Supports Intensity Scale – Adult Version®

Respondent Handbook

American Association on Intellectual and Developmental Disabilities
WHAT CAN THIS GUIDE DO FOR YOU?

This guide is designed to provide important information and resources about the Supports Intensity Scale - Adult Version® (SIS-A). It aims to inform individuals with intellectual and developmental disabilities, loved ones and other supporters about what to expect during a SIS-A interview, how to read the SIS-A report and possible uses of SIS-A information.

MAKING THE MOST OF THIS HANDBOOK

1. **Review**: Each section of this guide can be read independently. Please scan the guide for content and resources that are most helpful to you.

2. **Discuss**: Find time to discuss the information in the guide with your support coordinator, case manager and support team members. You can also use the resources for planning and goal setting.

3. **Participate**: Use the content of the guide to gain awareness about the SIS-A interview and empower your team to determine supports that provide meaningful opportunities.

ACKNOWLEDGEMENTS

This work was developed under the guidance of the American Association on Intellectual and Developmental Disabilities and SIS-A Senior Trainers. The team extends its appreciation to the many partners who provided valuable assistance.

LEGAL DISCLAIMER

This document contains resources that are provided for the user’s convenience. The inclusion of these materials is not intended to reflect their importance, nor is it intended to endorse any views expressed, or products or services offered. Information presented in this handbook may vary in use across SIS-A users, agencies, and jurisdictions.
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What is the purpose of the SIS-A?

The Supports Intensity Scale - Adult Version® is a standardized assessment that measures the pattern and intensity of supports adults 16 years and older with intellectual and developmental disabilities require to be successful in adult community life. Its purpose is to assess support needs fairly using a uniform procedure.

How do I know that it is a valid assessment?

The SIS-A is valid as it measures what it sets out to, that is, support need. Since its release in 2004, numerous studies conducted with the SIS-A have time after time determined it is a valid assessment. SIS-A is also reliable, in that, its results are consistent when administered correctly.

How is the SIS-A administered?

The SIS assessment uses a semi-structured interview process. This means that there is a facilitator, known as the Interviewer or Assessor who guides the discussion, explains the items and rating options, and helps determine scores to fit the person. Even if the individual is currently not participating in every activity, it is required to complete all questions in the assessment. This ensures a uniform process where each time the SIS-A is completed, every team consistently considers and rates all items.

Who participates in a SIS-A interview?

The people who attend the meeting are called Respondents and at least two must attend the entire interview. Respondents know the person being discussed very well (at least three months) and are comfortable sharing about the supports the person may need in a variety of settings like at home, at a store, at a job or when learning new things. Most importantly, the person that the SIS-A is for is encouraged to actively participate and help decide who speaks on their behalf. It is also helpful to share any accommodations needed or any sensitive or difficult topics prior to the interview.
Where does a SIS-A interview take place?

First and foremost, the setting should be comfortable for the person and respondents, free from distractions, and a safe environment to talk about confidential information.

How much time does the SIS-A interview take?

Conversations to determine accurate ratings may take time. Plan for around two to three hours. In some places, other required questions and information may add more time to the discussion. SIS-A is very comprehensive and includes three sections with multiple items in each section. During the meeting, the team discusses a section about exceptional medical and behavioral supports, a section with items about six areas of adult life, and a section about protection and advocacy. Plan to bring snacks, drinks and any assistive devices for your comfort and best participation.

What can I expect to happen during the SIS-A Interview?

The Interviewer guides the respondent group through all sections of the assessment. Respondents share and discuss the person’s support needs for all life activities. Plan for an open and honest discussion about support ratings that includes all team members and the person as much as possible.

Success is a term you will hear very often during the SIS-A interview. Success reflects a strengths-based approach that helps the team consider the person’s potential, positive attributes, ways to provide meaningful supports and a safe environment to explore new pursuits.

When the Interviewer uses that term, they are asking you to consider what supports would look like for the person be involved in the same life activities that other adults are involved in, at the same level of performance and participation. In other words, if provided the right combination of help, the person is an active participant in the same life activities that other adults of the same age are involved in within the community.
Respondent Guide

Section 1. Exceptional Medical and Behavioral Support Needs

RATING KEY

0 = No Exceptional Support Needed
(condition or behavior is not an issue, or no extraordinary support is needed to manage the medical condition or behavior)

1 = Some Exceptional Support Needed
(continuously aware, vigilant, monitoring, checking in, episodic active support, may not need in all environments)

2 = Extensive Exceptional Support Needed
(intense, hands on support occurs frequently, may need active supports in all environments, active support takes significant time and energy)

Section 1A: Exceptional Medical Support Needs (19 Items)
- Respiratory Care (4 Items)
- Feeding Assistance (3 Items)
- Skin Care (2 Items)
- Other Exceptional Medical Care (10 Items)

Section 1B: Exceptional Behavioral Support Needs (13 Items)
- Externally Directed Behavior (4 Items)
- Self-Directed Behavior (3 Items)
- Sexual Behavior (2 Items)
- Other (4 Items)
1. This scale should be completed without regard to the services or supports currently provided or available.
2. Scores should reflect the supports that would be necessary for this person to be successful.
3. If an individual uses assistive technology, the person should be rated with said technology in place.
4. Complete ALL items, even if the person is not currently performing a listed activity.

