About AAIDD

AAIDD is the world's oldest and largest interdisciplinary organization of professionals concerned with intellectual and related disabilities. Founded in 1876, AAIDD is a professional organization that promotes progressive policies, sound research, effective practices, and universal rights for people with intellectual and developmental disabilities.

Supports Intensity Scale[™] Information

2008



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American Association on Intellectual and Developmental Disabilities

444 North Capitol Street, NW, Suite 846 Washington, DC 20001

www.aaidd.org

Why SIS[™]?

The Supports Intensity Scale[™] (SIS) is part of the core mission of AAIDD to promote progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities. The SIS[™] is published exclusively by AAIDD and the association is committed to developing tools and resources that perpetuate best practices in the use of the instrument in the field.

"For those of us who work tirelessly for self-determination and the full inclusion of citizens with developmental disabilities in community life—our ship has arrived. The Supports Intensity Scale is the first assessment that doesn't fix blame and find what is wrong within the person. Instead, SIS helps us determine the supports necessary for someone to succeed."

Stephen Hall, Director, Georgia Office of MR/DD

WHY SIS?

The SIS provides a reliable framework to quantify the support needs of people with disabilities by:

- Fostering positive expectations for their life experiences
- Focusing on appropriate activities to enhance quality of life
- Identifying the requirements for planning the delivery of consumer-driven, individualized supports
- Collecting, scoring, and aggregating the data through a web-based data repository

SIS looks at needs, not deficits. Unlike traditional assessments, SIS does not look at what a person lacks, but what daily supports an individual needs to live a successful life in society.

SIS provides direct and valid results.

The assessment of support needs using SIS is done *directly* by talking with the consumer and the persons who know him or her the best. You avoid the error in inferring support needs statistically or by using expert judgment only.

SIS is reliable. SIS has a .87 inter-rater reliability coefficient, which puts the tool in an "excellent range" of reliability in assessment instruments.

SIS is transparent. The SIS directly measures the type of support, frequency of support, and intensity of supports required by an individual to participate in 57 distinct aspects of life in their communities. Twenty-three major behavioral and medical support needs are also considered. The Scale provides a straightforward basis for making decisions about personal goals, levels of care, or resource allocation.

SIS is engaging. Due to its interview format with family, friends, the person with a disability, and the case manager, SIS sparks discussion and ideas on how an individual might grow and flourish in ways not considered in a typical assessment.

SIS scores are useful for program planning.

State agencies and providers across the country are using SIS scores to create individualized service plans for people with disabilities as well as identify staffing and budgeting patterns. Not only does SIS give you a graphic display of high intensity versus low intensity areas of support, but a percentile ranking of persons needs based on national field test data. Service decisions can be based on realistic and practical information.

SIS is available as a web-based system.

SIS is one of the first disability planning tools to be made available entirely through the web through a sophisticated system called SISON-LINE[™], which comes with advanced reporting and data aggregation and analyses capacities.

SIS training offers in-depth product understanding. The AAIDD SIS training program is comprehensive and makes it easy for users of the tool to understand how it was developed and transition to a positive, supports-based assessment process.

SIS has international acclaim. Not only is SIS in use in at least 10 states within America, but it has also been translated into Chinese, Dutch, French, Icelandic, Italian, and Spanish.

SIS is an empowering tool. SIS gives a person with an intellectual disability an opportunity to plan a life of choice, and in the process, live a quality, independent life in the community.

SIS is fully endorsed by AAIDD. SIS is the latest initiative of AAIDD, always on the fore-front of progressive issues for the intellectual disability community, and a leader in information and resources on the supports paradigm.



The inter-rater reliability of SIS is .87, which is in the "excellent" range based on conventional standards for adaptive behavior scales. A recent study by Thompson et al. showed that being properly trained in administering SIS plays a major role in obtaining reliable results from a SIS assessment.

"The Supports Intensity Scale is one of the most significant tools to come along in my entire 35 years of service in the disability field, and I cannot say enough about the critical need for such an instrument in determining service needs, setting rates, and supporting the planning process for persons with developmental disabilities."

> Ron Wisecarver, President/CEO, Peoria ARC, Illinois

SIS QUICK FACTS

Instrument name: Supports Intensity Scale

Formats: (1) Print paper and pencil format (2) Electronic Scoring Program on CD-ROM (3) SISOnline, a web-based application for large organizations and states (4) SIS Venture stand alone module for Tablet PCs, laptops, and desktops.

