Memo on the Release of the SIS-A, Second Edition

Overview

The purpose of this memo from the American Association on Intellectual and Developmental Disabilities (AAIDD) is to alert all stakeholders to upcoming enhancements in the second edition of the Supports Intensity Scale-Adult Version® (SIS-A®). The SIS-A contains both normed and non-normed items to assess the support needs of an individual with intellectual and developmental disabilities (IDD) . The assessment was first published as the Supports Intensity Scale (SIS) in 2004 and was re-named the SIS-A (first edition) in 2015. The second edition of the SIS-A was released in January 2023 and includes updated norms as well as several enhancements. A plain text summary of this memo and a frequently asked questions (FAQs) on implementing the second edition of the SIS-A are available as separate documents.

The SIS-A

The SIS-A has played an important role in accurately identifying and measuring the intensity of supports that people with IDD need. Information gathered from the SIS-A contributes to the development of high-quality person-centered plans to help people achieve positive outcomes. SIS-A information is also used by providers and governmental entities to help understand the needs of the population they support and to more equitably allocate resources.

SIS-A Update Project

AAIDD completed a multi-year project at the end of 2022 to assure the ongoing benefit, quality, and integrity of the SIS-A. In this project, recent SIS-A assessment records of people with IDD were analyzed for three purposes:

- To confirm whether or not the SIS-A continues to be a psychometrically valid assessment of support needs among adults with IDD.
- To establish contemporary norms for the current U.S. population.
- To consider the statistical evidence for both (a) establishing norms for the supplemental *Protection and Advocacy* (*P&A*) scale and (b) incorporating P&A scores into the total Support Needs Index (SNI) score.

Data from over 100,000 SIS-A assessments conducted between 2017 and 2020 were analyzed. These assessments reflect a representative sample of U.S. residents with IDD and include people with autism spectrum disorder. The majority of assessments were completed with people who received supports under Home and Community-Based Services (HCBS) Medicaid waivers. It is important to note that numerous peer-reviewed publications comparing data from the U.S. and Canadian provinces indicate that SIS-A norms developed in the U.S. are valid with the Canadian population.

What were the results of the project?

The project accomplished its three goals.

1. **The project confirmed that the SIS-A continues to be a psychometrically reliable and valid assessment of support needs for adults with IDD**. The results of the comprehensive statistical analyses were not surprising, because the SIS-A has been extensively studied by researchers around the world, and they have come to the same conclusion. Accurate information on a person's support needs is crucial to developing high-quality person-centered plans of support. Understanding how a person's support needs vary across SIS-A domains helps to identify areas where supports are most needed.

2. **The project confirmed that the tool's norms, or standard scores, need to be updated to reflect a current peer group**. This result of the analysis was also not surprising, because the SIS-A's standard scores have been based on a sample of people with IDD that was assessed during the late 1990s and early 2000s. For a standardized assessment's norms to remain valid over time, it is necessary for it to be periodically re-normed with a contemporary population. Re-norming ensures that a person's raw SIS-A scores are compared to the scores of a sample of their peers today, rather than to a sample of people from over 20 years ago. A large representative sample of recent assessments was used to create updated norms for the second edition of the SIS-A.

3. **The project established norms for the supplemental P&A scale and provided evidence to support its incorporation into the standardized portion of the SIS-A.** The P&A scale identifies the support a person with IDD needs to advocate for themselves and has always been part of the SIS-A. Because norms were not available for the P&A scale in the first edition, it did not contribute to the overall SNI score. In the second edition, the P&A scale has been renamed *Advocacy Activities* to better reflect the agency of the individual being assessed and is included as the seventh scale in the standardized section of the SIS-A.

What is norming?

The term "norm" is short for the "norm-referenced scores" used in standardized assessments to describe a person's assessment results in comparison to the results of a similar group of people. Norm-referenced assessments are used widely in the fields of health care, education, and rehabilitation. To provide a meaningful comparison, the sample used to create norms must reflect (i.e., be representative of) the population for whom the assessment is intended. Standard scores are generated on the basis of assessment results from a representative sample. In the SIS-A, there are standard scores for each of the seven scales, and an overall (composite) standard score which is called the SNI score.