<table>
<thead>
<tr>
<th>TYPE OF SUPPORT</th>
<th>FREQUENCY</th>
<th>DAILY SUPPORT TIME</th>
</tr>
</thead>
<tbody>
<tr>
<td>What kind of dominant support is</td>
<td>If given the opportunity, how frequently is support needed for this activity?</td>
<td>On a typical day when support in this area is needed, how much support time should be devoted?</td>
</tr>
<tr>
<td>needed for success?</td>
<td>0 = none</td>
<td>0 = none</td>
</tr>
<tr>
<td>0 = none</td>
<td>1 = monitoring <em>(reminders)</em></td>
<td>1 = less than 30 minutes</td>
</tr>
<tr>
<td>1 = monitoring <em>(reminders)</em></td>
<td>2 = verbal/gestural prompting <em>(demonstration)</em></td>
<td>2 = 30 minutes to less than 2 hours</td>
</tr>
<tr>
<td>2 = verbal/gestural</td>
<td>3 = partial physical assistance <em>(help through doing)</em></td>
<td>3 = 2 hours to less than 4 hours</td>
</tr>
<tr>
<td><em>(help through doing)</em></td>
<td>4 = full physical assistance <em>(doing for required)</em></td>
<td>4 = 4 hours or more</td>
</tr>
<tr>
<td>3 = partial physical</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 = full physical</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Section 2 Support Needs Index

Section 2A: Home Living Activities (8 Items)
Section 2B: Community Living Activities (8 Items)
Section 2C: Lifelong Learning Activities (9 Items)
Section 2D: Employment Activities (8 Items)
Section 2E: Health and Safety Activities (8 Items)

Section 3 Supplemental Protection and Advocacy Scale
Protection and Advocacy Activities (8 Items)
The Interview and Profile Summary Results Report (SIS-A Family Friendly Report) includes general information about the person followed by a summary of the SIS-A interview results.

This feature of the SIS-A Report provides valuable information to include:
- Person Being Assessed
- General Information
- Interviewer Data
- Assessment Date
- Respondent Data
- Person Who Entered the Information
- Other Pertinent Information

This part of the handbook provides general descriptions of the Interview and Profile Summary Results Report (SIS-A Family Friendly Report). Each page number corresponds with the pages of the report.

Page 1: Profile & Demographic Information

Person Being Assessed:
- Last:
- First:
- Middle:
- Language Spoken at Home:
- Gender:
- Address:
- City:
- State/Province:
- Zip Code:
- Phone:
- D.O.B. (mm/dd/yyyy):
- Age:
- MCI:
- Medicaid Number:
- SSN:

Interviewer Data:
- Interviewer:
- Agency/Affiliation:
- Interviewer Address:
- City:
- State/Province:
- Zip Code:
- Position:
- Phone:
- Ext.:
- Interviewer Email:

Respondent Data: Information for the SIS ratings was provided by the following respondents:
<table>
<thead>
<tr>
<th>First Name</th>
<th>Last Name</th>
<th>Relationship</th>
<th>Agency</th>
<th>Email</th>
<th>Language</th>
</tr>
</thead>
</table>

Page 2: Rating Key for Sections 2 & 3

<table>
<thead>
<tr>
<th>Type of Support</th>
<th>Frequency</th>
<th>Daily Support Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Options provided determine the dominant or best fitting support type.</td>
<td>Options provided determine how often support would be needed for success.</td>
<td>Options provided determine how much support time would be needed in a typical day.</td>
</tr>
</tbody>
</table>

This page of the report describes the rating options for Sections 2 & 3 of the SIS-A assessment.
This is the major section of the report. It includes every item and rating decided on by the Interviewer and the Respondent team. This section may also include notes relating to the person’s support needs.

The Support Needs Graph also includes the Support Needs Index score. It is the overall intensity of support needs for the person in all activity subscales in Section 2.

The final pages of the report may also include supplemental information and/or items designated by the team as important to the person or important for the person.

Every domain (i.e., Home Living Activities, Health and Safety Activities, etc.) and each item (8-9 items) within those domains are included in this section of the report. The selected ratings and total score for each item are listed.