Website: www.siswebsite.org

Publication date:

SIS English Version: January 2004 SIS French Version: January 2008

Publisher: American Association on Intellectual and Developmental Disabilities, Washington, DC

Purpose: To measure practical support requirements of adults with intellectual and developmental disabilities in 85 daily living and medical and behavioral areas.

Ages: Adults ages 16-72

Administration: To be administered by a professional in the human services field with a 4-year degree. Under exceptional circumstances, others with experience conducting individual assessments and possess extensive knowledge of behavior rating or psychological testing principles may be acceptable. Refer to *User's Manual* for more details.

Test kit components: 128-page manual and 8-page pre-printed interview and profile forms.

Supplemental resources: *Guidelines for Including People with Disabilities: Supports Intensity Scale;* SIS Frequently Asked Questions and Scoring Clarifications; SIS Expanded Item Descriptions (available at <u>www.siswebsite.org</u>). Free quarterly newsletter, titled *SIS Vantage* at www.siswebsite.org/Newsletter/

Standardization: Normed nationally on 1,306 adults with developmental disabilities.

Reliability: SIS has a .87 inter-rater reliability co-efficient.

Who can use SIS: Professionals providing services to adults with developmental disabilities. These include psychologists, case managers, transition coordinators, nurses, occupational therapists, social workers, support brokers, teachers, trainers, special educators, doctors, and more.

Authors: James R. Thompson, Brian R. Bryant, Edward M. Campbell, Ellis M. Craig, Carolyn Hughes, David R. Rotholz, Wayne P. Silverman, Marc J. Tasse, Michael L. Wehmeyer.

Organization: 8-page interview form divided into 3 sections:

Section 1: The Supports Needs Scale. Includes 49 life activities grouped into six subscales: Home Living, Community Living, Life-long Learning, Employment, Health and Safety, and Social activities.

Section II: Supplemental Protection and Advocacy Scale. Includes 8 activities, but the score from this section is not used in the determination of the total Support Intensity Score.

Section III: Exceptional Medical and Behavioral Support Needs. Contains 15 medical conditions and 13 problem behaviors commonly associated with intellectual disabilities.



How to buy SIS: SIS is sold as a test kit of 25 forms and a 128-page *User's Manual*. The Scale is also available as a stand alone scoring program on CD-ROM. A web-based application called SISONLINE is also available on an annual subscription basis. SIS Venture stand alone software for tablet PCs, desktops, and laptops is also available.

If you are interested in purchasing the SIS Electronic Scoring Program or SISOnline, AAIDD currently recommends as a best practice that face-to-face interviews be conducted using a paper interview form and scores be transferred later into an electronic form.

Online: <u>http://bookstore.aaidd.org</u> (SISOnline purchases go through <u>help@sis-online.org</u>).

Phone: 1 (301) 604-1340 **Fax:** 1 (301) 208-9789 "The Supports Intensity Scale is an extension of AAIDD's groundbreaking work in the definition and classification of mental retardation. It is an important new tool for person-centered planners and public officials committed to creating the most appropriate mix of social, health behavioral and other supports necessary for maximum inclusion and participation."

> Valerie Bradley, President, Human Services Research Institute, Cambridge, Massachusetts

What is SIS?

The Supports Intensity Scale (SIS) is a planning tool specifically designed to measure the level of practical supports required by a person with an intellectual disability (i.e., mental retardation) to lead a normal, independent, and quality life in society. The Supports Intensity Scale comes with a *User's Manual* that explains how to administer, score, and interpret the scale as well as how to use the instrument to create individualized supports plans. A set of pre-printed 8-page interview form measures support needs of the respondent in medical, behavioral, and life activity areas. The SIS is meant to be administered by a qualified interviewer with feedback from one or more persons who know the respondent well.

"The government, service providers, families, friends, and people with special needs in the York region of Canada have been working towards finding ways we can uphold the ideals of person-centered planning and an inclusive society. I believe we have a solid start with SIS. Using SIS has helped me personally expand my view of people with developmental disabilities as well as strengthen both my interviewing and clinical skills."

> Ruth Pellman, Consultant, York Support Services, Canada

What formats is SIS available in?

The SIS is available as a (1) print paper and pencil, 8-page interview form; (2) Electronic Scoring Program on CD-ROM; (3) SISOnline, a web-based application for large organizations and states; and (4) SIS Venture stand alone module for tablet PCs, laptops, and desktops. Most states use SISOnline for the convenience of the web-based format as well as its data aggregating features. Learn more about SISOnline on page 13.

