Lockman Turner, 2019; Schalock et al., 2020; Shogren et al., in press). How another person perceives a person with intellectual disability's support needs can be impacted by multiple contextual factors. For example, researchers have found that responses on assessments of support needs, such as the 4

*Supports Intensity Scale–Children's Version* (SIS-C; Thompson et al., 2016), differ in systematic ways based on pairings of respondents, suggesting an influence of respondent characteristics and experiences with the person being rated.

Assessments of support needs, such as the SIS-C and the adult version of the scale, the Supports Intensity Scale- Adult Version (SIS-A; Thompson et al., 2004; 2015), were developed to provide a standardized assessment of the intensity of a person's support needs, consistent with social-ecological models of disability. Both the SIS-C and SIS-A are administered by trained interviewers who interview at least two respondents to generate item scores. Respondents can include anyone that knows the person well, including the person with ID themself. For respondents other than the person with ID, this is defined as knowing the person for at least 3 months where there were "recent opportunities to observe the person participate in one or more environments for long periods of time (at least several hours per setting)" (Thompson et al., 2014, p.6). The aforementioned research on the influence of respondent pairing on SIS-C scores found, across children aged 6 to 16 with ID, when respondents included only school professionals (e.g., teacher, paraprofessional), support needs scores tended to be lower than when the pair included a professional and a family member (e.g., mother, father; Hagiwara, Shogren, & Shaw, 2019). Moreover, there was a significant interaction of respondent pairings and other contextual factors. For example, pairings of only school professionals rated support needs much lower for older children with higher intellectual or adaptive functioning than the pairings of only family members (Hagiwara, Shogren, & Shaw, 2019). Such findings have been replicated in other areas of research, particularly work comparing self-report vs. other reports on assessments of psychological constructs. For example, Shogren and colleagues (2020) found systematic differences in scores on self-determination assessments based on whether the assessments were

completed by adolescents with disabilities themselves or by proxies, such as teachers. Proxy raters tended to report adolescent self-determination abilities lower than did adolescents with disabilities, and these differences were larger when other contextual factors, such as race/ethnicity and disability label, were considered. In quality of life assessments, differences have also been observed when comparing scores from self- and proxy-reports, although findings have been mixed. Across these studies, however, there is a consensus on the importance of providing the opportunity for people with disabilities to report their perspectives as they have a unique understanding of their experiences (Claes et al., 2012; Shogren et al., 2020).

Although previous research has examined the influence of respondent-level factors on scores on the SIS-C, a similar study has not been conducted to examine the impact of respondent-level factors on scores on the *SIS-A* (Thompson et al., 2004; 2015). As with the SIS-C, a structured interview is conducted by a trained SIS-A interviewer with two or more respondents to generate SIS-A item scores. The SIS-A User's Manual highlights that people with ID have unique insights that may not be brought up by other respondents; therefore, including people with ID as respondents provides valuable perspectives to the administration of the SIS-A and empowers them in the assessment process (Thompson et al., 2014).

Because the SIS-A and the SIS-C utilize a similar assessment format, it is important to investigate the potential impact of respondent characteristics on the SIS-A. Further, because including the person with ID is emphasized in the SIS-A User's Manual and consistent with best practice in adult supports and services, the impact of people with ID being included as one of the respondents on scores should be examined. Such work can inform recommendations for respondents on both the SIS-A and SIS-C and provide direction for future research and practice. As such, the purpose of this paper is to report on findings from an investigation of the impact of

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respondent-level factors on scores on the SIS-A. Specifically, the patterns of differences in SIS-A scores were examined based on the number of respondents and the pairings of respondents that were included in SIS-A interviews. The following research questions guided our analyses.

1) Does the number of respondents impact SIS-A scores?

- 2) Are there any differences in SIS-A scores when people with ID are included in the interview to generate scores?
- 3) Are there any differences in SIS-A scores when respondents in a SIS-A interview include a person with ID paired with a professional or a family member?

### Method

To address the research questions, we conducted secondary analysis of SIS-A data collected through the SISOnline. The SISOnline is a platform for SIS-A administration and scoring that was developed by the publisher of the scale, the American Association on Intellectual and Developmental Disabilities (AAIDD). The SISOnline is used by intellectual and developmental disability service systems in U.S. states and Canadian provinces (AAIDD, 2020). Among other purposes, jurisdictions use SIS-A results to inform the allocation of public funds for supports and services. In this section, we provide an overview of the SIS-A sample generated from SISOnline, the SIS-A assessment, and the data analysis plans.

### Sample

Data from 33,508 adults with ID across 16 U.S. states, collected between January 2017 and January 2018 were used in this secondary data analysis. Although more U.S. states utilize the SISOnline and more cases are available in SISOnline, to be included in the present analysis, cases had to include data on respondent characteristics as well as on the demographic characteristics of adults with ID that were the target of the SIS-A interview. This information was missing across multiple states which do not require it to be entered into the SISOnline system.

The gender distribution of the sample was 59.6% male and 40.4% female, which is s congruent with the range of males to females identified in the literature for people with ID (Maulik et al., 2011, 2013). The mean age of the total sample was 39.17 years old (SD = 15.93). Table 1 provides additional demographic information. It is important to note that other than gender and age, the majority of demographic information was missing because, as mentioned above, demographic information is not required to be entered in the SIS Online. Table 1 does include descriptive information collected as part of the SIS-A Section 1 (described in detail below), a non-standardized portion of the scale that captures information about exceptional medical needs and exceptional behavioral needs of adults with ID. In scoring this section, an adult is identified as having exceptional medical or behavioral support needs if they have one or more medical or behavioral items scored as a "2," or a total score over "5" on either the medical or behavioral section. This is interpreted as indicating that planning teams should consider these needs in supports planning, as the adult may have more intense support needs because they have exceptional medical or behavioral needs than do other adults who might have similar SIS-A support needs scores without exceptional medical or behavioral support needs (Thompson et al., 2015). Approximately 23% of the sample had at least one item scored as "2" and 21% of the sample had a summative score higher than 5 on the medical section. Approximately 28% of the sample had at least one item scored as "2" and 21% of the sample had a summative score higher than 5 on the behavioral section.

