Supports Intensity Scale

Supplemental Administration and Scoring Procedures

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American Association
on Intellectual and
Developmental Disabilities

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Supplemental Information on the Administration and Scoring of the Supports Intensity Scale

Since its publication in 2004, the Supports Intensity Scale™ (SIS™) has been used extensively by multiple entities for individual planning and budgeting, for systems evaluation and planning, and as one component in resource allocation models and decisions. During that same period, SIS authors and AAIDD staff have worked with national and international colleagues to develop interviewer training programs; to implement SIS at individual, agency, and systems levels; and to systematically evaluate the reliability and validity of the scale. The results of these efforts are summarized in this supplement as well as in a number of white papers that will be posted for downloading and commenting on the SIS Web site (www.siswebsite.org). The information found in this supplement focuses on issues surrounding the administration and scoring of SIS: Chapter 1 explains how to rate individual items; Chapter 2 presents expanded item descriptions; and Chapter 3 provides answers to frequently asked questions.

The Supports Intensity Scale has been translated into more than ten languages and has been widely adopted by organizations, states, regions, and countries. This widespread implementation and use needs to be viewed within the context of the current service delivery system for persons with intellectual and closely related developmental disabilities. In their contribution to the supplement and white papers, Charles Moseley and Nancy Thaler of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) indicated that the comprehensive evaluation of individuals' support needs lies at the heart of developmental disabilities service delivery. The profile and intensity of needed supports provide the basis for developing appropriate and effective support plans, identifying needed services, selecting providers, estimating costs, and developing individual budgets.

In the past, when services were delivered predominantly through large center-based programs, the needs assessment process was driven by clinicians and professionals, and designed to identify functional capacities and health conditions. Today, the role of the assessment process has broadened to support the development of a personal lifestyle that reflects the desires of individuals with intellectual and developmental disabilities and their families to lead regular lives in the community, become economically productive, and participate in social activities. This process is facilitated when the assessment tool (in this case SIS): (1) is constructed using an appropriate conceptual design and research

base; (2) is administered in reliable and valid ways; (3) is easy to employ in practical situations and used by professionals, nonprofessionals, and stakeholders with a wide range of skills; and (4) is accepted by the people who use the tool and those with disabilities whose lives are affected by its use. Correct administration and scoring of SIS is essential in fulfilling each of these four criteria.

This supplement has been developed to ensure that those four criteria are met and to assist SIS users in obtaining reliable and valid information regarding the support needs of their clientele. The material contained in the chapters that follow clarifies administration and scoring questions, and issues that have been raised over the last three years by current and potential SIS users. Throughout these chapters the reader will find material provided by those persons who have been most involved in SIS administration, scoring, training, and use. The material presented is meant to clarify the administration and scoring of SIS, not to revise it.

Special thanks are extended to Mark Eliason, Jim LeVelle, Colleen McLaughlin, and Alan Tribble for their work on the Expanded Item Descriptions as part of the AAIDD Task Force. This Task Force's work was based largely on initial work that was completed by the Louisiana Program Committee. We appreciate the invaluable feedback offered by Natalie Ihli and AAIDD Senior Trainers on the revised Expanded Item Descriptions.

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Scoring the Supports Intensity Scale: How to Rate the Individual Items

T he purpose of this document is to further clarify information contained in the administration of the Supports Intensity Scale™ (SIS™). It supplements—but does not replace—information in the SIS *Users' Manual*. SIS users need to consult the manual prior to administering SIS. This information was written by the editors and was based on discussions held with current SIS users and AAIDD trainers. Special appreciation is extended to the other SIS contributors for their thoughtful critiques and suggestions. SIS users need to keep in mind the following points, which are essential in rating the individual items:

1. Ratings should reflect the supports that would be necessary for this person to be successful in each activity. *Success* is defined as engagement in all aspects of an activity as judged against contemporary community standards, resulting in maximal involvement of the person in the activity. In other words, successful engagement entails a level of performance or involvement in an activity that is comparable to that of typically functioning adults without disabilities.

2. For each item, it must be assumed that the person has the opportunity to participate at levels potentially requiring maximum frequency, time, and type of support. Therefore interviewers and respondents should remember that ratings can reflect a maximum level of potential support.

3. The person should be rated based on his or her current use of assistive technology.

4. *All* items should be completed, even if the person is *not* performing the listed activity.

5. Ratings should reflect the supports a person would need to be successful as a typical adult; ratings should *not* be based on current support being provided.

6. Ratings are based on the supports a person would need to be successful as a typical adult, without regard to the current or potential availability of those supports.

7. Ratings on SIS do not of necessity imply that each of the activities rated must be incorporated into a person's individual plan. Those planning decisions will certainly be informed, but not dictated, by SIS. The individuals and their planning teams will use information discovered during the assessment to assist them as they identify and prioritize those areas of life or activities in which they want and need assistance.

Tips on Rating Support, Frequency, and Time

Since the publication of SIS, experienced interviewers have discovered that the interview flows better when they ask first about the type of support needed, then about the frequency of support, and finally about daily support time. The second edition of the Supports Intensity Scale, when published, will reflect this new order. In the meantime, it is recommended that you follow this order when rating.

Rating Type of Support

The respondent should focus on the following question when rating type of support: If a person were to engage in the activity on a regular basis over the next several months, what would be the nature of the extraordinary support (i.e., the assistance that most typically functioning adults would not need) that others would need to provide to enable the individual to be successful in the activity?

This scale is concerned with identifying the kind of support provided by others. Although different types of support are needed for different activities (e.g., verbal prompting and partial physical assistance may both be involved), the respondent is asked to identify *which type of support* best characterizes or most dominates the assistance that is provided.

Rating Options

0=none; 1=monitoring; 2=verbal/gestural prompting;
3=partial physical assistance; 4=full physical assistance

Rating Frequency

The respondent should focus on the following question when rating frequency: If the person were to engage in the activity on a regular basis over the next several months, how often would extraordinary support be needed to enable the individual to be successful in the activity? The intent of the frequency scale is not to measure how frequently the person currently engages in the activity but rather **how frequently the person would need support** if he were to engage in the activity.

All individuals must be rated as if they were going to engage in the activity on a regular basis over the next several months. The frequency rating should reflect the nature of the intensity of support the person would need to be successful. That is, raters should consider the person fully engaged in the activity and *determine the extent of assistance* that most typically functioning adults would not normally require.

> **Rating Options**
>
> 0=none or less than monthly; 1=at least once a month, but not once a week;
> 2=at least once a week, but not once a day (up to 6 days a week);
> 3=at least once a day but not once an hour (at least 7 days a week);
> 4=hourly or more frequently (24 hours a day)

For example, an individual requires assistance every time she or he attempts to complete work-related tasks with acceptable speed (Item D5). The frequency would most often equal 2. (This would mean at least once a week but not once a day, and up to 6 days a week, because the typical adult works 5–6 days a week. Only in rare cases would anyone routinely work 7 days a week.)

Rating Daily Support Time

The respondent should focus on the following question when rating daily support time: If a person were to engage in the activity on a regular basis over the next several months, during the course of a typical 24-hour day, how much total daily time would be needed to provide extraordinary supports to enable the individual to be successful in the activity? Extraordinary *supports* means the types of assistance that most typically functioning adults would not need.

This rating estimates the amount of time needed to provide these supports across a typical day when the support is provided. A day is defined as 24 hours. Thus, whether the support is needed every day or once a year, on a typical day when the support is needed—during that 24-hour cycle—how much total, cumulative time needs to be devoted to providing the support? The daily support time is NOT the amount of time required to complete the task but rather the extra time required in extraordinary support to the person.

Integrating the Three SIS Ratings

> **Rating Options**
>
> 0=none; 1=less than 30 minutes; 2=30 minutes to less than 2 hours;
> 3=2 hours to less than 4 hours; 4=4 hours or more

What follows is an example of integrating the three SIS ratings:

Type of Support (TS): The person has a full-time job and requires partial physical assistance, or 3, to "complete work-related tasks with acceptable speed" (Item D5 on SIS interview form) to meet the standards of the employer.

Frequency of Support (F): The individual requires assistance every time he works to "complete work-related tasks with acceptable speed" (Item D5), so the frequency rating would be 2 (at least once a week but not once a day) since the person works 5 days a week.

Daily Support Time (DST): For this individual the DST is a 4 (4 hours or more) since she needs more than 4 hours of support each day that she works. This score is dependent on the amount of support the person needs each day to meet the standards of her competitive work environment.

Summary: The ratings for this example are TS = 3, F = 2, and DST = 4.

Guidelines to Use When Determining Ratings

Consider Multiple Tasks Within an Activity

If the activity contains multiple elements, then greater emphasis should be placed on the essential element(s) that are at the heart of the activity when determining ratings; however, the secondary elements should not be disregarded. The task for respondents is to provide a rating that reflects their perceptions of a valid composite rating of primary and secondary elements. For example, Item 2 (Taking Care of Clothes) of Part A (Home Living Activities) on the SIS interview form refers to maintaining clothes, which "includes laundering, ironing, sewing, minor repairs, hanging clothes in closets, and/or folding/placing clothes in chest of drawers." The following is an example for applying these guidelines to the three ratings:

- If the person needs significant support on a weekly basis for the essential element of laundering (e.g., operating the washer and the dryer) as well as significant support on a monthly basis for several secondary elements, such as hanging and folding clothes, then a frequency rating of 2 would best reflect the frequency of support in its composite (2 = at least once a week but not once a day). In this example, most essential elements require significant support on a weekly basis, and therefore the higher rating is justifiable.