What does SIS measure?

The Supports Intensity Scale is divided into 3 sections:

Section 1: The Supports Needs Scale

The *Support Needs Scale* is the second section of SIS and consists of 49 life activities that are grouped into six subscales: Home Living, Community Living, Lifelong Learning, Employment, Health and Safety, and Social activities.

Section II: Supplemental Protection and Advocacy Scale

The third *Supplemental Protection and Advocacy Scale* measures 8 activities, but the score from this section is not used in the determination of the total Support Intensity Score.

Section III: Exceptional Medical and Behavioral Support Needs

This section measures supports needs in 15 medical conditions and 13 problem behaviors commonly associated with intellectual disabilities. An underlying assumption is that certain medical conditions and challenging behaviors predict that a person will require increased levels of support, regardless of her or his relative intensity of support needs in other life areas. For example, people with high support needs in terms of respiratory care need maximum support in their daily life regardless of their level of support needs in specific activities associated with home living, community living, and so forth. When completing this scale, the support needs for each life activity are examined with regard to three measures of support need:

Frequency, Daily Support Time, and Type of Support. *Frequency* is concerned with how often "extraordinary support" (i.e., support beyond that which is typically needed by most individuals without disabilities) is required for each targeted activity. *Daily Support Time* assesses the amount of time that is typically devoted to support provision on those days when the support is provided. *Type of Support* reflects the nature of support that would be needed by a person to engage in the activity in question.

Finally, a Supports Intensity Level is determined based on the Total Support Needs Index which is a standard score generated from scores on the 6 subscales mentioned above.

"The Supports Intensity Scale is an automated assessment system that reinforces what supports a person with developmental disabilities needs to be competent. This is not only a good way to support the person-centered values of Washington's Division of Developmental Disabilities, but such an assessment helps us provide information to our stakeholders, legislature, and others regarding the true needs of those we serve."

> Linda Rolfe, Director, Division of Developmental Disabilities, Washington



How was SIS developed?

The Supports Intensity Scale was developed over a period of five years by a team of national experts endorsed by the American Association on Intellectual and Developmental Disabilities, the world's leading organization for professionals in developmental disabilities field since 1876. The creation of SIS included: (a) an extensive literature review to identify initial items (i.e., candidate indicators of support needs); (b) a Q-sort by 50 professionals working in the field of intellectual disabilities to establish the content validity and initial grouping of items; and (c) three field tests where data was collected on over 1,700 persons with intellectual disabilities. Apart from being empirically based and field tested, SIS has excellent psychometric properties, with the inter-rater reliability correlation coefficient of the SIS Index Score is .87, which is in the "excellent" range based on conventional standards for adaptive behavior scales. The User's *Manual* discusses these properties in detail.

SIS and its use for people with Autism Spectrum Disorders

The Supports Intensity Scale may be a useful tool for planning teams interested in identifying support needs of people with Autism Spectrum Disorders (ASD). The same support needs assessment and planning process outlined in the SIS User's Manual, that is, using the SIS in conjunction with person-centered planning, is recommended. It is important to understand that the norm-referenced SIS Support Needs Index (i.e., the overall score) is based on a population of people with intellectual disabilities and related developmental disabilities. This population overlaps, but does not consume the population of persons with ASD. Please note that there are no separate norms for people with ASD. Also, for those people with autism whose intellectual functioning is higher and therefore whose social communication abilities are higher, SIS would not be as appropriate a tool to determine support needs.

An Introduction to SISOnlineTM

Based on the latest technology standards and universally accessible through a password protected site, the SISOnline system is simple and intuitive, with online screens that replicate the paper version of the Scale. Drop-down menus and mouse-over descriptions of each item facilitate ease of use. SISOnline aggregates all test scores and raw data on secure servers, and provides instant access to reports in PDF, HTML, EXCEL, or MS Word formats. We have included for your review one report produced by SISOnline at the end of this package. Assessment results are stored in a historical database, and designated users can aggregate reports on saved assessments or a subset based on a dozen criteria. The system can export large batches of data in CSV, Excel, XML or MS-Access formats to streamline data gathering and business operations.

