WHAT CAN THIS GUIDE DO FOR YOU?

This guide is designed to provide important information and resources about the Supports Intensity Scale - Children’s Version™ (SIS-C™). It aims to inform families and supporters of children with intellectual and developmental disabilities and related delays what to expect during a SIS-C interview, how to read the SIS-C report, and possible uses of SIS-C 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-C interview and empower your team to determine supports that provide meaningful opportunities for the child.

ACKNOWLEDGEMENTS

This work was developed under the guidance of the American Association on Intellectual and Developmental Disabilities (AAIDD) and its SIS-C 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-C users, agencies, and jurisdictions.
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What is SIS-C?

SIS-C is a standardized assessment that measures the pattern and intensity of support needs for children 5-16 years old with intellectual disabilities, as well as other developmental delays and disabilities, to successfully engage in multiple life activities.

How is the SIS-C administered?

The SIS-C assessment is administered using a semi-structured interview process. This means that there is a facilitator, known as the Interviewer, who will guide the discussion, explain the items and rating options, and help determine scores to fit the child. All questions in the assessment are completed, even if the child is not currently participating in every activity. This ensures each time the SIS-C is completed, every team considers and rates all items regardless of current or future settings, opportunities, or resources.

Who participates in a SIS-C interview?

The people who attend the meeting are called, “Respondents” and at least two must attend the entire interview. Respondents know the child being discussed very well and are comfortable sharing about the supports that child may need in a variety of settings like at home, in the community or at school. Most importantly, the child that the SIS-C is for is encouraged to participate in the assessment as the child and the guardian determine appropriate. It may also be helpful to share any accommodations needed or any sensitive or difficult topics prior to the interview.

Who participates Where does a SIS-C interview take place?

The setting should be comfortable for the child and respondents, free from distractions, and a safe environment to talk about confidential information.
How much time does the SIS-C 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-C is very comprehensive and includes two sections with multiple items in each section. During the meeting, the team discusses a section about exceptional medical and behavioral supports and a section with seven Life Activity subscales common to the lives of all children. Plan to bring snacks, drinks and any assistive devices for your comfort and optimum participation.

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

The Interviewer guides the Respondent group through all sections of the assessment. Respondents share and discuss the child’s support needs for all the life activities. Plan for an open and honest discussion including all team members about support ratings.

What does the SIS-C consist of?

There are two sections of the assessment. Section 1 is about exceptional medical and behavioral support needs. Some of the items may not apply to the child, but the Interviewer explains each item and the team rates each to be sure.

Successful participation is the focus of Section 2. The team explores the extra supports that are needed to help the child be involved in the same life activities that other similar aged children are involved in, at the same level of performance and participation. In other words, when provided the right combination of help, the child is an active participant in the same life activities that other children of the same age are involved in within the community.
PART I: EXCEPTIONAL MEDICAL AND BEHAVIORAL NEEDS

RATING KEY

0 = No Support Needed
1 = Some Support Needed [i.e., providing monitoring and/or occasional assistance]
2 = Extensive Support Needed [i.e., providing regular assistance to manage the medical condition or behavior]

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

Section 1B: Exceptional Behavioral Support Needs (14 Items)
- Externally Directed Behavior (4 Items)
- Self-directed Behavior (3 Items)
- Sexual Behavior (2 Items)
- Other Exceptional Behavioral Concerns (5 Items)
### Rating Key

<table>
<thead>
<tr>
<th>Type of Support</th>
<th>Frequency of Support</th>
<th>Daily Support Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 = none</td>
<td>0 = NEGLIGIBLE: The child’s support needs are rarely, if ever, different than same-aged peers in regard to frequency</td>
<td>0 = none</td>
</tr>
<tr>
<td>1 = monitoring</td>
<td>1 = INFREQUENTLY: the child will occasionally need someone to provide extraordinary support that same-aged peers will not need.</td>
<td>1 = less than 30 minutes</td>
</tr>
<tr>
<td>2 = verbal/gesture prompting</td>
<td>2 = FREQUENTLY: in order for the child to participate in the activity, extra support will need to be provided for about half of the occurrences of the activity.</td>
<td>2 = 30 minutes to less than 2 hours</td>
</tr>
<tr>
<td>3 = partial physical assistance</td>
<td>3 = VERY FREQUENTLY: in most occurrences of the activity, the child will need extra support that same aged peers will not need.</td>
<td>3 = 2 hours to less than 4 hours</td>
</tr>
<tr>
<td>4 = full physical support</td>
<td>4 = ALWAYS: on every occasion that the child participates in the activity, the child will need extra support that same-aged peers will not need.</td>
<td>4 = 4 hours or more</td>
</tr>
</tbody>
</table>

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**Supports Needs Scale**

Section A: Home Life Activities (9 Items)

Section B: Community and Neighborhood Activities (8 Items)

Section C: School Participation Activities (9 Items)

Section D: School Learning Activities (9 Items)

Section E: Health & Safety Activities (8 Items)

Section F: Social Activities (9 Items)

Section G: Advocacy Activities (9 Items)
The Interview and Profile Summary Results Report (SIS-C Family Friendly Report) includes general information about the child followed by a summary of the SIS-C interview results.