- If approximately 45 minutes of time is required for the essential element of laundering on a typical day that the individual completes laundering and if consideration of the secondary elements indicates that only a small investment of time is required, then a daily support time rating of 2 (30 minutes to less than 2 hours) would be the correct rating that best reflects daily support time in its entirety. In this example, there is not enough extra time required on a day the support is needed to complete the secondary tasks to justify a higher composite rating of 3 (2 hours to less than 4 hours or more per day).

- If the person requires only verbal/gestural prompting to do the essential element of laundering but needs partial assistance for folding/placing and hanging and full physical assistance in ironing and repairing clothes, then a type of support rating of 3 (partial physical assistance) is justified. In this example, enough physical assistance is needed to complete the activity of "taking care of clothes" on a regular basis to justify a composite rating of 3, or "partial physical assistance," for type of support.

Assess the Individual's Support Needs Holistically

The individual's skill level, use of assistive technology, motivation, health, behavior, and safety/vulnerability must all be considered when determining ratings. People should be rated in accordance with their current status and functioning. For example, a person with low motivation, short attention span, low tolerance for learning, and limited cognitive ability will likely require high levels of supports to meet the standard of "success" with many of the items.

If an individual uses assistive technology (AT), the person should be rated with that technology in place. That is, it is important to factor in the assistive technology that the person currently uses on a regular basis when determining the ratings. If assistive technology is not yet used or is not yet available to the person, it should not be considered when completing SIS. For example, an individual might need less support in "accessing public buildings" if he had access to a motorized wheelchair. However, because this person does not have access to a motorized wheelchair, ratings on SIS should reflect the reality of his situation and the support he needs, due to (a) his disabilities and (b) the lack of appropriate AT. In many cases, the intensity of an individual's support needs will decrease when provided with appropriate AT.

Base Ratings on Community Environments

Ratings should be community referenced. For example, ratings such as those related to employment should be based on competitive employment within the community. Similarly, transportation should be based on local public/private options. Ratings should not be based on disability-specific services, such as recreation, leisure, and/or transportation services.

Do Not Consider Services and Supports That the Person Is Currently Receiving

Ratings should be made for each activity without regard to the services or supports currently provided by organizational staff or by other people. Moreover, ratings should not be altered because of the availability of natural supports. That is, in instances where a co-worker, neighbor, or family member provides extraordinary support to an individual, the person should still be rated as needing the extraordinary support.

Do Not Consider the Current or Potential Availability of Supports

When rating, do not take into consideration the current availability or likelihood of future availability of supports. The rating is regarding the supports necessary for the individual to be successful in her community as any other typical adult. The fact that that person does not and/or may not have access to funding for those supports should not affect the rating.

Pay Close Attention to the Verb Used

The rating should consider the action verb that is used in the stem of the activity, since some verbs reflect a greater level of activity, which may have implications for needed support. For example, *going* somewhere will include transportation, whereas *participating* assumes that one is already there; *shopping and purchasing goods* involves the use of money and potential vulnerability issues, whereas *accessing* services may require only a contact or phone call; and a person may require little support to *avoid* health and safety hazards, but more support to *obtain* health care services that involve not just making appointments but also communicating with the medical staff.

Expanded Item Descriptions for the Supports Intensity Scale

Since its publication, users of the Supports Intensity Scale™ (SIS™) have expressed the need for more detailed descriptions and examples of the items measured by SIS in addition to the information found in the 2004 SIS *Users' Manual* (Tables 2.1–2.9). A workgroup was formed in early 2005 to expand these item descriptions, and the results of this work were published on the AAIDD SIS Web site (www.siswebsite.org). Work has continued since that time, with the result being the expanded item descriptions that follows. Users should find both the expanded descriptions and the user-friendly format of the tables to be helpful. It is important that both interviewers and respondents realize that these descriptions are examples for use as a reference, and they do not need to consider every example. The examples used should be what are considered typical for the person's immediate environment.

Definition of Supports: Supports are defined as resources and strategies that promote the interests and welfare of individuals, and that result in enhanced personal independence and productivity, greater participation in an interdependent society, increased community integration, and/or improved quality of life. *Supports are* not limited to *performance of a task; they also include training*.

Section 1: Supports Needs Scale

Part A: Home Living Activities

Expanded Item Descriptions

Home Living Activities	Includes Supports To:	Does Not Include:
Set the Scene: This section involves everyday activities performed in the home.		
1. Using the Toilet: The focus of this item is on supports to accomplish all of the activities necessary for a person to void in a socially acceptable manner in all environments throughout the day. ***Essential Elements: Completing all steps of toileting***	• Access the bathroom (e.g., mobility getting to the bathroom, operation of the door, communicating need to use the bathroom) • Accomplish steps before and after toileting in a socially acceptable manner (e.g., undoing clothes, fasteners, etc.; pulling down clothes, rebuckling, resnapping, etc.; pulling up clothes,	

Expanded Item Descriptions

Home Living Activities	Includes Supports To:	Does Not Include:
	getting on and off toilet; changing briefs; cleaning self; and washing hands, etc.) • Move out of the bathroom and back to a previous activity • Use other voiding alternatives (e.g., catheter, colostomy, care for incontinence or other supports to maintain an appropriate way to void) • Preserve dignity and privacy associated with toileting	
2. Taking Care of Clothes: The focus of this item is on supports to accomplish activities involved in taking care of personal clothing. *Essential Elements: Maintaining clothing (cleaning and putting away)*	• Do all steps to clean clothes. These include recognizing and gathering items to be cleaned, sorting clothes, putting clothes in washer and dryer, measuring soap, operating washer and dryer, and any other actions that are directly associated with cleaning clothes. • Fold and put clothing away in dressers, closets, and so on, or hang clothes in closet • Take clothes to a dry cleaner • Iron, sew, and make minor repairs	• Transportation to and from a laudromat or cleaner (B1) • Waiting time while clothes are in washer/dryer
3. Preparing Food: The focus of this item is on supports associated with the preparation of meals and snacks that require more than one step, not simply opening a package or can. *Essential Elements: Cooking simple meals throughout the day*	• Prepare and/or cook desired meals (breakfast, lunch, dinner, and snacks) within his/her budget (not specialized gourmet foods) • Menu/meal planning • Prepare, wash, cut, chop, blend, and/or mix food • Use kitchen appliances (e.g., stove, microwave, toaster oven, blender, coffee maker) to prepare food • Prepare foods for specialized eating arrangements where relevant (e.g., pureeing foods in blender or adding thickeners to beverages)	• Shopping for food (B6) • Cleaning up after meal preparation or meals (A5) • Operate advanced kitchen appliances
4. Eating Food: The focus of this item is on supports associated with the ingesting of foods and beverages for nourishment in all environments throughout the day. *Essential Elements: Eating safely, using utensils*	• Set up the food for ingestion (e.g., setting up tube feeding, arranging mechanical devices that aid eating, providing specialized eating utensils, setting up a plate for a person with visual impairments using a "clock" method, etc.)	

Expanded Item Descriptions

Home Living Activities	Includes Supports To:	Does Not Include:
	• Assist with or teach use of utensils, including appropriate use of a knife, fork, and spoon or adaptive utensils • Cut food on plate to appropriate size • Assist with positioning to facilitate chewing, swallowing, and digestion (where relevant) • Assist during tube feeding (e.g., waiting, checking for residuals, flushing the tube with water, etc.) • Regulate food intake (e.g., preventing choking or eating too fast)	• Table manners (covered in F6)
5. Housekeeping and Cleaning: The focus of this item is the entire household and supports associated with housekeeping and cleaning tasks necessary to maintain a presentable and healthy living environment. ***Essential Elements: Completing common household chores***	• Maintain a clean and presentable living area, including sweeping, mopping, dusting, vacuuming, making bed, and changing sheets • Straighten things up in all living areas, put items away • Clean bathroom (e.g., sanitizing toilet, bathtub, sink, mirror) • Put trash in trash can; take out trash; throw out spoiled food; clear and clean after meals; wash/dry dishes or properly use dishwasher; and clean appliances, such as microwave, stove, toaster, blender, and so on • Properly use cleaning supplies (e.g., dish soap, window cleaner, sanitizers)	• Purchasing cleaning items/products (B6) • Plant care • Lawn maintenance • Home repairs • Home maintenance • Changing light bulbs • Putting clothes away
6. Dressing: The focus of this item is on supports required to get dressed following typical community standards as related to age, culture, and weather, and/or to change one's clothes during the day when necessary. ***Essential Elements: Putting on and taking off clothes***	• Select clothes appropriate for the day's changing activities (e.g., work, recreation, formal events, bed time) • Put on and take off clothes, including zippers, snaps, buckles, buttons, laces, bras, and belts • Identify and/or assist when clothing needs to be changed due to being soiled, dirty, or inappropriate • Choose weather- and age-appropriate clothing for the occasion	