A total of 98,147 respondents were interviewed by AAIDD trained SIS-A interviewers to complete the 33,508 assessments. The relationship of each respondent to the adult with ID was

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included as a descriptive field. To quantify the type of respondent, we created and then numerically coded all descriptive fields for five broad relationship categories: (a) self, (b) family, (c) professional (e.g., direct service provider, case manager, school professional), (d) guardian, and (e) friend. Table 2 shows the number of respondents in each category as well as a definition for each respondent type. The range of respondents per assessment was 2 to 8.

To answer Research Question 1, we grouped adults with ID by the number of respondents who were interviewed by the SIS-A interviewer to generate SIS-A scores: two respondents (n = 15,028 or 45%), three respondents (n = 11,079 or 33%), four respondents (n = 4,780 or 14%), and five or more (n = 2,621 or 8%). Next, to answer Research Question 2, we focused on adults with ID who had a total of two respondents as this is the minimum requirement for SIS-A administration and most common in the data. We grouped the 15,028 individuals into one-of-two groups: those that included an adult with ID as a respondent (n = 2,583) and those that did not (n = 12,445). Finally, to answer Research Question 3, we split the adult with ID as a respondent (n = 2,583) group into two smaller groups; a group of adults with ID that were paired with a family member as a respondent (n = 1,063) and a group paired with a professional as a respondent (n = 1,403). Table 3 provides information about sample sizes in relationship to each research question.

### Supports Intensity Scale-Adult Version (SIS-A)

The SIS-A is a standardized, norm-referenced measure designed to assess the intensity of support needs of adults aged 16 to 64 with ID (Thompson et al., 2014). The SIS-A was developed to inform person-centered planning processes focused on developing individualized support plans based on the needs and preferences of a person with ID. The use of SIS-A scores has expanded to inform individualized supports budgeting and resource allocation practices in

multiple U.S. states (Thompson et al., 2018).

As noted, SIS-A assessments are administered through a structured interview. All of the SIS Online data included in the present analysis were from assessments completed by AAIDDapproved SIS-A assessors/interviewers who (a) had earned at least a baccalaureate degree, (b) had a work history in the developmental disabilities field, and (c) successfully completed multiday AAIDD-approved training on how to administer and score the SIS-A (the training culminates in a series of quality control evaluations where candidates must demonstrate they can correctly conduct assessments and accurately score responses).

In administering the SIS-A, SIS-A assessors must interview at least two respondents who know the person well. An interview session can be conducted (a) individually, with separate respondents with the interviewer aggregating information, (b) with a group of respondents who provide information in a shared setting, or (c) through a combination of group and individual interviews. SIS-A assessors are required to consult as many respondents as needed to obtain accurate and thorough information and must ask follow-up questions as well as probe respondents until complete information is collected. However, it is not an assessor's responsibility to bring respondents to consensus on item ratings. Rather, SIS-A assessors are charged with making decisions regarding final ratings for each item based on the information that has been collected across the respondents.

The SIS-A itself consists of three sections. Section 1, which does not contribute to standardized scores, focuses on an adult's exceptional medical and behavioral support needs. Examples of exceptional medical support needs include supports for purposes of suctioning, tube feeding, positioning, and managing diabetes. Examples of exceptional behavioral support needs include supports to prevent and intervene in cases of self-injury, assault to others, and wandering (when it presents a danger to self). The relative intensity of support needed for each item in this section is rated on a 3-point scale (i.e., 0 to 2). As noted previously, Section 1 is not part of the standard scores, but is useful for informing the supports needed for each item in Section 2, the standardized portion of the scale. Section 2 includes 49 items rated on three dimensions (i.e., frequency, daily support time, and type). These 49 times are group into six life domains/subscales:

- Home Living Activities (eight items) activities which take place in a home such as eating and housekeeping/cleaning.
- Community Living Activities (eight items) activities involved in being a member of community such as using transportation, participating in preferred activities, and using public services.
- Lifelong Learning Activities (nine items) activities related to engaging in learning such as learning self-determination skills and participating in training/educational decisions.
- Employment Activities (eight items) activities required in an employment setting such as interacting with coworkers and supervisors and completing work-related tasks.
- Health and Safety Activities (eight items) activities associated with personal safety and health such as taking medications and obtaining health care services.
- Social Activities (eight items) activities such as using appropriate social skills, making and keeping friends, and engaging in volunteer work.

Standard scores are generated for each subscale, as well as an overall Support Needs Index (SNI) score. The SNI is a standard composite score and reflects the aggregation of scores in the six subscales. Higher SNI scores indicate the presence of more intense support needs while lower SNI scores indicate less intense support needs (Thompson et al., 2014). Section 3, the Protection and Advocacy (P&A) Scale, is included as a supplemental section on the SIS-A and does not contribute to standardized scores (Thompson et al., 2015). The eight items on this scale are structured and scored the exact same way as items in Section 2, and are related to activities required to be the causal agent in one's life such as making choices and exercising legal as well as civic responsibilities. Thompson et al. (2004) originally concluded that SIS interrater reliability findings (from untrained interviewers) were "mixed", and therefore, the decision was made to not include it in the standardized portion of the SIS-A. Subsequent research has suggested that this decision should be reconsidered in revisions to the SIS-A (Shogren et al., 2016; Shogren, Thompson, et al., 2014). Like Section 1, although this section does not generate standard scores, the information is relevant to planning supports.