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

This page of the report describes the rating options for Sections 2 of the SIS-C assessment.

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 Addr:
- City:
- State/Province:
- Zip Code:
- Position:
- Phone:
- Ext.:
- Interviewer Email:

Assessment Data:
- Interview Date (mm/dd/yyyy):
- ISP Begin Date:
- SIS ID:

Respondent Data:
Information for the SIS ratings was provided by the following respondents:
- First Name
- Last Name
- Relationship
- Agency
- Email
- Language

Page 2: Rating Key for Sections 2

<table>
<thead>
<tr>
<th>Type of Support</th>
<th>Frequency</th>
<th>Daily Support Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 options to determine the dominant or best fitting support type.</td>
<td>5 options to determine how often support would be needed for success.</td>
<td>5 options to determine how much support time would be needed in a typical day.</td>
</tr>
</tbody>
</table>
Pages 3-9: Section 2

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 **raw scores** (actual) are included for all ratings, too.

<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>7. Complying with basic community standards, rules, and/or laws</td>
<td>4 - Full Physical Support</td>
<td>4 - Always</td>
<td>4 - 4 Hours or More</td>
<td>12</td>
</tr>
<tr>
<td>1. Moving around the neighborhood and community</td>
<td>4 - Full Physical Support</td>
<td>4 - Always</td>
<td>3 - 2 Hours to Less Than 4 Hours</td>
<td>11</td>
</tr>
</tbody>
</table>

Cole uses a wheelchair and needs to have an accessible vehicle.

Page 10: Support Needs Profile Graph

The Support Needs Graph provides a visual way to see summary of the child’s ratings for every activity subscale in Section 2.

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

Page 11: Section 1 Rating Key

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

Page 12-13: Section 1

Every item and rating within Section 1A and 1B is listed and ranked by those with higher ratings first.

The final pages of the report may also include supplemental information and/or items that were designated by the team as important to or important for the child.
SIS-C Profile: Demographic Information

This feature of the SIS-C 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. Completing household chores</td>
<td>3 - Partial Physical Assistance</td>
<td>4 - Always</td>
<td>2 - 30 Minutes to Less Than 2 Hours</td>
<td>9</td>
</tr>
<tr>
<td>7. Keeping track of personal belongings at home</td>
<td>3 - Partial Physical Assistance</td>
<td>3 - Very Frequently</td>
<td>2 - 30 Minutes to Less Than 2 Hours</td>
<td>8</td>
</tr>
</tbody>
</table>

A total score provides a convenient summary of the amount of support required for all 61 life items in Section 2: Support Needs Scale, Sections A-F. The total score of each item is the sum of three ratings, Type of Support, Frequency and Daily Support Time. The example above shows 3+4+2 = 9 for the first item and 3+3+2=8 for the seventh item from the Home Life subscale as listed on a SIS-C report.
Standard Scores and Percentiles represent a child's total rating scores compared to the group of children with intellectual and developmental disabilities of the same age that originally had teams answer the same questions when the SIS-C was developed.

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

Example: A Standard Score of 10 and a Percentile of 50 means a child’s support needs, in that Activity Subscale, represents a child of the same age that may require 50% out of 100% of the possible support needs.

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

*What this means:* The SNI is a way to compare a child’s support needs related to other children with intellectual and developmental disabilities. The higher the SNI number the more support a child requires for the activity subscales in Section 2 of the SIS-C.

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

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The Support Needs Profile Graph provides a visual way to see a child's support percentiles for every activity subscale in Section 2 of the SIS-C.

*What this means:* The graph is a simple way to review a child's support needs in seven life activity domains.

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

Three possible steps to use SIS-C 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-C report provides.

1. **Prioritize & Select Items:**
   While reviewing the SIS-C Report, select items of importance and value to the child 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 child’s life.

2. **Break Down Items into Achievable Steps**
   Once important items are selected, determine which portions of the item have the potential to make a meaningful difference to the child’s development and involvement in meaningful life activities.

3. **Align Supports to What is Needed for Success**
   Chart out how supporters will help the child engage in the selected portions of the items. Consider using the SIS-C rating descriptions to provide supporters examples of needed supports that are unique to the child.
During a review of the Health and Safety subscale on Joey’s SIS-C report, the team noticed a rating pattern among the highest rated items. They were all rated a frequency of always or “4”. The SIS-C report reinforced the team’s concerns for Joey’s well-being. The team found ways to prioritize learning opportunities and checking in with Joey during his daily routine by all using the same strategies and focus areas.
While Joey reviewed his SIS-C report with his mother, this item caught their attention. Joey’s mother noticed this item required less support than other items in the School Participation subscale. Joey and his mother discovered the reason for the lower support is because it is important to Joey to have all of his belongings in his favorite backpack. Joey’s team made sure to include a picture with him carrying his backpack in his plan and added in care items important to his health needs to a side pocket.

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