Part A: Home Living Activities

Expanded Item Descriptions

Home Living Activities	Includes Supports To:	Does Not Include:
7. Bathing and Taking Care of Personal Hygiene and Grooming Needs: The focus of this item is on supports to assist individuals with tasks associated with personal cleanliness, bathing, and proper grooming. ***Essential Elements: Bathing, personal cleanliness, and proper grooming***	• Recognize the need to address personal hygiene and identify when bathing and grooming is needed • Safely get in and out of tub or shower; make appropriate water adjustment • Thoroughly clean the body in either a shower or bath • Brush teeth, shave, wash and brush hair, wash hands, have hair cuts, denture care, maintain nail/skin care, and so on • Assist with menstrual care • Keep clean throughout the day • Change clothing protectors (e.g., bibs, ponchos, aprons, etc.)	
8. Operating Home Appliances: The focus of this item is on supports associated with the functional operation of common home appliances that are used on a regular basis. ***Essential Elements: Operation of common household items not covered in other A1 items***	• Use items such as the television, telephone, VCR/DVD, radio, air conditioners, heaters, fans, stereo, telephone, and so on	• Appliances used for cleaning, such as vacuum cleaner (A5) • Appliances used for cooking, such as a microwave (A3) • Washer/dryer (A2) • The amount of time the appliance is running (e.g., time TV is on) • Advanced features or devices, such as programming a VCR to record a program • Irons • Thermostats • Lamps or overhead heating

Part B: Community Living Activities

Expanded Item Descriptions

Community Living Activities	Includes Supports To:	Does Not Include:
Set the Scene: This section is about general activities that take place in the community.		
1. Getting From Place to Place **T Throughout the Community (Transportation):** The focus of this item is on activities to support an individual to get from from one location in the community to another effectively. ***Essential Elements: Community transportation***	• Get to and from places in the community, including essential places (e.g., grocery stores, place of employment, banks, shopping centers, medical/therapy appointments, volunteer opportunities, etc.) as well as recreational places (e.g., bowling and aerobics classes, movies, restaurants, etc.) • Use some mode of transport (e.g., walk, wheelchair, ride a bus, ride a bike, take a taxi or private car) • Know routes to and from desired destination • Get in and out of a vehicle safely (e.g., get a wheelchair in and out of a vehicle)	• Wait time at an appointment • Time the person is not in the vehicle • Transportation out of convenience • Going to visit friends and family (B4) • Accessing training or educational settings (C5)
2. Participating in Recreation/ Leisure Activities in Community Settings: The focus of this item is on supports to assist an individual to participate in community recreation/leisure activities. ***Essential Elements: To take part in and perform community activities***	• Take part in recreation/leisure activities in community settings (e.g., bowling; going to a movie; eating out; dancing; playing bingo; attending club/ organization meetings, concerts, and sporting events; hiking; taking walks in the park, swimming) • Know what to do at the activity (e.g., purchasing tickets, obtaining equipment/materials/snacks)	• Transportation to and from the activity • Supports to access recreation/leisure activities • School or work • Vacations (since they are not a typical day/ week) • Agency sponsored activities/events or other segregated events such as Special Olympics

*T = Transportation: item used to assess transportation support needs.

Part B: Community Living Activities

Expanded Item Descriptions

Community Living Activities	Includes Supports To:	Does Not Include:
3. Using Public Services in the Community: The focus of this item is on supports to assist individual in using services in the community that are available to the general public. ***Essential Elements: Identifying and using public/governmental community services***	• Identify/convey the need for services • Use post office, library, bank, food and clothing banks, shelters • Meet with relevant public-service providers and government agencies in the community (e.g., case managers, health care clinics, child care services, housing assistance, public incentive or benefit programs) • Complete tasks to use needed services, including Medicaid, food stamps, social security, identification cards, driver's license, and utilities bills (e.g., reading and completing applications, signing forms, filling out a deposit slip)	• Supports needed to access public services • Transportation to and from activity • Shopping for food
4. Going to Visit Friends T and Family: The focus of this item is on supports to assist an individual in going to places where he/she can interact with friends and family. ***Essential Elements: Planning, transportation, and interaction with visits***	• Get the individual to places where he/she has an opportunity to interact with others who are considered close friends or family members • Use local transportation (generally within an hour's drive) • Arrange or plan visits, including the support needed for the visit and supports needed during the visit (e.g., setting up assistive devices, interpreters, behavioral supports, medical supports, such as diabetic or catheter supplies) • Interact appropriately with friends and family	• Visiting with paid staff persons • Vacations
5. Participating in Preferred Community Activities (Church, Volunteer): The focus of this item is on supports to participate in preferred community activities ***Essential Elements: To take part in favorite activities important to the individual***	• Take part in activities that the individual *truly values* (e.g., participating in a religious function; attending church, synagogue, mosque, or temple; going to restaurants, bars, and nightclubs; volunteering for a community organization, such as programs for seniors or children, animal shelters, hospitals, support groups, and participating in public activism, such as politics and demonstrations)	• Items covered in B2 • Transportation to and from activity • Planning for an event • Disability related service

Expanded Item Descriptions

Community Living Activities	Includes Supports To:	Does Not Include:
6. Shopping and Purchasing Goods and Services: The focus of this item is on supports to shop for goods/services and make purchases either at a store, through a catalog, or online. ***Essential Elements: Buying an item or service***	• Identify items to purchase • Select appropriate items • Pay for items (e.g., debit card, credit card, check, cash), count change, write checks, get refunds • Interview to purchase a service (e.g., housekeeper, plumber, electrician) • Purchase through catalogs and/or shop for a specific item on the Internet.	• Using the Internet without the specific intent of shopping • Transportation
7. Interacting With Community Members: The focus of this item is on supports to promote positive and effective interactions with community members in whatever context they occur. ***Essential Elements: Interaction and communication with the general public***	• Interact with community members (e.g., neighbors, store clerks, police officers, waiters) in a socially-acceptable manner • Communicate effectively in a variety of settings (e.g., shopping, joining recreational events, eating out, using public services) • Use social conventions such as shaking hands and saying please and thank you • Maintain socially appropriate boundaries (e.g., privacy, respect, physical proximity, touching, personal safety) • Know when to initiate conversations and with whom • Be understood	• Transportation • Interactions with friends and family
8. Accessing Public Buildings and Settings: The focus of this item is on supports to assist the individual in entering and exiting public settings and abiding by the rules of the setting. ***Essential Elements: Enter, exit, and obey rules of public settings***	• Physically enter public buildings and settings (e.g., libraries, parks, stores, swimming pools, locker rooms, public restrooms, community employment sites accessible to the public) • Follow rules for entering, exiting, and using the facility (e.g., adhering to hours a park is open, finding a room number, being quiet in libraries, using doors for entering and exiting) • Understand the consequences if rules are not followed • Use elevators, escalators, steps, and doors	• Transportation to and from activity where public building and setting is located • Using the services of the building

Part C: Lifelong Learning Activities

The focus of this section of SIS is to capture the importance of lifelong learning as an ongoing process for everyone. Whether through a formal college setting, informal community center, or daily learning opportunities, these opportunities add enrichment to our lives and perspective to our thinking. The interviewer should keep in mind the following guidelines to assist respondents in considering "typical" learning environments:

- Questions C1, C2, C4, and C5 relate to more formal training settings. For many adults, a formal class might occur at least once a week for approximately 2 hours. For some, support may need to be provided outside of class to successfully prepare for active engagement in training environments.

- Questions C3, C6, C7, C8, and C9 relate to ongoing learning situations that may take place at home, in the community, or other nontraditional educational settings. For individuals learning activities outside of formal settings, small increments of time throughout the day may be required to ensure the greatest possible chance to acquire skills.

- It is important to remember that this section is looking for the support needs to best support a person's learning style. Some individuals are visual learners while others prefer a hands-on approach. The type of support needed to learn may reflect the type of teaching that best fits the person's needs. A type of support of a 3 or 4 would also describe a cognitive step or support being provided not just physical assistance. For example, the caregiver must complete some of the cognitive steps necessary to support learning problem-solving strategies.

- This section also requires respondents to consider the individual being assessed in a learning capacity, not necessarily a mastery of skill or successful completion of an activity. Successful completion of an activity will be addressed in other sections.

- An important factor to learning is applying what is learned to the appropriate situation or setting. For some individuals, more support time may be needed to remind an individual of how/when to apply a learned skill than to spend a lot of time teaching the fundamentals of the skill.

- When considering supports an individual needs to learn, it may be helpful to ask: "What supports would need to be provided to give an individual the best possible opportunity to learn?"