### **Data Analysis**

We utilized confirmatory factor analysis (CFA; Bollen, 1989) to test a series of models that enabled us to address our three research questions. CFA is a multivariate technique that parses out variance that is unrelated to the construct being measured, allowing population inferences that are free of measurement error (particularly when comparing the impact of different factors on model fit). As a preliminary step, we estimated a CFA using the entire sample to ensure that the data fit our proposed structure (six indicators of the overall Support Needs Index representing Home Living, Community Living, Lifelong Learning, Employment, Health and Safety, Social). Specifically, we estimated a single factor model which is in alignment with the assumptions of classical test theory which was leveraged to validate the SIS-A. All CFA models were identified using the fixed factor method (Bollen, 1989) whereby the latent variance and mean were fixed to 1.0 and 0.0, respectively. Benefits of using this approach include: (a) factor loadings, representing the variance shared among indicators, can all be freely estimated, (b) indicator reliability, representing the proportion of variance explained by the latent variable, can easily be determined, and (c) factor scores (i.e., Supports Needs) are interpreted as z-scores; therefore, scaling was done with respect to the latent variable. To evaluate model fit, we consulted approximate fit indices (AFIs) as the chi-square test of exact fit becomes overly sensitive to minor misspecifications (Bentler, 1995). Specifically, we were guided by the comparative fit index (CFI; Bentler, 1990), the Tucker-Lewis index (TLI; Tucker & Lewis, 1973), the root mean square error of approximation (RMSEA; Steiger & Lind, 1980), and the standardized root mean square residual (SRMR; Bentler, 1995). Estimates of 0.95 or greater for the CFI and TLI indicate a close-fitting model; whereas, estimates of 0.05 and 0.08 or lower indicate a close-fitting model for the RMSEA and SRMR, respectively (Hu & Bentler, 1999). After confirming the single factor structure of the SIS-A, we proceeded to investigate this study's research questions pertaining to the impact of the number of respondents on SIS-A scores (Research Question 1), the impact of including an adult with ID being assessed as one of the two respondents (Research Question 2), and the impact of including an adult with ID paired with a family member or a professional in the interview (Research Question 3). Because each research question required estimating multiple group models, we present information below that is relevant to all of them.

### **Multiple Group Models**

Multiple group confirmatory factor analysis (MG-CFA; Jöreskog, 1971; Sörbom, 1974) was used to compare groups with respect to the functioning of the SIS-A (measurement invariance) and if appropriate, latent comparisons (latent invariance). As shown in Table 3, Research Question 1 corresponds to a four-group model (two, three, four, or five or more respondents); Research Question 2 corresponds to a two-group model (groups including an adult with ID versus groups not including an adult ID); and finally, Research Question 3 corresponds to a two-group model (an adult with ID paired with professional versus paired with a family member).

Before carrying out group comparisons on the latent parameters (e.g., expected overall support need scores and the variability around this estimate), it was necessary to ensure the SIS-A functioned the same across groups. This was accomplished by examining measurement invariance. Measurement invariance involves testing whether the same pattern of fixed and free parameters (i.e., the factor structure is the same) hold true across groups, known as form invariance. Next, we tested whether the factor loadings could be constrained across groups, known as metric invariance (i.e., concerns the variance structure). Finally, we tested whether the manifest intercepts could be constrained across groups, known as scalar invariance (i.e., concerns the mean structure). We evaluated model fit using the criteria set by Cheung and Rensvold (2002). Namely, if the change in CFI ( $\Delta$ CFI) was 0.01 or less moving from one model to the next (e.g., form versus metric; metric versus scalar), we concluded the constraints were tenable. In order to make meaningful latent comparisons, metric and scalar invariance are required to investigate group differences on latent variances and means, respectively (Byrne, et al., 1989). To determine whether groups differed from one another on the latent support need construct, we assessed latent invariance. Specifically, we constrained a given parameter (e.g., latent variance) to be the same across groups and conducted a chi-square difference ( $\Delta \chi^2$ ) test. Because each research question concerned different groupings, we tested for measurement invariance and latent invariance separately.

Prior to estimating latent variable models (e.g., CFA and MG-CFA), we first examined missing data rates across the six domains. Because we observed a small amount of missing data

across the SIS-A domains (i.e., no more than 1% missing across the domains), we elected to employ full information maximum likelihood to simultaneously recover the missing data while estimating the model parameters. All CFA and MG-CFA analyses were conducted in R (R Core Team, 2019) using the lavaan package. Specifically, we chose to utilize the robust maximum likelihood (MLR) estimation method due to slight departures from multivariate normality. Due to our use of MLR for estimation, we executed the appropriate  $\Delta \chi^2$  test taking into account the scaling factors (Satorra & Bentler, 2001).

### Results

Using the entire sample available (n = 33,508), we fit a single-factor CFA model, resulting in a significant  $\chi^2$  test of model fit ( $\chi^2_{df=9}$ : 5489.7, p < 0.001); however, when consulting the AFIs, we found contradictory evidence. The SRMR was estimated to be 0.023, and the CFI and TLI were estimated to be 0.965 and 0.941, respectively; whereas, the RMSEA was estimated to be 0.135. Because the RMSEA indicated a poor fitting model, we examined the modification indices. We found large modification indices ranging from 1789.7 to 2451.3, which suggested allowing the following pairs of manifest residuals to covary: Home Living and Health and Safety, Home Living and Lifelong Learning, Home Living and Community Living, and Lifelong Learning and Employment. These modifications suggested that after controlling for the latent variable (i.e., latent support needs), the identified pairs of indicators still had common variance among one another. In a serial fashion, we inserted these modifications into the model to examine their impact on data-model fit and eventually observed notable improvement. Specifically, this revised model ( $\chi^2_{df=5}$ : 590.6, p < 0.001) had an RMSEA of 0.07 and a SRMR of 0.01; while the CFI and TLI were 0.996 and 0.988, respectively. See Table 4 for these parameter estimates.