> "Availability of technical staff via phone to solve problems and provide support in a prompt and very respectful manner was very helpful. Jim Anderson and his team were available through Internet and phone. They always answered my questions and were able to give excellent and easyto-follow instructions via email."

SISOnline also accommodates the following advanced features:

Multiple user access and workflow management

The SISOnline system is capable of providing a variety of levels of access, based upon whether the person accessing the system is an administrator, supervisor, or a user. The system can also be integrated into existing legacy and case management systems to avoid high costs of re-entering data. Further, SISOnline can be customized in look and feel, and can initiate workflow features such as emailing reminders or transferring data to other systems. Each item in SISOnline can have text notes attached, plus checkboxes to designate an item as "Important To" and "Important For" the individual.

Adding supplemental items

While SISOnline ranks all the items on a SIS assessment, the system also allows enterprises to collect additional data during the SIS interview by adding additional pages of profile information, plus clinical items to Section 4 of the Scale. Examples of such data are the individual's living situation, current level of natural supports, expanded risk assessment, profile data for person-centered planning, employment programs, and specific information about health, behavior, or court-ordered requirements.

Security and risk considerations

The SISOnline system protects the confidentiality of assessment data by ensuring full compliance with HIPAA. A detailed document in HIPPA protection is at the end of this package. The system is backed up daily and includes features such as disaster recovery plans, dual fire walls, and 128-bit encryption of data transmissions and SSL certificates to ensure no breach of the system security. Closed-circuit monitors and locked cabinets at the data center ensure physical security of the system.

SISOnline Help Desk Service

All users of SISOnline benefit from a Help Desk that accepts calls and emails 24 hours a day and 7 days a week. Phone calls and emails are answered by application specialists.

Benefits of SISOnline

With SISOnline, you have access to an advanced supports-oriented system of assessment for people with intellectual disability available in a convenient web-based format. Since it is web-enabled, the system allows fast, convenient, and easy access to assessments stored in centralized location, and access to valuable, historical database of key assessment information on each consumer. You can obtain aggregate reports across your organization or state user database and get a global snapshot of support and service trends. Needless to say, you eliminate lost assessments and the time taken to deliver assessments to other parties. Sharing of data among multiple users and monitoring of interview progress in real time validating data as it is entered, leads to improved data quality.

Best practices note

AAIDD encourages users of the Supports Intensity Scale to conduct the face-to-face interview using a paper form and entering assessment information into SISOnline after the interview is conducted.



SIS Venture

The new SIS Venture software, an extension of the web-based SISOnline system, now allows users the convenience of entering SIS assessment data offline without being connected to the Internet. A convenient, in-built alert system prompts a user to upload assessments once the system detects a connection to the Internet. After the data is uploaded to SISOnline, users can retrieve the scores and reports. Maintaining the same look and feel of SISOnline, SIS Venture works on laptops, Tablet PCs, or desktop computers. Users save time and errors associated with data entry and will not have to worry about slow Internet connections. "It was amazing we got the SIS assessments done under tough circumstances of hurricanes Katrina and Rita, but what kept us going was our faith in its implications for an equitable allocation of resources to our citizens living with an intellectual disability. The SIS is becoming a very important face in the service delivery system of Louisiana—from conducting assessments to determining resource allocation for people with intellectual disabilities."

> Scott Meche, Project Director, SIS/Louisiana Plus



The overall goal of AAIDD SIS training programs is to ensure reliable and accurate assessment results, so that service and resource decisions for people with intellectual disabilities are made fairly and equitably. To achieve this, professionals who administer SIS have to be trained to be excellent interviewers who understand the unique, supportsoriented intent of the Scale, have essential skills in interacting with consumers, and clearly understand each item measured by SIS.

"Before and after a SIS training session was like night and day for me. SIS training helped solidify the mentality of SIS, which is to not gauge skills and lacks, but support needs of a person. Without a proper understanding of SIS and its mindset, scores will be skewed and at the end of the day, SIS will profit you very little."

> Johnathon Crumley, Regional Supervisor, Middle Georgia Behavioral Services

Reliability: Foundation of the SIS training program

Reliability is a word you will see used often in AAIDD SIS training programs. Simply stated, reliability means consistency—that is, results obtained by the persons trained to administer the instrument would be consistent with the results obtained by the developers of the Scale, respecting its original intent in measuring the support needs of an individual. Once reliability is established, any trained interviewer who administers the tool will obtain comparable results (plus or minus an acceptable error rate). This is especially true in situations where multiple people are needed to assess large numbers of individuals. In these instances, establishing the inter-rater reliability of each interviewer becomes essential to the overall interview process. The more people trained to administer the Supports Intensity Scale, the more clear the strategies are for assessing the inter-rater reliability of those individuals. Only in this way can the integrity of the data obtained from SIS assessments be assured, and by doing so, resources and services to people with intellectual disability are allocated in a fair and accurate manner.