A representative sample of the population is one that reflects society's diversity. In addition to characteristics like age, gender, diagnoses, race, ethnicity, and other personal characteristics, factors that are a part of contemporary society must be considered. For instance, certain technology that is common today (e.g., the smart phone) is much different than what was used just a few decades ago. The data used for a representative sample need to be updated periodically to make sure that comparisons are made with people in today's society instead of with people from long ago. Because norms let us know how an individual's score compares with those of their peers, the peers on whom the norms are based need to be from contemporary society.

To keep current, all standardized assessments must be re-normed from time to time. It is common for a person's standard scores to change when an assessment is re-normed, even in instances where a person's raw scores may have not changed. This is because with new norms, the person's raw score is compared to different—and more current—standardization sample scores. These changes do not mean that the instrument is wrong or flawed. Changes in norms reflect the reality that a peer-group sample that is representative of today's population is different than a sample from an earlier time.

In addition, the SIS-A helps identify elements of a person's overall support need that may be especially important to an individual (e.g., assistance with tube feeding) but are not practical to norm-reference because only a small number of people require these supports. For this reason, a section dedicated to a person's exceptional medical and behavioral support needs is included in the SIS-A but is not normed.

What enhancements are found in the second edition of the SIS-A?

The project identified several ways to enhance the SIS-A in its second edition.

1. **The project confirmed that the SIS-A is valid and reliable for use with people up to age 84.** The current tool was normed with a population aged 16–64 years; however, the SIS-A has been frequently used with adults older than 64. Analysis of assessment data from people aged 65–84 years confirmed that the SIS-A provides a psychometrically valid and reliable measure of the support needs of adults up to age 84. Stakeholders can have confidence that the SIS-A accurately measures the support needs of older adults with IDD.

2. **The project identified several additional items that contribute to understanding of a person's overall support needs.** Several items have been added to the section of the SIS-A that identifies exceptional medical and behavioral support needs that might have an overarching impact on a person's support needs. These additions will help identify finer distinctions in support need and ensure that important support needs are not overlooked.

3. **The project identified several areas in the SIS-A where text could be clarified, streamlined, or reorganized.** A notable change was the renaming of Section 2 of the interview profile form as *Support Needs for Life Activities*. Other changes included changing the order of the subscales within the assessment, reordering items within three subscales, and changing the names of two subscales (to *Work Activities* and *Advocacy Activities*).

The remaining adjustments to the SIS-A involved minor edits. For example, items found under "Other Exceptional Medical Care" have been clarified to focus on the management of the condition(s). Additionally, several headers in the profile form were reworded for clarity. These changes were made to enhance the flow and efficiency of the SIS-A assessment for interviewers and respondents.

How will these changes to the SIS-A benefit stakeholders?

The Person Who Is Assessed and Their Family: At this most direct level, the second edition of the SIS-A will do what it is intended to do—that is, accurately measure the pattern and intensity of a person's support needs. The results of the SIS-A assessment will continue to provide important information to inform the individual's person-centered support planning.

The re-norming of the SIS-A will result in some standard score differences at reassessment. Some people will see some of their standard scores and/or their overall SNI score increase or decrease when they are reassessed, even if their actual raw scores and their daily needs for support have stayed the same. These changes are expected because the person's raw scores are being compared to the scores of a different standardization sample than they were before. In addition, depending on the extent (if any) of the person's exceptional medical and behavioral support needs, the addition of new items in the second edition of the SIS-A may result in increased total scores in the non-normed portion of the assessment.

Service Providers: The SIS-A will continue to provide useful information to organizations that support people with IDD. At this level, the second edition of the SIS-A will enable organizations to identify and understand the pattern and intensity of the support needs of the people they support. The results of SIS-A assessments will continue to provide planning

teams with information to identify a person's new or changing needs, consider new strategies to meet a person's goals, and leverage new resources to enhance a person's level of support within a person-centered planning process.