### **Research Question 1: Impact of the Number of Respondents on SIS-A scores**

To investigate the impact of the number of respondents had on SIS-A scores, we estimated the revised model from above using multiple group CFA (MG-CFA) to test measurement invariance. We estimated the form invariant model to determine whether the same pattern of fixed and free parameter was appropriate for all four groups: two respondents (n =15,027), three respondents (n = 11,075), four respondents (n = 4780), and five or more respondents (n = 2,621). This model ( $\chi^2_{df=88}$ : 853.5, p < 0.001) was found to have acceptable fit where the CFI and TLI were estimated to be 0.996 and 0.988, respectively; while the RMSEA and SRMR were estimated to be 0.07 and 0.01, respectively. After establishing form invariance, we proceeded to test for metric (factor loadings) and scalar (manifest intercepts) invariance. In this process, we observed a change in CFI ( $\Delta$ CFI) of 0.001 moving from the form invariant to the metric invariant model, thus establishing metric invariance. Next, we observed a  $\Delta$ CFI of 0.005 moving from the metric to the scalar invariant model, thus establishing scalar invariance. Establishing both metric and scalar invariance afforded us the opportunity to examine group differences on the latent variance and latent mean, respectively. See Table 5 for all measurement invariance model details.

Using the scalar invariant model, we proceeded to compare our groups of interest on the latent variance and estimated an initial model whereby the latent variance was constrained across all four groups. The  $\chi^2$  difference test was found to be significant ( $\Delta \chi^2_{\Delta df=3}$ : 529.4, p < 0.001) and therefore, was not tenable. In a serial fashion, we attempted to constrain the latent variance to be the same across some groups, however, none of these constraints were tenable, meaning that each group had a different latent variance. Next, we explored whether the latent mean could be constrained across all groups and found that this was not tenable ( $\Delta \chi^2_{\Delta df=3}$ : 188.7, p < 0.001).

Through the process of decomposing the latent mean, we found that the latent mean could be constrained to be same for groups with two and three respondents (Est.: 9.57, SE: 0.012), whereas a unique latent mean was required for the four respondent group (Est.: 9.80, SE: 0.022) and the five or more respondent group (Est.: 9.94, SE: 0.026).

To better understand these group differences, we estimated latent *d* (Hancock, 2001) where the threshold for small, medium, and large effects are 0.23, 0.56, and 0.89, respectively. For each of the five group differences, a small effect was observed with latent *d* ranging from 0.10 (four respondents versus five or more respondents) to 0.22 (three respondents versus five or more respondents). Overall, the groups of two respondents had the largest variability in SIS-A scores on average, but SIS-A scores on average were higher among the groups of four or more respondents. See Table 5 for more detailed group comparisons.

# Research Question 2: Differences in SIS-A Scores when People with Intellectual Disability Served as a Respondent

After establishing measurement invariance across groups that differed in the number of respondents, we focused only those with two respondents to examine if there were any differences in SIS-A scores when people with ID were included as one of the two respondents in the interview to generate scores. We focused on the groups of two respondents for the following reasons: first, the SIS-A User's Manual (Thompson et al., 2015) requires at least two respondents, which represented approximately 45% of the groupings in the sample and second, a certain level of balance results whereby half of the support information comes directly from the individual with ID. The number of groups that included a person with ID being assessed as one of the two respondents was 2,583 out of 15,028 (17%).

As before, we first estimated a form invariant model and observed acceptable model fit

 $(\chi^2_{df=44}: 389.0, p < 0.001)$  where the CFI and TLI were 0.996 and 0.988, respectively; while the RMSEA and SRMR were 0.071 and 0.008, respectively. Progressing through the steps to examine measurement invariance, we observed a  $\Delta$ CFI of 0.007 (form to metric invariant models) and 0.00 (metric to scalar invariant models), thus establishing both metric and scalar invariance. Using the scalar invariant model, we investigated whether the latent variance could be constrained across the two groups. This resulted in a significant  $\chi^2$  difference test ( $\Delta \chi^2_{\Delta df=1}$ : 504.9, p < 0.001). Next, we examined whether the latent mean could be constrained across groups and found this constraint to be untenable ( $\Delta \chi^2_{\Delta df=1}$ : 1921.9, p < 0.001). Specifically, when an adult with ID was not included in the interview, the latent mean was estimated to be 9.96 (SE: 0.016) compared to 7.66 (SE: 0.042) when an adult with ID was included. Therefore, it is expected that when individuals with ID are included in the interview process latent support needs are lower than when they are not included. Even though the variability around this mean was higher, 4.17 (SE: 0.105) when the person with ID is included compared to 2.47 (SE: 0.04) when they are not, this translates to a latent effect size of 1.38 which corresponds to a large effect. See Table 5 for all measurement invariance model details.

# Research Question 3: Differences in SIS-A Scores when an Interview Included a Person with Intellectual Disability Paired with a Professional or a Family Member

We further drilled down to examine the impact of having a professional respondent (n = 1,403) versus a family respondent (n = 1,063) along with an adult with ID. First, we assessed measurement invariance on this basis prior to making group comparisons on the latent parameters. As such, we fit the form invariant model. We found acceptable model fit ( $\chi^2_{df=44}$ : 134.6, p < 0.001), with the CFI and TLI estimated to be 0.992 and 0.976, respectively, while the RMSEA and the SRMR were estimated to be 0.10 and 0.013. Working through the steps for

assessing measurement invariance, we observed  $\Delta$ CFI of 0.001 moving from both the form invariant to metric invariant models and from the metric invariant to scalar invariant models. Due to establishing both metric and scalar invariance, we examined group comparisons on the latent variance and latent mean.

Using the scalar invariant model, we constrained the latent variance to be the same across groups and found this was not tenable ( $\Delta \chi^2_{\Delta df=1}$ : 8.6, p < 0.01). Next, we constrained the latent mean across groups and found this was also not tenable ( $\Delta \chi^2_{\Delta df=1}$ : 18.9, p < 0.001). As such, the latent mean was estimated to be 7.85 (SE: 0.062) for the group that paired an adult with ID with a family member compared to 7.50 (SE: 0.057) for the group that paired an adult with ID and a professional. The latent mean was estimated to be lower when there was a pairing of an adult with ID and a professional and the latent variance was estimated to be larger, 4.03 (SE: 0.150) compared to 3.49 (SE: 0.150) when an adult with ID was paired with a family member. Therefore, when the pairings of respondents were composed of an adult with ID, the adult's support needs scores are, on average, lower than when the pairings included an adult with ID and a family member. Even though the variability in scores is larger for the pairings of an adult with ID and a professional, this translated to a latent *d* of 0.18, corresponding to a small effect. See Table 5 for all measurement invariance model details.