Part C: Lifelong Learning Activities

Expanded Item Descriptions

Lifelong Learning Activities	Includes Supports To:	Does Not Include:
Set the Scene: This section is about learning and applying skills in formal and informal settings within the community.		
1. Interacting With Others in Learning Activities: The focus of this item is on supports to promote appropriate interactions with fellow students and instructors in formal educational settings. ***Essential Elements: Interaction with students and instructors in a class***	• Interact in formal educational settings with fellow students and instructors (e.g., classroom at community college or YMCA) • Express oneself • Understand others • Follow instructions • Communicate need for assistance • Get along with others in a structured learning environment (e.g., respect other learners' personal space, and know when to speak up in class and to other learners)	• Nonintegrated learning environments
2. Participating in Training/ Educational Decisions: The focus of this item is on supports needed to review options, select course(s), and plan a course schedule in keeping with learning goals. ***Essential Elements: Reviewing options, selecting course(s), and planning a schedule***	• Understand and express choices concerning learning options and goals • Locate courses, classes, or workshops (e.g., cooking, art, nutrition, dance, computer) offered through formal venues include (e.g., the parks department, community college, community education programs) • Participate in the planning process of an educational pursuit/goal • Develop a course schedule	• Disability-specific learning settings • Any disability-specific planning process
3. Learning and Using Problem-Solving Strategies: The focus of this item is on supports needed to learn and apply problem-solving strategies in an effort to resolve problems, issues, and so on in real-life situations. ***Essential Elements: Learn and apply strategies to solve problems***	• Identify when something goes wrong or there is a problem • Identify strategies to solve problems • Learn how to solve problems in situations, such as, but not limited to, what to do when you miss a bus or an appointment; what to do to safely travel across town; what to do when you lock yourself out of your home; how to report problems at work or home; or rescheduling missed appointments • Apply learned strategies to real-life situations	

Part C: Lifelong Learning Activities

Expanded Item Descriptions

Lifelong Learning Activities	Includes Supports To:	Does Not Include:
4. Using Technology for Learning: The focus of this item is on supports to use technology as an aid for learning/participation and the completion of assignments. ***Essential Elements: Use of technical devices for learning***	• Operate computers or other technology that that person needs to participate in instructional programs • Use computers; calculators; augmentative communication devices; note taking devices, such as voice recorder; TDDs and TTYs; and devices needed to view educational materials (e.g., online instruction, DVD materials, video streaming)	• Use of a technology for entertainment or leisure activities
5. Accessing Training / **T Educational Settings:** The focus of this item is on getting to and from the educational setting and locating the classroom. ***Essential Elements: Getting to/from class***	• Locate courses or workshops offered through a variety of community providers (e.g., parks district, YMCA, colleges) • Obtain resources for paying tuition for classes • Obtain transportation and/or get to and from the training/educational setting • Locate the specific room where the course will be held	• Participating in the class

*T = Transportation: item used to assess transportation support needs.

Part C: Lifelong Learning Activities

Expanded Item Descriptions

Lifelong Learning Activities	Includes Supports To:	Does Not Include:
6. Learning Functional Academics (Reading Signs, Counting Change): The focus of this item is on supports to learn and apply functional academics within community settings and scenarios. ***Essential Elements: Learn reading, writing, adding, subtracting, and apply to real-life situations***	• Learn to read and write • Learn to add and subtract • Apply reading and writing skills (e.g., reading and following simple instructions, completing forms and applications, typing on a computer) • Apply math skills (e.g., learning money management and budgeting) • Learn to tell time, keep a schedule, count money for purchases, read bus schedules, identify day of the week and date on a calendar, find telephone numbers, and so on	
7. Learning Health and Physical Education Skills: The focus of this item is on supports for the development and use of health and physical education skills, and applying concepts learned to real-life situations. ***Essential Elements: Learn how to stay healthy, fit, and safe***	• Learn when/why to make medical and dental appointments • Learn to apply medications and special treatments; report side effects • Learn to recognize and report health-care needs • Learn to follow and maintain proper diet and exercise • Learn about good nutrition and understand the effects of poor nutrition • Learn personal safety skills (e.g., avoiding traffic and poisons in home, learning about contagious illnesses and unsafe sexual practices) • Apply learning to understand the benefits of healthy lifestyle routines	
8. Learning Self-Determination Skills: The focus of this item is on supports to obtain the knowledge and skills to engage in self-directed activities that guide one's life. ***Essential Elements: Learn to speak up for oneself and direct one's life***	• Learn to identify and express personal goals and individual preferences • Learn consequences and responsibilities associated with choices and decisions • Learn to self-direct daily living activities • Learn individual rights • Apply skills to make plans and decisions to achieve personal goals • Apply skills to direct personal supports • Speak up for oneself	

Expanded Item Descriptions

Lifelong Learning Activities	Includes Supports To:	Does Not Include:
9. Learning Self-Management Strategies: The focus of this item is on learning and applying self-management strategies to real-life situations. *Essential Elements: Learn strategies to keep oneself in control of his/her actions and life*	• Learn to reward oneself for achieving a goal or completing a task • Learn and use strategies to manage and resolve conflict • Learn and use strategies to maintain routines that are desired and effective at home and in the community, including time management strategies • Learn and use strategies to spend money within one's budget • Learn impulse control, anger management, and self-restraint • Learn to follow through with commitments, be trustworthy and truthful • Learn to adapt to changing situations • Learn and use self-management strategies for self-control/restraint (e.g., modifying harmful behavior, decreasing anxiety, controlling eating)	

Part D: Employment Activities

Expanded Item Descriptions

Overview Note: In this section of SIS, the interviewer should use a broad definition of work and be sensitive to how people respond to items about work. In that regard:

- There are many activities that a person may choose that can potentially earn money (e.g., making and selling items, running Internet businesses, participating in the arts, setting up a microbusiness). If the person believes that there are potential earnings, then it should be considered work.

- The standard for deciding the amount of supports needed should be based on the supports needed for a person to reach a competitive wage or to provide reasonable efforts toward his/her business goal in self-employment/microenterprise.

- Although many activities are worthwhile and meaningful (e.g., unpaid jobs, volunteer work, vocational skill training, going places and doing things, day habilitation programs, prevocational programs), the focus of Part D is on gainful employment. The standards would be equal to a typical adult, 5–6 days a week, 6–8 hours a day.

- Some people with disabilities or family members of those with disabilities may be sensitive about work issues. This may be due to past failures, a lack of desire to work, a view of the questions as pressure to work, or a view of the questions as insulting because of the extensive limitations of the person being interviewed (e.g., paralysis, severe cerebral palsy, lack of awareness of surroundings, intensive medical or behavioral needs).

- The interviewer may need to explain that this section must be addressed in order to produce meaningful results. This may include explaining how each section is relevant to the total support scores produced by SIS.

Part D: Employment Activities

Expanded Item Descriptions

Employment Activities	Includes Supports To:	Does Not Include:
Set the Scene: This section is about supports needed to work a competitive job in the community. The typical employee works 5–6 days a week, 6–8 hours a day.		
1. Accessing/Receiving Job/Task Accommodations: The focus of this item is on supports to identify, arrange, and obtain reasonable job accommodations or modifications necessary for the successful completion of work activities. ***Essential Elements: Identify and obtain job accommodations***	• Identify, communicate, develop, obtain, and implement job accommodations (Ratings should reflect the support needed to obtain the accommodation. Assistance with job tasks is addressed elsewhere.) • Advocate for accommodations and problem solve regarding accommodations, and garner resources for the implementation of the accommodation (e.g., a quiet workplace, proper height of work surface, wheelchair accessibility, modified job strategies, lifting restrictions, scheduling of work time, work sharing)	• Transportation • Assistance with specific job skills
2. Learning and Using Specific Job Skills: The focus of this item is on developing specific job skills and applying these skills to all aspects of work assignments. ***Essential Elements: Learning and applying job skills to complete assigned tasks***	• Learn the job and achieve all aspects of acceptable job performance, not just skills for manipulation of tasks • Communicate the need for help to complete a task • Follow company rules and policies (e.g., keeping work areas clean, following safety requirements)	
3. Interacting With Coworkers: The focus of this item is on supports for positive formal and informal interactions with coworkers when at work. ***Essential Elements: Positive and appropriate communication with coworkers***	• Communicate with coworkers regarding work-related matters and informally socialize with coworkers • Understand the appropriate amount of time to socialize during work • Understand rules regarding socializing and breaks • Avoid arguments or disputes with coworkers, using polite language and so on • Request assistance/information from coworkers • Be understood by coworkers	

Part D: Employment Activities

Expanded Item Descriptions

Employment Activities	Includes Supports To:	Does Not Include:
4. Interacting With Supervisors/ Coaches: The focus of this item is on supports for positive formal and informal interactions with supervisors. *Essential Elements: Positive and appropriate communication with supervisors*	• Communicate with supervisors and job coaches regarding work-related matters, and informally socialize with supervisors and job coaches • Communicate problems • Ask for training/information when needed • Request assistance from supervisors • Avoid arguments or disputes with supervisors, using polite language and so on • Be understood by supervisors	
5. Completing Work-Related Tasks With Acceptable Speed: The focus of this item is on supports to perform work at a pace that is consistent with the productivity of other workers with the same job throughout the day. *Essential Elements: Remaining productive, keeping up pace throughout the work day*	• Work at the same level of productivity as that of a typical worker throughout the day • Minimize and/or avoid distractions • Maintain focus/attention on work tasks • Reduce frustration, disinterest, anxiety, and/or agitation with work tasks	
6. Completing Work-Related Tasks With Acceptable Quality: The focus of this item is on supports to achieve work-related tasks at the quality and accuracy of a typical worker. *Essential Elements: Completing quality work*	• Perform work at a level of quality that is consistent with the performance of other workers with the same job • Discriminate what an acceptable standard of quality work is (e.g., development and use of a quality checklist) • Recognize and correct mistakes	
7. Changing Job Assignments: The focus of this item is on supports in adapting to changes in work tasks/ schedules and successful transitions. *Essential Elements: Adapting to change on the job*	• Adjust to changing job assignment or task, both new and known • Take on and transition to new assignments or routines that may be more difficult and challenging, and respond/adapt to such situations • Respond/adapt to unexpected changes at work (e.g., changes in schedule)	• Learning and/or completing a work task/job