Points to consider before selecting the right training program

Ninety percent of work is in preparation. Spending the time building internal training capacity to successfully implement SIS is critical to its success. Pre-selection steps include:

Clearly articulate what you expect SIS to do for your state or organization. Creating this vision, desired outcomes, and timeframe will support the decisions to be made concerning implementation of SIS. Write down the vision, outcomes, and timeframe, and share it with the people you support, their families, providers, and other key stakeholders. Modify it as necessary. For example, one expectation is: "We are committed to using SIS to help develop individual objectives and to assure the equitable allocation of our resources among all those we support. We envision supporting 4 staff persons to become proficient teaching our 15 support coordinators on how to successfully conduct a SIS interview. Once trained, each support coordinators will complete 30 interviews before December 2."

- Identify your need for trainers. Your vision, desired outcomes, and timeframe will help guide this process. There are no set rules on how many trainers you will need to implement SIS. This varies greatly depending on the scope and intensity of work. One state may need 300 interviewers while for another, 20 may suffice.
- Determine the role of SIS trainers. Are these individuals responsible for training only or will they be responsible for completing interviews as well?
- Will they be full-time or part-time trainers? If part-time, what current work/responsibilities will they "give up" in order to have the time to meet this training need? You may decide you need full-time trainers for a set timeframe and part-time trainers thereafter.
- Identify the reporting relationships. Define who the trainers will report to. This may require a matrix management strategy where the trainer receives clinical supervision (content expertise on SIS) from one person and programmatic supervision (scheduling, who is to be trained, when) from another.
- Define your internal inter-rater reliability (IRR) process. Individual IRR is an AAIDD requirement for successful completion of the Train-the-Trainer program. Annual IRR is also required. It is also recommended that an internal IRR process between and among internal trainers be implemented. In addition to building a sense of team, an internal IRR process will also ensure a continued focus on the integrity of the interview

process. Frequency, scheduling, and tracking of IRR should be considered. Additionally, identifying an internal data management strategy around IRR data will identify difficult interview areas for the interviewers and suggest possible training topics or other quality improvement efforts.

- Determine the available pool of SIS trainers. Where will they come from and how will availability be determined? How will they be approached? Sharing information and allowing time for trainers to become comfortable in their new role prior to beginning the process will also contribute to the success of your SIS implementation plan.
- Determine strategies for managing potential real or perceived conflict of interest. In situations where states are pursing the Train-the-Trainer model and will use state staff to conduct interviews, an inherent conflict of interest may exist. This is especially true when the SIS is being used for resource allocation purposes.

Follow-up Trainer Supports

Training on a regular basis can be challenging. The trainers may require follow-up supports that may include:

- Opportunities for sharing training experiences, frustrations, new approaches, and recommended changes. These may include, but are not limited to, quarterly trainer meetings, a listserv, or periodic teleconferences where issues and concerns can be discussed.
- Developing a "community of trainers" among the group. As a natural support group, they rely on each other for problem solving, sharing what they are learning, or for improving the overall effectiveness of your SIS implementation process.
- Developing strategies for dealing with interviewer (and trainer) turnover.

 Supporting the analysis of IRR data to determine potential training trends, identify individuals for whom interviews are difficult and improve the overall quality of the training process.

Proper preparation and selecting the right SIS trainers for your organization is essential to a successful SIS implementation plan.

AAIDD Training Offerings

1. Orientation Session and Guided Practices

This training component is a one-day, intensive and interactive group session. It is designed to provide an in-depth overview of the AAIDD Supports Intensity Scale, including:

- Historical and philosophical framework of SIS
- Instrument design, including item selection, validity, and reliability
- Item analysis
- Scoring process
- Interview strategies
- Data use and management.

Prerequisites: Each applicant is required to read the Support Intensity Scale *User's Manual* before attending the training.