Jurisdictional or Governing Level: The SIS-A will continue to provide useful aggregated information for jurisdictional decision makers. At this level, the second edition of the SIS-A will provide a useful tool to identify and understand the pattern and intensity of the support needs of a large population, like the residents of a state or province. Over approximately 20 years, 24 U.S. states and three Canadian provinces have collected and thoughtfully examined their SIS-A assessment data to better understand the needs of the people they support. These jurisdictions have worked hard to transform their IDD systems on the basis of valid and reliable data on their particular populations. SIS-A data have been used to inform changes to public policies at the jurisdictional or governing levels that better meet the needs of citizens with IDD.

In their strategies to equitably distribute funds for IDD services, jurisdictional or governing entities have developed practices that are informed, in part, by both standardized and non-standardized SIS-A assessment results. Other key elements that inform practices are service rates and public policies that are specific to a jurisdiction. As governmental entities tailor their resource allocation strategies to their own unique context, the relationship between SIS-A scores and service provision is not uniform across jurisdictions.

In the second edition of the SIS-A, new items have been added to the non-standardized portion of data collection (*Exceptional Medical and Behavioral Support Needs*) to provide finer distinctions in the nature of the support needed and to ensure that important support needs are not overlooked. The effect of these additions to the non-standardized portion of the second edition of the SIS-A is that the upper limit of summed scores (i.e., total scores) increases from 38 to 50 in *Exceptional Medical Needs* and from 26 to 28 in *Exceptional Behavioral Needs*. It is important to acknowledge that all of these new items could be identified under "other" the first edition of the SIS-A. Data from the standardization sample and the expert consultation indicated that these items merited inclusion in the second edition SIS-A so that important support needs were not overlooked and to provide finer distinctions in the nature of the support people need.

The effect of the new norms and the addition of the *Advocacy Activities* scale on standard scores in the second edition of the SIS-A are slight. Overall, most people (roughly 67%) will see no or almost no difference (3 or fewer points) between their overall, composite SNI score using the old and new norms. Among those with score shifts of 4 or more points, data analyses suggests that roughly 3% of people will see their overall SNI score decrease and 30% will see their overall SNI score increase. (People with higher SNI scores have more intense support needs.)

Jurisdictional or governing entities will want to examine their data to estimate the number and pattern of shifting scores that might be expected for those they support as their next scheduled reassessments occur. While only slight overall shifts in standard scores can be seen when comparing raw scores applied to the old and new norm tables, *AAIDD recommends that jurisdictional or governing entities analyze their data to determine the extent of the impact which changing scores based on the new norm tables might have on their individual systems.* In analyzing their data, states and stakeholders may find opportunities to consider changes in public policy, service rates, the breadth and quality of supports to be provided, and other areas to further transform systems in response to the changing environments and needs of people with IDD.

When do these changes go into effect?

At the beginning of 2023, AAIDD released the second edition of the SIS-A, reflecting the new norms and other changes described here. At same time, a new version of the SISOnline was launched which calculates standard scores and generates reports that reflect the new norms.

AAIDD will continue to support the first edition SIS-A assessment and SISOnline until approximately June 2024 and will assist users in transitioning to the new SISOnline. During this transition period, AAIDD will maintain two versions of the SISOnline so users can continue to use the SIS-A's current norms as they prepare to transition. The timeline is as follows:

- Changes to the SIS-A were announced in February 2022.
- The second edition SIS-A norms, manuals, forms, SISOnline, and reports were rolled out in January 2023.
- The first edition SIS-A and SISOnline will continue to be supported for approximately 18 months following the release of the second edition. AAIDD will maintain two editions of the SIS-A and SISOnline until mid-2024 or until all jurisdictions have transitioned, whichever comes first.

Acronyms	
AAIDD	American Association on Intellectual and Developmental Disabilities
HCBS	Home and Community Based Services
IDD	Intellectual and Developmental Disabilities
FAQ	Frequently Asked Questions
P&A	Protection and Advocacy
SIS	Supports Intensity Scale
SIS-A	Supports Intensity Scale-Adult Version
SIS-C	Supports Intensity Scale-Children's Version
SISOnline	SIS online scoring platform
SNI	Support Needs Index