Part D: Employment Activities

Expanded Item Descriptions

Employment Activities	Includes Supports To:	Does Not Include:
8. Seeking Information and Assistance From an Employer: The focus of this item is on supports required to communicate with an employer regarding employment information, such as employment benefits and other company information. ***Essential Elements: Asking for company information***	• Acquire information from employer regarding the benefits of the company (e.g., accrued vacation, sick time, insurance benefits, employee assistance programs) • Acquire information from employer about company policies and procedures (e.g., dress code, sick/vacation-leave policies, approval process for leave requests, asking for a raise) • Identify the process and need for accessing desired information • Identify the appropriate department/person for securing information • Complete the necessary forms and steps	• Seeking assistance with work skills

Part E: Health and Safety Activities

Expanded Item Descriptions

Health and Safety Activities	Includes Supports To:	Does Not Include:
Set the Scene: This section considers supports needed to ensure a person's health and safety.		
1. Taking Medications: The focus of this item is on supports to follow prescriptions and use over-the-counter medications to address an illness or injury. ***Essential Elements: Taking medications properly***	• Understand the purpose, desired effects, and potential side effects of all medications that a person takes/applies/injects • Report side effects to caregiver or physician • Recognize labels • Take/apply/inject medications at prescribed levels and times, or as recommended • Fill a pillbox, refill medications/prescriptions, and so on • Prepare medications for ingestion/injection/application	• Medication administration recording/documentation unless required by the physician (e.g., documentation of glucose levels, blood pressure)
2. Avoiding Health and Safety Hazards: The focus of this item is on supports to be aware, and avoid health and safety hazards, harmful situations, and materials in everyday living. ***Essential Elements: Awareness and avoidance of all hazards***	• Recognize dangerous situations and personal vulnerability at home and in the community • Utilize things designed to promote safety (e.g., safety rails, nonslip mats, seatbelts, crosswalks, locking doors at night, safety stickers, smoke and carbon monoxide detectors, fire alarms) • Be aware of and follow safety procedures for storing chemicals, poisons, and so on to avoid potentially harmful situations • Use safe practices at home and in the community (e.g., reading safety and danger signs, obeying traffic laws) • Recognize personal vulnerability (e.g., identifying dangerous strangers, engaging in unsafe sex)	

Part E: Health and Safety Activities

Expanded Item Descriptions

Health and Safety Activities	Includes Supports To:	Does Not Include:
3. Obtaining Health-Care Services: The focus of this item is on supports to obtain preventive and ongoing health-care services to maintain good physical and mental well-being. ***Essential Elements: Get medical/behavioral help when needed***	• Recognize and communicate health care needs with caregivers and medical personnel (e.g., doctors/dentists/therapists) • Make medical appointments with doctors, specialists, dentists, and/or therapists • Participate in an office visit • Get prescriptions filled as needed • Obtain medical services (e.g., MRI, lab work) • Have appropriate medical and insurance cards • Coordinate health-care services	
4. Ambulating and Moving About: The focus of this item is on supports to safely and effectively move around at home and in the community. ***Essential Elements: Safe movement***	• Make transfers (e.g., to/from bed, chair, walker, wheelchair) • Move from one place to another (e.g., walking, using a wheelchair, walker, prostheses) • Put on a prosthesis relevant to mobility • Negotiate even and uneven terrain, steps, curbs, and so on	• Supports needed to prevent wandering, behavior-related mobility issues (e.g., sitting down in the street, refusing to move, court-mandated restrictions)
5. Learning How to Access Emergency Services: The focus of this item is on supports to know when and how to contact emergency personnel and how to appropriately respond. ***Essential Elements: Learn and apply emergency skills***	• Learn to and when to request the right type of assistance, contact 911, provide key information to dispatcher, such as address, type of crisis, and so on • Learn and use a personal emergency response system when needed • Plan and develop an emergency preparedness plan (e.g., phone numbers near phone or on refrigerator, self-identification to first responders, ensure specialized emergency devices are in working order) • Plan and practice prescribed responses or drills to prepare for emergencies (e.g., fire and other natural disasters, injury of caregiver/roommates/family)	

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Part E: Health and Safety Activities

Expanded Item Descriptions

Health and Safety Activities	Includes Supports To:	Does Not Include:
6. Maintaining a Nutritious Diet: The focus of this item is on supports required to eat a nutritious diet and avoid problems associated with poor nutrition, as well as to promote a healthy lifestyle. ***Essential Elements: Healthy eating***	• Practice good nutrition and understand the effects of poor nutrition • Make healthy choices in selecting foods to eat • Plan healthy and nutritious meals	• Shopping • Transportation
7. Maintaining Physical Health and Fitness: The focus of this item is on supports to promote physical health and fitness to sustain a healthy lifestyle. ***Essential Elements: Staying active and fit***	• Select and plan activities for physical health and fitness • Engage in physical fitness activities on a routine basis to avoid medical problems associated with poor physical health, fitness, and/or obesity • Locate a gym or activity, and access facilities or locations for maintaining fitness	
8. Maintaining Emotional Well-Being: The focus of this item is on supports to promote emotional stability and well-being of the individual, and to sustain a healthy outlook on life. ***Essential Elements: Maintain positive mental health***	• Maintain a lifestyle conducive to avoiding serious mental health problems, such as depression or panic attacks • Use relaxation techniques, appropriate coping strategies to self-manage behavior (e.g., anger-management techniques, stress relief, anxiety-control strategies) • Build confidence and self-esteem • Access mental health resources or clinical therapy services if needed • Participate in therapeutic homework and positive-behavior support plans • Plan a structured day as related to maintaining mental well-being	

Part F: Social Activities

Expanded Item Descriptions

Social Activities	Includes Supports To:	Does Not Include:
Set the Scene: This section is about supports needed to communicate effectively in a variety of settings.		
1. Socializing Within the Household: The focus of this item is on supports to promote use of positive interactions and communication in the household as well as learning to respect the privacy of others. ***Essential Elements: Effective interaction/communication with others in the home***	• Facilitate/promote verbal or nonverbal social interaction that is meaningful to the person and understood by others in the home (e.g., sign language, gestures that others understand, writing) • Know when to socialize • Share interests or information in a cooperative way in the home • Discuss important issues (e.g., upcoming events, sharing chores) • Set up and use augmentative communication to interact with others • Demonstrate respect for privacy and boundaries	• Recreation/leisure activities covered in F2
2. Participating in Recreation/ Leisure Activities With Others: The focus of this item is on supports to interact in recreation/leisure activities with others at home and in the community. ***Essential Elements: Appropriate interactions with others***	• Engage in social interactions during recreation and leisure activities • Cooperate and interact with others during recreation/leisure activities (e.g., taking turns, sharing, respecting diversity, relying on other team members, being a good sport, accepting limitations/boundaries) • Use assistive devices/technology to interact if relevant	• Completion of tasks/ steps/motions of an activity

Part F: Social Activities

Expanded Item Descriptions

Social Activities	Includes Supports To:	Does Not Include:
3. Socializing Outside the Household: The focus of this item is on supports to promote use of effective interactions and communications outside of the household with familiar people (e.g., neighbors, friends/acquaintances, coworkers, associates). ***Essential Elements: Appropriate social exchange with familiar people outside of the home***	• Communicate effectively and facilitate/promote verbal or nonverbal social interaction that is meaningful to the person and understood by others (e.g., sign language, gestures that others understand, writing) • Be understood • Set up and use augmentative communication devices if relevant • Maintain a conversation or discussion (e.g., knowing to maintain respectful length, topic, boundaries, and space) • Expressing oneself respectfully (e.g., disagreeing appropriately, listening to the other speaker, tolerant of different opinions)	• Transportation
4. Making and Keeping Friends: The focus of this item is on supports needed to make friends and maintain friendships. ***Essential Elements: Make and keep friends***	• Learn social and other skills related to friendships • Locate programs/activities where friendships may become possibilities (e.g., groups, clubs, associations formed around common interest) • Communicate with peers and arrange opportunities to get together with others • Accept invitations to participate in activities with friends • Use the phone and other communications to maintain friendships	
5. Communicating With Others About Personal Needs: The focus of this item is on supports needed to communicate verbally and nonverbally about needs important to/for the individual. ***Essential Elements: Expressing need to appropriate person***	• Inform others about personal desires and/or problems using verbal, nonverbal, and/or assistive technologies to communicate with others • Identify that a need/problem exists • Recognize the importance of communicating about a need/problem • Inform the appropriate individual what the need/problem is • Use effective strategies to talk about needs (e.g., labeling emotions; accepting responsibilities; and avoiding lying, blaming, denial) • Personal items can include private or embarrassing issues, discreet needs, important requests, hygiene products, and so on	