Class size: Up to 20 people

2. Train-the-Interviewer program

This training component ensures confident and competent SIS interviewers. The AAIDD SIS Trainer conducts an interview modeling the SIS interview process, including:

- Interview set up
- Information gathering processes
- Information interpretation
- Item determination and scoring

Participants complete an inter-rater reliability review with the AAIDD Trainer. Successful candidates must obtain an inter-rater reliability coefficient of .85 or higher. This means that the AAIDD Trainer observes the participant complete an interview without comment. The interviewer and the AAIDD Trainer then score the interviews separately and independently of each other. The participant's total sub-scores for each area on the SIS must agree with the AAIDD Trainers score for at least 85% of the time.

Each day begins with the AAIDD Trainer clarifying any questions participants may have, including item clarification, scoring, and interviewing techniques. This is followed by the AAIDD Trainer observing the first participant conduct a full SIS interview and determining the participant's inter-rater reliability. Two inter-rater reliability reviews can be completed in a day.

(Note: Annual or quarterly inter-rater reliability review is required to ensure staff maintain skill level)

Prerequisites: SIS orientation session and guided practices

3. SIS Train-the-Trainer program

This component ensures competent staff to train others on SIS including the SIS orientation course and training interviewers to conduct inter-rater reliability reviews. Further, the SIS train-the-trainer program ensures content integrity of each trainer. The trainer standing in front of a group fielding questions and comments requires more in-depth knowledge of the Supports Intensity Scale. They must know the process in a different way than what is required to conduct an interview. The trainer must demonstrate competency in teaching others the intent of SIS, the nuances of each item on the Scale, as well as the scoring process and analysis of the information obtained.

Areas covered during a SIS train-the-trainer program include:

- Understanding of the overall intent and supports-oriented philosophy of SIS as well as the meaning of each line-item on the Scale.
- Mechanics/style: Communicate the intent of SIS effectively using respectful language and examples that the consumer

understands and with which s/he can easily relate. Demonstrate flexibility as an interviewer using a conversational style to complete SIS subscales and not necessarily go in the order in which SIS is organized

- Suitable interviewing techniques: Use verbal and non-verbal cues; set a scene for each subscale; tackle sensitive issues such as using people first language and dealing with difficult topics; and keep interview on track
- Scoring and interpreting data: Explain reasoning for scores chosen; learn to properly calculate scores; and obtain consistent results

Throughout the training, the AAIDD Trainer provides in-depth feedback and guidance to the trainee and also observes the instructors ability to appropriately conduct an inter-rater reliability review with participants.

Prerequisites: SIS orientation course; interrater reliability of .85 or higher

Guidelines for choosing staff for a SIS Trainthe-Trainer program

If you choose the AAIDD train-the-trainer program, how do choose who becomes the SIS trainer for your organization? In one regard, the selection process is fairly straight forward. The desired attributes for a trainer are listed below. However, a significant attribute required for a SIS Trainer is the willingness to understand and implement a new, progressive supports-oriented assessment process. The ability to transition from a skills focus while conducting assessments to a needs and supports orientation is a must. A SIS interviewer must be willing to listen to the respondents and gather feedback, rather than recording a perception of what s/he thinks the person requires as supports and services. Some skills required include:

- Effective communication skills
- Public speaking skills
- Ability to relate well to groups

- Ability to work well with people with various backgrounds
- Effective audience management skills
- Availability to work when needed, including commitment to completing work within designated timeframes.
- Willingness and eagerness to participate as an internal trainer
- Analytical skills to address difficult questions or problematic participants
- Ability to effectively use audio-visual equipment
- Effective time management skills
- Flexibility to modify presentation based on audience
- Strong organizational skills
- Practical knowledge of adult learning strategies

The selection process may offer other challenges as well. This includes gauging the spirit of the person. While difficult to assess, the following attributes contribute significantly to the overall process:

- Ability to deal with ambiguity (the rules will not always be clear or multiple changes may need to occur).
- As ambassadors of the SIS implementation strategy, the person selected should present a positive view of the process and have a solid understanding of the SIS process and the tool.
- Always seek to improve effectiveness and achieve greater efficiencies in the implementation strategy. Be part of the solution and not part of the problem
- Demonstrating a sense of humor and the ability to promote humor in a training session is essential.

4) SIS Inter-rater Reliability Observation

This new service is among key enhancements of the SIS training program to establish con-

sensus on use of the instrument by those who administer it. The AAIDD Trainers will observe the targeted trainers conducting the IRR process with a sample group of trainees to ensure understanding of this procedure. Specifically, this process includes the IRR observation, follow-up with in-depth critiques, a question and answer session, and a written evaluation of the process.