<table>
<thead>
<tr>
<th>Item</th>
<th>Type of Support</th>
<th>Frequency</th>
<th>Daily Support Time</th>
<th>Total Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>2 - Verbal/Gesture Prompting</td>
<td>2 - At Least Once a Week, But Not Once a Day</td>
<td>2 - 30 Minutes to Less Than 2 Hours</td>
<td>8</td>
</tr>
<tr>
<td>2.</td>
<td>2 - Verbal/Gesture Prompting</td>
<td>2 - At Least Once a Week, But Not Once a Day</td>
<td>2 - 30 Minutes to Less Than 2 Hours</td>
<td>8</td>
</tr>
</tbody>
</table>

The Support Needs Graph provides a visual way to see summary of an individual's ratings for every activity subscale in Section 2.

The page describes the three rating options for the exceptional support needs for medical conditions and behavioral concerns.

Every item and rating within Section 1A and 1B is listed ranked by those with higher ratings first.
SIS-A Profile: Demographic Information

This feature of the SIS-A Report provides general information determined by each state or jurisdiction. For example, the report may include:

- Person Being Assessed Information
- Interviewer Data
- Assessment Date
- Respondent Data
- Person Who Entered the Information
- Other Pertinent Information

Total Score on Each Item

<table>
<thead>
<tr>
<th>Item</th>
<th>Type of Support</th>
<th>Frequency</th>
<th>Daily Support Time</th>
<th>Total Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Getting from place to place throughout the community (transportation)</td>
<td>2 - Verbal/Gesture Prompting</td>
<td>2 - At Least Once a Week, But Not Once a Day</td>
<td>2 - 30 Minutes to Less Than 2 Hours</td>
<td>6</td>
</tr>
<tr>
<td>2. Participating in recreation/leisure activities in the community</td>
<td>2 - Verbal/Gesture Prompting</td>
<td>2 - At Least Once a Week, But Not Once a Day</td>
<td>2 - 30 Minutes to Less Than 2 Hours</td>
<td>6</td>
</tr>
</tbody>
</table>

A total score provides a convenient summary of the amount of support required for all 57 life items in Section 2: Support Needs Index and Section 3: Protection and Advocacy Activities. The total score of each item is the sum of three ratings, Type of Support, Frequency and Daily Support Time. The example above shows $2 + 2 + 2 = 6$ for both items from the Community Living domain of a SIS-A report.
Standard Scores and Percentiles represent an individual's total rating scores compared to the group of individuals with intellectual and developmental disabilities that originally answered the same questions when the SIS was developed.

What this means: Each person receives fair and consistent results.

Example: A Standard Score of 8 and a Percentile of 25 means an individual's support needs, in that Activity Subscale, represents an individual that may require 25% out of 100% of the possible support needs.

The Support Needs Index (SNI) is the overall intensity of support needs for the individual in all activity subscales in Section 2 of the SIS-A.

What this means: The SNI is a way to compare an individual's support needs related to other individuals with intellectual and developmental disabilities. The higher the SNI number the more support an individual requires for the activity subscales in Section 2 of the SIS-A.

Example: The SNI represents an individual's support needs in all Section 2 activity subscales. A SNI of 39 means an individual may require 39% out of the possible 100% of support needs.

The Support Needs Graph provides a visual way to see an individual's percentiles for every activity subscale in Section 2 of the SIS-A.

What this means: The graph is a simple way to review an individual's support needs in six life activity domains.

Example: This graph shows each bar and how it represents an individual's support needs in each activity subscale.
The SIS-A assessment information provides various roadmaps to help teams determine the pathway to fit a person’s interests, strengths, and aspirations.

Three possible steps to use SIS-A information are described here. These ideas provide a jumping off point for discussion and planning for support teams to consider. Try these out and continue to build on the potential and practical support information the SIS-A report provides.

<p>| | |</p>
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| **1** | **Prioritize & Select Items:**  
While reviewing the SIS-A Report, select items of importance and value to the person and team. Discuss which items stand out to help the team focus in on items to consider for planning or continuing to address in the person’s life. |
| **2** | **Break Down Items into Realistic Steps**  
Once important items are selected, determine which portions of the item have the potential to make a meaningful difference to the person’s participation and involvement in adult life activities. |
| **3** | **Align Supports to What is Needed for Success**  
Chart out how supporters will help the person engage in the selected portions of the items. Consider using the SIS-A rating descriptions to provide supporters examples of needed supports. |
SIS-A Use: Practices

Three ways to use SIS-A information is described in this part of the handbook. Samples from Jane’s report and her team’s actions are included to provide an example of how to make use of each method.

During a review of the Lifelong Learning domain of Jane’s SIS-A report, the team noticed a rating pattern among the informal learning items. They all were rated a weekly frequency or “2”. The SIS-A report revealed that regular teaching and review is an effective way for Jane to learn new things. The team found ways to work together at including learning opportunities into Jane’s daily routine by all using the same teaching strategies and focus areas.
Jane’s team decided to focus on this item because Jane is currently visiting friends and family on an irregular basis. The SIS-A report helped alert the team to the notion that Jane may enjoy and benefit from weekly visits. They identified the barriers keeping Jane from spending time with loved ones. They also scheduled regular visits to move closer to the SIS-A ratings.