Part F: Social Activities

Expanded Item Descriptions

Social Activities	Includes Supports To:	Does Not Include:
6. Using Appropriate Social Skills: The focus of this item is on supports needed to use social graces in all situations. ***Essential Elements: Social skills suitable to the situation***	• Learn and use social skills when interacting with others (e.g., good manners, social etiquette, maintaining personal space/boundaries) • Recognize how others feel and express emotion that fits the situation (e.g., not laughing when someone is crying) • Learn and be able to use expected behaviors and social exchanges in different situations (e.g., good manners, initiation of social greetings and partings, maintaining personal space, yelling at football games and not in libraries, hugging loved ones and not strangers) • Learn and use socially acceptable table manners (e.g., avoid burping, spitting, and playing with or throwing food)	
7. Engaging in Loving and Intimate Relationships: The focus of this item is on supports needed to initiate and maintain a special intimate or romantic relationship. ***Essential Elements: All steps of beginning and maintaining a romantic relationship***	• Plan dates and activities to promote healthy relationships that may lead to intimacy • Learn activities that are related to intimate relationships, such as dating skills, understanding personal boundaries, and respect for partner • Learn and understand concept of what "consent" means • Express feelings for partner fittingly (e.g., sharing of private moments/feelings and sexual interactions) • Maintain intimate relationships, including but not limited to sexual interactions	• Transportation • Friendships, family, and acquaintances
8. Engaging in Volunteer Work: The focus of this item is on supports needed to participate as a volunteer in an organized project or program. ***Essential Elements: Take part in volunteer activities***	• Identify causes and issues of interest • Learn how to apply personal skills to the volunteer effort • Participate in organized activities as a volunteer • Contact community groups seeking volunteers (e.g., "clean the park" day, working in a hospital or a shelter, charity fundraising, walk-a-thons)	• Transportation • Activities associated with employment

Section 2: Protection and Advocacy Activities

Protection and Advocacy Activities

Expanded Item Descriptions

Protection and Advocacy Activities	Includes Supports To:	Does Not Include:
Set the Scene: This supplemental section is about supports that a person needs to speak up and protect oneself. This information can be used for planning purposes.		
1. Advocating for Self: The focus of this item is on supports needed to express personal preferences, including needs and wants and explaining why these things are important. ***Essential Elements: Speaking up for self***	• Advocate in all aspects of life, including speaking up for oneself (or communicating) to exercise control over one's life • Learn to advocate in a respectful manner • Recognize and understand choices and decisions related to responsibilities and consequences, whether good or bad • Express personal preferences, needs, and wants • Explaining why things are important in various settings and situations (e.g., a person may need support advocating in certain personal relationships due to low self-esteem and a need for acceptance but may not have difficulty at work or school)	
2. Managing Money and Personal Finances: The focus of this item is on supports needed to budget money, maintain banking accounts (e.g., checking and savings), and pay bills. ***Essential Elements: Handling all money related needs***	• Provide protections that an individual may need in place to assure responsible management of money (e.g., supports to live within means, controls to protect person from overdrafts, cosignatures and other identified protections as mutually agreed upon) • Reduce possibility of exploitation (e.g., assessing understanding of money, keeping and reviewing bank records and spending, monitoring spending and relationships, loaning money, credit cards and ATM card guidelines and use) • Learn and apply positive decision-making and protection strategies	

Protection and Advocacy Activities

Expanded Item Descriptions

Protection and Advocacy Activities	Includes Supports To:	Does Not Include:
3. Protecting Self From Exploitation: The focus of this item is on supports needed to identify when an exploiter is attempting to take an unfair advantage (i.e., to promote his/her own interests at the expense of one's own interests), and then take action to prohibit the exploiter from gaining this advantage. ***Essential Elements: Guard against being taken advantage of***	• Learn and practice skills relevant to recognizing and avoiding exploitation (e.g., being taken advantage of or being manipulated) • Plan for protections against exploitation (e.g., frequently asking to borrow money, taking food that was not offered, taking personal items, using the phone excessively, borrowing belongings and not returning them, and other situations in which a exploiter is promising great things or unjustly requesting something that belongs to the individual)	
4. Exercising Legal Responsibilities: The focus of this item is on supports to abide by the laws of the community and exercise civic responsibilities. ***Essential Elements: Typical civic laws/duties that the general public abides by***	• Understand and exercise civic responsibilities and rights as a community member/citizen (e.g., voting) • Understand and comply with basic laws (e.g., not littering, not jay-walking, not loitering, not soliciting, wearing a helmet when riding a bike, not hitting others)	
5. Belonging To and Participating In Self-Advocacy/Support Organizations: The focus of this item is on supports to participate in activities of self-advocacy and support organizations. ***Essential Elements: Participation in organizations***	• Participate in self-advocacy organizations (e.g., People First) • Serve on advisory boards and committees • Identify with support groups for a particular life situation, such as grief and recovery, substance abuse, victims of violence, and so on • Take an active membership role, including assuming responsibilities (e.g., attend meetings, committee work, voting)	• Transportation
6. Obtaining Legal Services: The focus of this item is on supports to contact an attorney for legal advice and/or employ an attorney for legal services. ***Essential Elements: Attain legal assistance***	• Identify when legal assistance is needed • Access/employ legal assistance (e.g., legal aid, parole) • Attend and participate in initial visits with attorney to explain issues/concerns	

Expanded Item Descriptions

Protection and Advocacy Activities	Includes Supports To:	Does Not Include:
7. Making Choices and Decisions: The focus of this item is on supports required to make personal decisions. This includes understanding the consequences/responsibilities associated with a decision and also following through on personal decisions. ***Essential Elements: Making informed choices and decisions***	• Understand that choices and decisions are related to consequences and responsibilities • Identify people or things that influence choices and/or decisions • Access opportunities to make choices and decisions based on multiple options • Differentiate between the types and level of importance of choices and decisions (e.g., choosing what to wear versus who to hire as a caregiver) • Make informed decisions; understand and be responsible for the consequences of various decisions	
8. Advocating for Others: The focus of this item is on supports needed to help advocate for others. ***Essential Elements: Speak up for others***	• Identify opportunities and situations where advocacy of another person is warranted • Get involved in self-advocacy organizations, civic activities, and walk-a-thons in an effort to advocate for others • Assist others in speaking out when they cannot speak out for themselves or express personal preferences • Know when and how to help others (e.g., timing, knowing when to help versus minding one's own business, adopting a respectful approach) • Teach others ways to speak up for their beliefs, needs, wants, and so on	

Section 3: Exceptional Medical and Behavioral Support Needs

When determining whether an item should be rated as a 1 or a 2 in Section 3, the interviewer should consider the following:

- The significance of the medical condition or behavior for the person in regard to extra support required.

- The consequences if the exceptional medical or behavioral support is not provided. (Does it pose a significant health or safety risk?)

- The occurrence of the support to assist with the medical condition or to prevent the harmful behavior. (e.g., Does it occur in most environments or only some? Does assistance happen regularly or only on occasion?)

- List, rate, and specify all "other" medical or behavioral support needs separately (III.A.16; III.B.13).

Section 3A: Medical Supports Needed

Medical Supports Needed	Description
Respiratory Care	
1. Inhalation or oxygen therapy	• Uses nebulizer, oxygen, and/or C-PAP
2. Postural drainage	• Needs positioning to help drain secretions/mucus in the lungs
3. Chest PT	• Needs chest physical therapy to help with drainage of secretions (e.g., chest percussion for Cystic fibrosis)
4. Suctioning	• Needs suctioning of secretions (e.g., suctioning a tracheotomy)
Feeding Assistance	
5. Oral stimulation or jaw positioning	• Needs physical assistance or oral stimulation to help with nourishment
6. Tube feeding (e.g., nasogastric)	• Uses a nasogastric or gastrostomy tube for nourishment
7. Parenteral feeding (e.g., IV)	• Uses intravenous tube for nourishment
Skin Care	
8. Turning or positioning	• Needs assistance with repositioning or turning in chair or bed to prevent sores
9. Dressing of open wound(s)	• Needs assistance with cleaning and dressing wounds of chronic open sores

Section 3A: Medical Supports Needed

Medical Supports Needed	Description
Other Exceptional Medical Care	
10. Protection from infectious diseases due to immune system impairment	• Requires universal precautions to prevent infectious disease due to weakened immune system (e.g., HIV, chemotherapy, cancer, hepatitis, allergies, multiple sclerosis)
11. Seizure management	• Needs assistance with seizure precautions and management (e.g., helmet, bite block, controlled environment, timing seizures, PRN prescriptions). Does not include taking medication on a regular basis as it is covered in E1.
12. Dialysis	• Uses peritoneal dialysis or hemodialysis
13. Ostomy care	• Needs assistance with ostomy (e.g. colostomy, tracheotomy, or any other stoma)
14. Lifting and/or transferring	• Needs assistance for lifting and/or transferring person to and from chair, bed, and so on
15. Therapy services	• Needs assistance in implementing recommendations given regarding physical therapy, occupational therapy, speech-language therapy, or individual or group psychological therapies.
16. Other(s)—Specify	• Should include a listing of any exceptional medical needs that are not accounted for in the previous items. List, rate, and specify each support separately.