### Discussion

The purpose of this data analysis was to explore if there were patterns of differences in SIS-A scores based on the number of respondents included in the SIS-A intervention and the impact of including people with ID as respondents on scores. The largest group in the sample included two respondents in the SIS-A interview (45%), consistent with the requirements established in the SIS-A administration guidelines. However, relatively large numbers of SIS-A

interviews included more respondents, including 33% of the sample with three respondents, 14% with four respondents, and the remainder with five or more (8%). When examining the impact of different number of respondents, we found that having fewer respondents led to a greater variability in SIS-A scores while having more respondents led to higher mean, overall support need scores. Limited work, to our knowledge, has examined the impact of varying number of respondents on scores on standardized assessments, therefore, these results suggest the importance of further replicating and exploring these findings. For example, it is possible that having more respondents bring a wider range or more in-depth information, that leads to interviews having more possible discussion points to consider and ultimately leading to higher support needs. It is also possible that people with more intense support needs may also be more likely to have more respondents, as interviewers may recognize the importance of having multiple perspectives across life domains (e.g., Health and Safety, Community Living). However, because the majority of the respondents (64%) across the total sample knew the adult with ID assessed in a professional capacity (e.g., case manager, direct service professional), this could also suggest that professionals make higher ratings, although this is inconsistent with other findings, such as those with the SIS-C where the inclusion of professionals led to lower scores (Hagiwara, Shogren, & Shaw, 2019). Future research is needed that systematically explores the impact of varying numbers of respondents, matched by other personal characteristics (e.g., intellectual functioning, adaptive behavior, exceptional medical support needs, exceptional behavioral support needs) to further explicate the factors that shape the findings of the present study, and to guide future recommendations for administration protocols for the SIS. For example, if the number of respondents is a factor that systematically influences scores, the recommendations provided for interviewers must reflect these considerations and provide

decision-making guidance.

Although fewer respondents led to lower overall support needs scores, the larger variability in scores when there were two or three respondents is important to acknowledge. This finding may support the hypothesis that with fewer respondents there is less overlapping information available to interviewers, leading to more variability in scores; however, given the limited research available to inform such hypotheses, future research is needed to replicate and further test the factors that impact the differences in mean scores and variability in addition to the number of respondents.

When exploring Research Questions 2 and 3, the results suggest that that including the person with ID as a respondent had an impact on the scores. Our findings suggest that when including an adult with ID in the SIS-A interview, the latent mean was significantly lower with a large effect size even taking into account the large variability that was also found in the group of respondents that included the adult with ID. It is important to note that in 13% of SIS-A interviews conducted in the data analysis for this project, adults with ID were included as respondents. This finding suggests that although including adults with ID as respondents was not common, it is feasible. Moreover, including adults with ID as respondents is recommended in the SIS-A User's Guide and also is identified as a best practice in promoting self-determination and agency in the disability field (Shogren et al., 2020; Thompson et al., 2014). Ongoing research is needed to examine the characteristics of people with ID who are respondents in SIS-A assessments. It is probable – although we were not able to explore this in the present data analysis – that adults with ID with relatively less intense support needs were more likely to be included as respondents compared to adults with relatively more intense support needs.

Seo et al. (2017) found that the presence of medical and/or behavior support needs

showed a strong link to overall intensity of support needs; specifically, higher medical/behavior support needs were linked to higher support needs in some of the SIS-A domains. Thus, there is a possibility that the adults' exceptional medical and behavioral support needs might have influenced how respondents perceived the adults' support needs in general, as well as their decisions to include participants with ID in interviews. However, this alone does not explain the much lower level of participation of adults with ID.

People with ID can offer unique perspectives regarding their own needs for support, and further research is needed to examine the factors that shape both the invitation to participation and the participation of adults with ID. Simply having more intensive support needs should not preclude the participation of adults with ID in SIS-A interviews. Ongoing research is needed that focuses on how to support all respondents, including those with ID with the most extensive support needs, to provide meaningful information on the intensity of support they need to be fully engaged in community environments. It is essential that a variety of perspectives be gathered during the assessment process (Hatch, 2015; Shogren & Broussard, 2011).

The findings of Research Question 3 suggest that others who are included with the adult with ID as respondents may influence scores on the SIS-A. When examining the impact of pairing a respondent with ID with either a professional or family member, the latent mean for overall support needs scores was higher when the pairing included a family member versus a professional, although the variability in scores was larger when a professional was included. This might be influenced by the contexts where different respondents provide supports for adults with ID. Different respondents may see support needs across different life domains (e.g., home, community, employment; Bogenschutz et al., 2014); therefore, professionals may have different experiences than family members. Given that this comparison only included interviews that had a respondent with ID, removing the possible impact of an interaction of intensity of support need with the likelihood of an adult with ID being included as a respondent, these findings suggest that the type of respondent may interact with other factors to influence scores. These findings are consistent with findings from SIS-C secondary data analysis, which found that the pairings including a family member tended to rate the support needs of a child with intellectual disability higher than the pairings including a professional (Hagiwara, Shogren, & Shaw, 2019).

Although not directly related to support needs assessment, our findings align with research on other psychological constructs that suggests an impact of respondents. While other research studies have typically not involved interviewers who integrate information from different respondents to generate scores, other researchers have found distinct patterns of differences in outcomes of assessment based on the respondent. For example, Carter and colleagues (2010) found teachers tended to report self-determination capacities on the AIR Self-Determination Scale (Wolman et al., 1994) lower than did students themselves. However, teacher-reported scores were higher than those of parents. Recently, Shogren and colleagues (2020) found a similar pattern of reporting student self-determination on the Self-Determination Inventory (SDI; Shogren & Wehmeyer, 2017). Teachers tended to report student selfdetermination lower than did their students, although discrepancies varied depending on student disability status and race/ethnicity. Collectively, this body of work suggests that more attention needs to be directed to understanding the contextual factors that influence people's responses, as well as the impact of using multiple sources of information to generate scores through a standardized interview process. This is particularly important for scales such as the SIS-A and SIS-C where using different respondents can impact assessment results.

Although the SIS-A User's Guide (Thompson et al., 2014) suggests including at least two

respondents who know the adult with ID well from different contexts and emphasizes the importance of including adults with ID as respondents in SIS-A interviews, the findings from this study suggest a need for ongoing work to determine if and how these best practice recommendations could be further grounded in research to minimize variability based on the number of respondents and types of respondents. As noted, ongoing work is particularly needed to examine how other contextual factors (e.g., adult with ID characteristics, respondent-level characteristics) would interact with the impact of the number of respondents and differing groupings of respondents. For example, as mentioned earlier, a significant interaction effect across the respondent pairings and personal characteristics (e.g., intellectual functioning) of the child with ID was evident on the SIS-C scores (Hagiwara, Shogren, & Shaw, 2019), and future research is needed to examine this for SIS-A scores. However, our findings that there was a relatively low level of participation of adults with ID (13% of sample) in interviews suggests that other factors are likely at play in shaping which adults with ID are invited to participate.

### Limitations

In interpreting the findings, there are three main limitations that must be considered. First, there was significant missing demographic data (see Table 1) that resulted from this information not being required in the SISOnline system. This limited our ability to examine the interaction of intelligence, adaptive behavior, and other personal factors on scores, in combination with respondent-level factors. Ongoing research with robust data sets is needed to further examine these factors, particularly the influence of personal characteristics on the participation of adults with ID as respondents, including the presence of exceptional medical or behavioral support needs.

Second, the initial single-factor CFA resulted in an RMSEA that indicated unacceptable

model fit. To remedy this, based on modification indices, we allowed for covariance between pairs of life domains to be estimated. This approach may have violated the assumption of local independence. The assumption of local independence suggests that after controlling for the latent variable (overall support needs) all shared variance among the indicators should be explained (Bollen, 1989). Because the series of the analyses used standard scores that were determined from sum scores across the dimensions (type of support, frequency of support, and daily support time) per item and then summing these sum scores across items within each life domain (e.g. Health and Safety Activities), it is clear that many dependencies were not incorporated into the analysis. The SIS-A was validated and normed using classical test theory which requires a single construct; therefore, we chose to utilize the standard scores and fit the single-factor model. However, future research should investigate a modeling procedure that would be conducted at the item level rather than at the aggregate.

Lastly, it is unknown how decisions were made about respondents to include in the interview, including decisions about including adults with ID. As noted, the adults with ID who were included as respondents in this present analysis might have been recruited because they demonstrated less intensive support needs than others, although only between 8 and 23% of the sample had exceptional medical or behavioral support needs. Additionally, we do not know how decisions were made in regard to the number of respondents or types of respondents to get valid information across all of the life domains. Although the findings suggest there is an impact of respondent, additional work is needed to further examine the process of recruiting different respondents as sources of information for the assessment.

### **Conclusion and Implications for Future Research and Practice**

Overall, the results suggest that the number of respondents and types of respondents included in SIS-A interviews influence SIS-A scores, but ongoing research is needed that more robustly allows for examining of the reasons why this occurs, specifically if some of the differences observed as not reflective of real differences in support needs and instead measurement error resulting from inconsistent inclusion of numbers and types of respondents. For example, ongoing work to determine how decisions are made about the inclusion of respondents is needed. Additional analysis is also needed of the process used by interviewers to weigh different sources of information, particularly when this information is conflicting. Also, although the inclusion of adults with ID as respondents in 13% of total SIS-A interviews is positive and shows the feasibility of including the voice of a person with a ID, more research is needed on decision-making about including the person with ID, the degree to which other personal factors, such as intellectual functioning and communication abilities, influence decisions about inclusion justly or unjustly.

Finally, ongoing work is needed to explore how the inclusion of the person with ID shapes the interview process, particularly when group interviews are used. For example, research findings from person-centered planning and transition planning are suggested that having the person with ID as part of the process changes the tone of the conversation (Seo et al., 2015). Is this also found in SIS-A interviews? And, is this moderated by who is in the room, given the findings of systematic differences based on whether a person with ID is paired with a professional or family member? The findings of this study suggest that ongoing work to inform assessment processes is needed to continue to enhance the validity of SIS-A scores, and systematic consideration and clear decision making around the selection of respondents is critical to ensure that the most meaningful assessment information is being used to make decisions about

support needs and inform supports planning.

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Demographic Information of Adults with ID (N = 33,508)

Variable	n	%
Gender		
Male	19,984	59.6
Female	13,524	40.4
Missing data	0	0
Age Mean	39.17	( <i>SD</i> = 15.93)
Race/ethnicity		
White	6,747	20.1
Black	1,903	5.7
Two or more races	347	1.0
Asian	335	1.0
LatinX	297	0.9
Other	188	0.6
Missing	23,691	70.7
Additional disability diagnoses		
Mental health diagnosis	2,859	8.5
Chronic health condition	2,224	6.6
Speech/language disorder	1,993	5.9
Autism spectrum disorder	1,818	5.4
Physical disability	1,410	4.2
Low vision/blindness	845	2.5
Deaf/hard of hearing	546	1.6
Missing data	21,813	65.1
Intelligence level		
< 50	1,499	4.5
51-70	1,595	4.8
>70	185	.6
Missing data	30,229	90.2
Adaptive Behavior Level		
< 50	910	2.7
51-70	533	1.6
>70	58	0.2
Missing data	32,007	95.5
Exceptional Medical Support Needs		
Mean Score	1.76	(SD = 2.70)
Number of Adults who had a sum score higher than 5	2,567	7.7
Number of Adults who had on at least one "2"	7,694	23.0
Missing	9	0
Exceptional Behavioral Support Needs		
Mean	3.19	(SD = 3.52)
Adults with a sum higher than 5	7,096	21.2
Adults with at least one one "2"	9,446	28.2