Section 3B: Behavioral Supports Needed

Expanded Item Descriptions

Behavioral Supports Needed	Description
Externally Directed Destructiveness	
1. Prevention of assaults or injuries to others	• Hits, punches, kicks, bites, or intentionally harms others
2. Prevention of property destruction (e.g., fire setting, breaking furniture)	• Defaces property, breaks windows, damages furniture, sets fire, and so on
3. Prevention of stealing	• Steals or takes others' property or shoplifts, and so on, either deliberately or otherwise
Self-Directed Destructiveness	
4. Prevention of self-injury	• Engages in self-injurious behavior, such as head banging, eye gouging, skin picking, cutting, and so on
5. Prevention of pica (ingestion of inedible substances)	• Eats inedible substances, such as cigarette butts, paper, or other objects
6. Prevention of suicide attempts	• Attempts to hurt oneself with the intention of suicide
Sexual	
7. Prevention of sexual aggression	• Engages in sexually aggressive behavior, including pedophilia, sexual assault, and so on
8. Prevention of nonaggressive but inappropriate behavior (e.g., exposes self in public, exhibitionism, inappropriate touching or gesturing)	• Engages in inappropriate behavior, such as masturbating in public places, exhibitionism, stalking, and so on
Other	
9. Prevention of tantrums or emotional outbursts	• Screams, curses, throws objects, threatens physical violence or verbally demeans others, and cries excessively
10. Prevention of wandering	• Runs away and wanders off with the risk of getting lost or injured
11. Prevention of substance abuse	• Engages in excessive consumption of alcohol, misuses prescription medication, uses illegal drugs or other toxic substances, such as sniffing glue, paint, and so on
12. Maintenance of mental health treatments	• Takes psychotropic medication and complies with prescribed mental health treatments
13. Prevention of other serious behavior problem(s) Specify:	• Should include a listing of any exceptional behavioral concerns that are not accounted for in the previous items. List, rate, and specify each support separately.

Answers to Frequently Asked Questions

Since its publication in 2004, AAIDD and the authors of the Supports Intensity Scale™ (SIS™) have published answers to questions repeatedly asked either during the training sessions or by potential or actual SIS users. The following is an updated and consolidated list of those questions and answers.

Q1. Can I interview more than one respondent at a time?

A1. Yes. It is acceptable for an interviewer to interview respondents individually or in a group setting, interviewing two or more respondents at the same time. Field-test data was collected in both conditions and the *Users' Manual* indicates that both practices are acceptable. Extensive SIS interview experience has shown that interviewing respondents in a small-group format seems to be more conducive to gathering the kind of information that allows the interviewer to make the best rating decision, as well as generating ideas and suggestions that can later be implemented in the person's Individualized Support Plan. The authors recommend that SIS assessment occur in a face-to-face setting—while not precluding the gathering of additional supportive information during the interview by a conference call or, subsequent to the interview, via phone or e-mail with respondents who may possess pertinent information. It is the responsibility of the interviewer to consult as many respondents as needed to obtain accurate and complete information and to use his clinical judgment to reconcile any contradictory information gathered from respondents, whether interviewed as a group or separately. Therefore, outside of needing at least two respondents, the selection of the interview grouping is left up to the clinical judgment of the interviewer.

Q2. Do I have to ask about the activity items in the sequence in which they are listed?

A2. No. *All* items on SIS must be rated for the individual's support needs. However, the order of the interview/presentation of the items or domains will not affect the individual's score. Some individuals feel uncomfortable starting SIS administration with Section I, Part A, Item 1, "Using the Toilet." It is permissible to start with Part B and end with Part A. Most respondents will be less sensitive to Section I, Part A, Item 1 when it is administered at the end of SIS. The interviewer could choose to start and end with any of the subscales or parts of SIS.

Since the publication of SIS, experienced interviewers learned that the key to a smoother interview is to ask first about the type of support needed, then about the frequency of support, and finally about daily support time. Work is currently in progress to change the SIS interview form to reflect this order. In the meantime it is recommended that you follow this order when rating, even though it is currently in a different order.

Q3. Where is transportation in the Activity Domains?

A3. Supports needed for transportation within a community are embedded within three items of SIS: Section I, Part B, Item 1, "Getting From Place to Place Throughout the Community (Transportation)"; Section I, Part B, Item 4 "Going to Visit Friends and Family"; and Section I, Part C, Item 5 "Accessing Training Educational Settings." Once an individual's transportation support needs are captured in these three items, transportation support needs should not influence the assessment of the remaining items in SIS. There are people with intellectual or developmental disabilities who have driver's licenses and own their own cars, or have access to friends' cars. Others may use public transportation. Such individuals may have no extraordinary transportation support needs. Other people with intellectual or developmental disabilities may not be able to drive and may not have access to public transportation. Thus, they rely on family, friends, or paid staff to transport them. When the support needed for transportation is imbedded within an item, the rating of 4, or "full physical assistance," would apply to any individual who could not drive himself and could not access public transportation independently. A person who uses public transportation on a regular basis but simply needs to be monitored, would receive a rating of 1, or "monitoring." However, consider the item holistically when deciding on frequency and daily support time.

Q4. Can I add items to SIS?

A4. Section III, Part A and Part B, "Exceptional Medical and Behavioral Support Needs," allow for additional items to be added. This is to allow states/practitioners to gather additional information that may be useful for planning or resource allocation purposes. *Those items are not scored and do not constitute part of the normed SIS instrument.* Including additional items does not create a new assessment. You can think of it as simply a convenient place to put additional information.

SIS is *not* the only piece of information people collect when assisting individuals to identify and plan for their services and supports. SIS information should only be considered along with other important types of information.

Q5. We have some consumers who use door-to-door, pick-up/drop-off bus services for people with disabilities. These individuals can call the service independently, get on/off the bus independently, give the driver the needed information, and basically do it all independently. Because this is not the "typical" public transportation system, would we count this as no support needed?

A5. Do not determine ratings based on a person's support needs to access a disability-specific transportation system. Consider what type of support he would need to either drive his own car or to take the "typical" public transportation. Taxis would not be considered public transportation. The supports necessary for an individual to independently access a taxi might be similar to those needed to get a ride from a friend with additional aspects, such as knowing where to tell the driver to take her, determining the cost of the fare, getting change, how much to tip, what to do once the driver drops her off, and so on.

Q6. What about rating the support needs for activities that the person does not do, has never done, and has no intention of doing?

A6. It is important to remember the following instruction: *"All items should be completed, even if the person is not currently performing a listed activity."* This is especially true for certain items like "Obtaining Legal Service" (Section II, Item 6). The biggest concern is ensuring that the interviewers remember this instruction throughout the administration of SIS. When an individual is not currently performing an activity, it is critical for the interviewer, using her clinical judgment, to guide the respondent in estimating the support needed for that individual to be successful in participating in the activity. Thus, one needs to assess the individual's support needs holistically and in accordance with his current status and functioning. A person with low motivation, short attention span, low tolerance for learning, medical fragility, and/or limited cognitive ability will likely require high levels of support to be successful in the activity.

Q7. Can you clarify how best to think about "learning" and "applying" as related to Lifelong Learning Activities?

A7. These items need to be looked at holistically across a variety of environments. Avoid looking too concretely at a specific task but rather look across days or areas of life. Regardless of an individual's current functioning level, interviewers are assessing what support a person needs, or would need, to be able to learn and apply, not what supports are necessary to do the task for the person. Keep respondents from jumping into the discussion of what is currently provided for the person but rather have them look at what sort of supports the person would need to be successful at accomplishing the task(s) as any typical adult in the community.

Talk first about the support a person would need to learn the task and then move onto talking about what sort of support would be needed for the person to then apply what he had learned. Try reading back the scoring to yourself and the respondents, saying something like, "If staff in central office who do not know this person were looking at this score, they would see that this person needs partial physical assistance (3), once a week (2), for a total of 30 minutes to less than 2 hours (2) to access training and educational settings." If this is a person who has significant disabilities, then this scoring might accurately reflect what it takes for the person to physically be in one class a week at the community center, but it certainly does not reflect the support that he would need to be successful as a typical adult—for example, to find out what classes are available, how he will pay for the class, how he will get there, or how to be a successful participant/student in the class.

Here is an example from the "Learning and Using Problem-Solving Strategies" section, which might help with clarification: If a typical adult lost her car keys and needed to get to work, she would have several options at her disposal. She might call a friend for a ride; she might decide to walk, if that was an option; she might choose to take public transportation, and would then deal with all that entailed; she might go next door to the neighbor where she leaves a spare set because she is always losing her keys; she might call her car dealer to get a replacement; or she might call AAA. In addition, she would call work, if she were going to be late, to let them know the situation.

Some individuals with disabilities might be able to handle this situation with little to no support, but many would need a significant level and variety of supports to learn skills and apply these solutions to a variety of situations. There are also some individuals who would be able to tell you what they would do in specific situations (learn), but when faced with an actual problem, they would not know what to do (apply). The frequency and amount of time required to learn the behaviors and tasks involved in any one of the solutions, let alone multiple solutions (most typical adults would be able to employ several of these strategies not needing to depend on only one), would potentially be quite substantial. This would be only one of many possible opportunities in everyday life when a typical adult needs to employ problem solving.

Q8. Why does SIS penalize a person who uses assistive technology (AT)? If funding is related to the relative intensity of a person's support needs, then the person who has relatively less intensive support needs because his needs for AT have been addressed will be penalized in terms of funding.

A8. An assumption underlying SIS is that people with disabilities differ in terms of their intensity of support needs. A major reason why SIS was developed was to provide a tool to measure individual differences related to intensity of support needs. Just as a thermometer attempts to identify differences in body temperature relative to the expected norm, SIS attempts to identify differences in intensity of support needs relative to others with intellectual disability. To carry the analogy a step further, if someone takes an aspirin and her body temperature goes down, a good thermometer will register this change. Similarly, if someone uses AT and his functional capacity in terms of communication, strength, and/or ambulation is increased, then it is likely that his need for supports will be less intense. Thus, it is probable that someone whose AT needs are properly addressed would have a lower Support Needs Index Score than if his AT needs were not properly addressed.

It is important for interviewers to understand that SIS needs to be completed without regard to the implications for how scores may or may not be used. Certainly it would not make any sense to reduce funding for a person who used AT, especially if the new level of funding was not sufficient to maintain the person's AT system and resulted in the person's overall needs for support becoming more intense.

Q9. When completing SIS, what is the best way to handle the observation that it is obvious that the individual needs full support, 24/7, in every category? I know we are supposed to ask about each category, but halfway through SIS it begins to insult or waste the person's time. Is it appropriate to agree during SIS to rate the highest level of support need?

A9. All items must be asked and rated. An interviewer is acutely aware of sensitive questions, remains respectful of respondents, and is professional throughout the process. Therefore if you have someone for whom respondents are "absolutely sure the person needs full support, 24/7," it is still necessary to probe and look for potential differences among items in level of supports needed by the person.

Q10. How do I rate a support need when a frequent and intense support is needed temporarily or for a short period of time, but less support is needed later?

A10. The interviewer/respondent should rate the individual's support needs as the person is *currently functioning*. It does not matter whether the person's functioning might improve because of skill acquisition or assistive technology. SIS should be filled out based on the person's *current status and condition*. What support does she need at this current time? If one believes that a person may require less support in the future, then SIS should be repeated at that future time and the individual's support needs should be reassessed.

Q11. How do I rate varying support needs—sometimes it is full physical, but most of the time only monitoring is needed?

A11. The instructions call for rating the individual in regard to *the typical intensity of support* that is needed. The interviewer and respondent must fully consider the life activity as it is described and come up with a composite rating that best reflects the person's support needs. In the case where someone's intensity of support need seems to be right on the borderline between a lower and a higher rating, *the higher rating should be selected*. Think about the following example from Section I, Part E, Item 1, "Taking Medications": An individual needs to take insulin medication for his diabetes and a psychotropic medication for his thought disorder. Generally, this individual needs only 1, "Monitoring" (Type of Support), to take insulin medication; however, he is resistive to taking his psychotropic medication and needs 2, "Verbal/Gestural Prompting," to take his medication. In this case, the interviewer/respondent should rate the higher of the two types of support—that is, 2, "Verbal/Gestural Prompting."

Q12. What if it is discovered well into the SIS interview that the person has exceptional medical and/or behavioral needs that have not been considered in rating previous items?

A12. Additional information regarding factors influencing a person's need for supports may come to light later in the interview (e.g., information about a person's skill level, use of AT, motivation, health, behavior, and/or safety/vulnerability). If such factors were not considered earlier in the interview, then the interviewer has an obligation to probe respondents about earlier ratings and assure that prior ratings were accurate.

The SIS interview is a discovery process that integrates these factors into the rating system. We use what we learn throughout the interview to determine the final SIS ratings. Information is revealed throughout the process. For some individuals, the person's skill level, use of AT, motivation, health, behavior, and safety/vulnerability are revealed early in the process, whereas for others, the total picture may not be revealed until later. In either case, the final SIS ratings need to reflect the integration and careful consideration of all information. Therefore the interviewer must score each item independently, based on information from respondents and the interviewer/team's clinical judgment.

Some interviewers choose to start the SIS interview with the "Exceptional Medical and Behavioral" section to avoid this issue. Since it is acceptable to ask the items in any order, this might be a good solution.

Q13. I have a question about the percentile ratings on SIS. If the results work out to be: Percentile of Support Needs Index = 32. Does that mean that (a) 32% of the general population has less intensive support needs than the person being rated; or that (b) 32% of the population with intellectual or developmental disabilities has less intensive support needs than the person being rated?

A13. B is correct. SIS was not normed on a typically functioning population. SIS was normed on people with intellectual or developmental disabilities.

Q14. In "Community Living Activities, Getting From Place to Place," I was speaking with a person who takes the bus on known routes quite well without support, but he indicated that he would need supports to learn new routes to banks, shopping centers, or other locations. The support he would need is being told to get off at a certain stop and get on a certain number bus when it arrives (not get on the other three buses that stop there). Is the intent of this question to gauge the support he needs once he has learned a route, or to gauge the support he would need to learn different routes as he chooses to engage in different community activities in new areas?

A14. The intent of the item is to measure supports needed to get from place to place in the community. This includes places the person already knows as well as places that he does not know but would need to access. The ratings should reflect both of these areas. Certainly interviewers and respondents should keep in mind vulnerability issues as well as learning-curve issues when deciding on ratings for this item. As with all other items, the key is to focus on extraordinary supports that most others from the general population would not need. Remember, too, that transportation

support needs can be greatly affected by geography and seasonal weather conditions. When there is a mix of types of support needed by an individual, scoring in this area, as in others, should be made based on the predominate need. It is possible that the person with an intellectual disability would be so experienced and proficient in using public transportation that she may not need any type of extraordinary support. However, in many cases some type of additional support, such as the types of support that you have described, will be necessary.

Q15. How do I help respondents think about "learning" and "applying" for employment items?

A15. Be sure to go to the underlying intent of this item, which is learning to be a valued employee: to learn how to perform and keep a job. This section is not asking about the level of support currently provided if the person is in a supported employment setting. It is asking about the type, frequency, and amount of support necessary for an individual to successfully learn and use job skills as the typical adult would—that means 32–40 hours per week of competitive employment. Conversely, just because someone does not have a job does not mean that she needs no support in that arena of life. Try not to get caught up with a specific job situation, "be a fry cook," but rather consider what supports the person would need to be a successful employee.

Again it may be useful to break up the item to first discuss what supports might be needed to learn job skills and then look at what sort of supports would be needed to maintain those skills once they have been acquired. Learning may involve substantial type, frequency, and amounts of support, whereas maintaining ongoing job performance may look quite different. Choose the type of support that best characterizes or most dominates the assistance needed.

If someone has been in a job for a long time it may be difficult for the respondents to think about what it would take to learn a new job. Depending on the respondents, you may be able to ask them to think back to the type, frequency, and amount of support needed when the person first started the current job. Or if the person is working only a partial shift / carved job, ask them to think about what supports would be needed to assume more responsibilities or more tasks in the job.

Q16. What about the case studies published in the 2004 SIS *Users' Manual*?

A16. It is important for users to understand that the case studies (Simmons, Garcia, & Thurber, 2004) presented in the SIS *Users' Manual* were not intended to be exemplars regarding how to score individual items. It is important to understand that these case studies were based on real-life individuals and were completed by professionals who knew these individuals well. These professionals had generously

agreed to pilot the scale and provide their results for publication. The accuracy of each rating was not checked, and the interviewers were not asked to defend individual ratings. As a result, some of the individual ratings are difficult to explain.

The purpose of these case studies was to illustrate how SIS might be applied to three very different cases, not to illustrate proper scoring of individual items. The case studies show how SIS can be applied to: (a) an individual who had relatively low-support needs, (b) an individual with a relatively high IQ and adaptive behavior skills but significant challenging behaviors, and (c) an individual with considerable physical and orthopaedic needs. The case studies should be used to provide an overview of the instrument and demonstrate the different types of information that can emerge as a result of an assessment. *However, the case studies should not be held up as exemplars for scoring individual items.* Too little background information is known about the cases to defend each rating, and there are a few items that are particularly difficult to explain.

Q17. **When I am rating the frequency within SIS, I rate the support time not the time spent doing an activity. However I have been finding it helpful to establish how often an activity takes place for a "normal" individual of the same age and then mark how much support is needed so the individual could be successful in that task. Is this approach correct?**

A17. You are correct in thinking that the frequency and daily support time ratings are specific to the time needed to provide support, not how often or the length of the activity. While it is okay to work with respondents to help determine the scores, you may find this approach is only needed initially. Once the respondents catch on to what you are asking, they most often begin to focus only on support time. It may also be wise to verify answers to ensure that they are only taking into account the support time needed.

On a separate note, you may want to provide guidance to respondents if the item/subscale is rarely or not currently something that the person takes part in. For example, the employment section may be best introduced by informing respondents that the items are to be considered in the context of a competitive employment setting, around 5 days a week, 6–8 hours a day, just as you or I would work.