Missing	1	0
Adults with at least one one "2" on both Medical and	3,067	9.2
Behavioral Support Needs		
Missing	5	0
<i>Note</i> Percentages of additional diagnoses are calculated by each di	sability category. A	possible

*Note.* Percentages of additional diagnoses are calculated by each disability category. A possible total points on Exceptional Medical Support Needs are 38. A possible total points on Exceptional Behavioral Support Needs are 26. "2" indicates as Extensive Support Needed.

Definition of Dear	nondont Dolationali	na and Number	f Dognou doute a	an A dult with ID
Definition of Kes	oonaeni Keiaiionsni	ps ana number oj	j Kesponaenis j	per Aauli wiin ID

		n	%
Definition of Rela	ationships		
Self	Adult with ID that is the target of assessment	12,966	13%
Family	Mother, father, parent, sibling, uncle, aunt,	19,855	20%
	grandmother, grandfather, cousin, child, or		
	partner		
Professional	Direct service provider (e.g., respite provider,	62,370	64%
	residential services staff), case manager (e.g.,		
	residential services manager,		
	support/service/program coordinator), or		
	teachers		
Guardian	Legal guardian or authorized representative	2,228	2%
Friend	Advocate, mentor, or roommate	728	1%

	Group 1	Group 2	Group 3	Group 4
Research Question 1	2 Respondents	3 Respondents	4 Respondents	5+ Respondents
	n = 15,028	n = 11,079	n = 4,780	n = 2,621
Research Question 2	Included adult with ID as respondent	Did not include adult with ID as respondent	-	-
	n = 2,583	n = 12,445	-	-
Research Question 3	Adult with ID and Family Member as respondents	Adult with ID and Professional as respondents	-	-
	n = 1,063	n = 1,403	-	-

## Sample Sizes and Groups for each Research Question

**Overall Sample Parameter Estimates** 

SIS-A by	Est.	SE	Standardized
Home Living Activities	1.281	0.008	0.805
Lifelong Learning Activities	0.938	0.005	0.870
Employment Activities	0.822	0.004	0.877
Social Activities	1.000	0.000	0.886
Community Living Activities	0.955	0.005	0.898
Health and Safety Activities	1.158	0.005	0.922
Manifest Residuals			
Health and Safety Activities	0.732	0.009	0.150
Community Living Activities	0.673	0.009	0.193
Social Activities	0.848	0.011	0.216
Employment Activities	0.626	0.008	0.231
Lifelong Learning Activities	0.869	0.010	0.243
Home Living Activities	2.744	0.031	0.352
Correlated Residuals			
Home Living with Lifelong Learning	-0.132	0.009	-0.085
Lifelong Learning with Employment	0.127	0.006	0.172
Home Living with Community Living	0.408	0.013	0.300
Home Living with Health and Safety	0.486	0.012	0.343
Latent Variance			
Overall Support Needs Construct	3.084	0.031	
Latent Mean			
Overall Support Needs Construct	9.633	0.011	

## Measurement Invariance and Latent Invariance

	Step	χ2	df	Scaling Factor	RMSEA	SRMR	TLI	CFI	$\Delta CFI / \Delta \chi \Delta df, p$	Tenable
Number of Re	spondent	ts								
Form	1.0	613.87	20	1.39	0.07	0.008	0.988	0.996	-	Yes
Metric	2.0	760.413	35	1.401	0.059	0.031	0.992	0.995	0.001	Yes
Scalar	3.0	1739.08	50	1.287	0.072	0.039	0.988	0.99	0.005	Yes
Latent										
Variance	4.0	2372.54	53	1.307	0.083	0.198	0.984	0.986	529.39, 3, < 0.01	No
2 & 3 vs.										
4 & 5+	4.1	1852.17	52	1.293	0.073	0.106	0.987	0.989	109.078, 2, < 0.01	No
2 & 3	4.2	1817	51	1.286	0.073	0.086	0.987	0.989	80.556, 1, < 0.01	No
4 & 5+	4.3	1774.47	51	1.294	0.072	0.059	0.987	0.989	35.268, 1, < 0.01	No
Latent										
Mean	5.0	1918.07	53	1.279	0.073	0.052	0.987	0.989	188.673, 3, < 0.01	No
2 & 3 vs.										
4 & 5+	5.1	1767.84	52	1.277	0.071	0.04	0.988	0.99	18.235, 2, < 0.01	No
2 & 3	5.2	1746.98	51	1.282	0.071	0.039	0.988	0.99	0.703, 1, 0.402	Yes
4 & 5+	5.3	1760.1	51	1.282	0.072	0.04	0.988	0.99	17.469, 1, < 0.01	No
2 & 3 & 4	5.4	1875.43	52	1.283	0.073	0.049	0.987	0.989	143.35, 2, < 0.01	No
With Adult wi	th ID ver	sus Without								
Form	1.0	298.568	10	1.303	0.071	0.008	0.988	0.996	-	Yes
Metric	2.0	817.565	15	1.189	0.092	0.052	0.979	0.989	0.007	Yes
Scalar	3.0	873.199	20	1.163	0.081	0.054	0.984	0.989	0	Yes
Latent										
Variance	4.0	1140.92	21	1.134	0.09	0.152	0.98	0.986	504.9, 1, < 0.01	No
Latent										
Mean	5.0	2560.65	21	1.156	0.136	0.129	0.954	0.968	1921.9, 1, < 0.01	No
Adult with ID	with Far	nily versus Ad	lult with	ID with Pro	ofessional					

1.0	110.793	10	1.215	0.1	0.013	0.976	0.992	-	Yes
2.0	142.155	15	1.11	0.087	0.028	0.982	0.991	0.001	Yes
3.0	160.401	20	1.085	0.079	0.026	0.985	0.99	0.001	Yes
4.0	168.812	21	1.065	0.078	0.045	0.985	0.99	8.6, 1, < 0.01	No
5.0	178.688	21	1.081	0.081	0.038	0.984	0.989	18.9, 1, < 0.01	No
_	1.0 2.0 3.0 4.0 5.0	1.0110.7932.0142.1553.0160.4014.0168.8125.0178.688	$\begin{array}{cccccccccccccccccccccccccccccccccccc$	$\begin{array}{cccccccccccccccccccccccccccccccccccc$	1.0       110.793       10       1.215       0.1         2.0       142.155       15       1.11       0.087         3.0       160.401       20       1.085       0.079         4.0       168.812       21       1.065       0.078         5.0       178.688       21       1.081       0.081	1.0       110.793       10       1.215       0.1       0.013         2.0       142.155       15       1.11       0.087       0.028         3.0       160.401       20       1.085       0.079       0.026         4.0       168.812       21       1.065       0.078       0.045         5.0       178.688       21       1.081       0.081       0.038	1.0       110.793       10       1.215       0.1       0.013       0.976         2.0       142.155       15       1.11       0.087       0.028       0.982         3.0       160.401       20       1.085       0.079       0.026       0.985         4.0       168.812       21       1.065       0.078       0.045       0.985         5.0       178.688       21       1.081       0.081       0.038       0.984	1.0       110.793       10       1.215       0.1       0.013       0.976       0.992         2.0       142.155       15       1.11       0.087       0.028       0.982       0.991         3.0       160.401       20       1.085       0.079       0.026       0.985       0.99         4.0       168.812       21       1.065       0.078       0.045       0.985       0.99         5.0       178.688       21       1.081       0.081       0.038       0.984       0.989	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$

*Note.* 2 = grouping of two respondents; 3 = grouping of three respondents; 4 = grouping of four respondents; 5 + = groupings of five or more respondents.

	Reviewers' Comments	Where	
			Changes
			were Made
1	I think the biggest limitation of this manuscript and the interpretation and generalizability of the findings is the fact that there is a large proportion of missing data on the participant's level of functioning (e.g., IQ - 90%, AB - 96%). It seems a huge artifact of the findings regarding self-report is the IQ level and communication skill level of the adult with ID being able to participate in self-reporting on his/her support needs. I know the authors mention this as a limitation but is the mention of the limitation sufficient? Not being able to control or account for IQ or communication ability almost negates the authors ability to say anything meaningful about self- report.	We agree this is a limitation; but as we cannot control the data available as it collected by state intellectual and developmental disability systems) and the SISOnline system does not require demographic information, we further acknowledge this issue in the limitations. Additionally, we decided to incorporate the other reviewer's suggestions related to adding additional information on exceptional medical and behavioral support needs as this provides additional descriptives on the sample. Therefore, we added information on the sample's medical and behavioral support needs based on the SIS-A Section 1, including the percentage of adults with exceptional medical/behavioral needs.	Main text Method: p. 8 Discussion: p. 24 Table 1: Demographic Information of Adults with ID
2	<ul> <li>Examined the levels of exceptional medical and behavioral support needs of the assessed person and looked at how intensity of support needs across this section impacted/correlated with the assessed person providing self-reported information?</li> <li>Are the adults providing self-report more typically individuals with few exceptional behavior support needs or exceptional medical support needs?</li> <li>Are the individuals with ID providing self-report + parent different on exceptional medical medical/behavioral support needs than the adults with ID</li> </ul>	We appreciated this feedback. The focus of this paper and its research questions was to take the first step in examining how groupings of respondents impacted the standardized portion of the SIS-A, and as these sections are not part of the standardized portion of the scale, we decided not to include in the current analyses. We did however add descriptive data on the exceptional medical and behavioral support needs of the sample to provide information and identify directions for future research. We agree future research should focus on subgroup analyses that determine the impacts of exceptional medical and behavioral	Main text Discussion: p. 26

### No. AJIDD-D-20-00066 Revision Points

	providing self-report + professional?	support needs. We note this in the discussion as a direction for future research, highlighting work by Seo et al (2015) work with the SIS-C as something that could provide guidance for ongoing research now that this preliminary work identifying the impacts of groupings of respondents on standardized scores.	
3	One conclusion made by the authors contrasted these findings with those from the children's version of the SIS and how having teachers/school professionals led to lower overall support intensity scores versus having parents. Clearly, more research is needed to unpack the contribution and differences in ratings between parents and professionals but also setting is an important factor. I would expect that professionals who interact with the assessed person only in a school setting may have a somewhat different capacity to assess support needs across settings compared to professionals who interact with an adult assessed person - in which case they might have interacted with the assessed person in the home, community, work place, leisure, etc.	We appreciate this feedback and agree that professionals and adult service providers interact with adults with ID in a wide range of capacities. Therefore, we add information in the discussion addressing this issue. We agree this needs more focus in future work and hope the current study can provide guidance for such work.	Main text Discussion: p. 22
3	One interesting finding from this study is that only 13% of SIS-A included the adult with ID providing self-report. Considering that a majority of adults with ID would have the cognitive capacity and communication skills to effectively participate in providing input on their support needs - why was the number of self-reports so low?	We agree this is a critical question to be addressed in ongoing research. The current data does not provide information to allow for examination of the decision making for who is included as respondents. In the discussion, we further discussed the low percentage of adults with ID who were included and that this could not fully be explained by other available demographic variables, such as	Main text Discussion: p. 22 and 26

having both exceptional	
medical/behavioral support needs.	
We highlight that it is important to	
create the supports for including	
adults with IDD as respondents for	
the SIS-A.	