AAIDD SIS Training Costs

Price is based on trainer fees, cost of training materials, and trainer expenses. For a cost estimate, please write to <u>jula@aaidd.org</u> with the type of training service required, and the number of people anticipated in the training.

Other AAIDD SIS Training Services

- Information/Data Management: This includes support to interpret results, implications for individual planning, and implications for organizational/state (system) planning.
- SIS Data Integrity Assurance: This includes observation of a percentage of all interviews completed by internal staff to ensure the accuracy of SIS data. This is especially important to state directors. We would recommend between 5–10% of all interviews completed. Two observations per day are possible.
- Staff interviews: This is intended to provide support to agency staff who participate in the interview process. Similar to the SIS orientation training, this helps agency staff understand their role in providing information, what type of information is needed, and how to support the person with disabilities during the interview process.



Feedback from past participants of SIS training program

"SIS training was essential in ensuring that the instrument is administered in a fair, reliable, and professional manner."

Ruth Pellman, York Regional Community Services, Canada

"The SIS training provided by AAIDD was very productive for Delta staff and county Supports Coordinators who joined us for the training. Our trainer was very effective in explaining the instrument and demonstrating its administration. SIS is a tremendous tool for identifying how to support an individual in very practical ways. The Scale will certainly enable us to improve the quality of our individual support plans, leading to better allocation of resources and ultimately, better results for the people we support."

Dave Wyher, President and Founder, Delta Community Supports Inc., Pennsylvania

"The training was essential to the use of the tool. It really clarified how to use it and answered lots of questions the staff had. Our trainer was very knowledgeable about the different areas of the SIS tool. We found it very helpful to role play and go through different scenarios we may come across. Overall, the training was very helpful and much appreciated!"

Connie Miller, Community Living Manager, Milwaukee Center for Independence, Wisconsin

"We are very pleased with the SIS trainers in Georgia. They did a great job training on how to use the SIS to develop goals. I also like the inter-rater reliability process that they used."

> Christine Hammond, Georgia Office of Developmental Disabilities



"The SIS training provided an in-depth understanding of the tool, i.e., how it was developed, why, the basis and uses. Further, it provided me personally with a firmly established "changed philosophy" of how to use the concept of helping/supporting individuals with developmental disabilities. It taught me how to view success for individuals with disabilities as compared to non-disabled persons and to think of intensity of help/support needed for success."

> Willie Ingram, Mental Health/ Developmental Disabilities Services Director, Georgia Regional Hospital, Atlanta

"The most valuable part of the training was trying out the interviews and getting feedback from the instructor on the scoring and which questions worked. Because of the need to have the instructor give feedback on interviews you conduct, the advanced training is essential to ensure proper administration of SIS."

> Steve Mason, Chief Operating Officer, Hillsborough ARC (HARC), Tampa, Florida

SIS Use in States

Numerous states are currently using SIS and taking advantage of additional services from AAIDD to assist them in implementing this assessment.

"The SIS yields more reliable and valid information about individual support needs and, thereby, a better foundation for linking funding to such needs. The Division of Developmental Disabilities believes that Colorado would be best serviced by selecting the Supports Intensity Scale and looks forward to the anticipated benefits identified on behalf of individuals receiving services."

> Fred DeCrescentis, Director, Division for Developmental Disabilities, Colorado

SIS USE IN STATES

| | I I | STATE | | | | | | | | PROVINCE | | | |
|----------------------------------|-----|-------|----|----|----|----|----|----|----|----------|----|----|----|
| SIS USAGE | CO | GA | LA | MO | NC | ОК | OR | PA | UT | VA | WA | MB | ON |
| SIS start year | 06 | 05 | 05 | 07 | 07 | 07 | 07 | 07 | 06 | 05 | 06 | 07 | 06 |
| Scope of use* | W | С | W | W | Р | | Р | | С | | С | Р | |
| SIS—paper | | | | | | | | | | | | | |
| SIS—CD | | | | | | | | | | • | | | |
| SISOnline | • | • | | • | • | • | • | | • | • | | | |
| Customization | • | • | | • | | | • | | • | • | | | |
| Integration | | • | | • | | | | • | • | | • | | |
| SISOnline—state server hosted | | | • | | | | | • | | | • | | |
| Use supplemental tools w/SIS | | • | • | | | | • | | | | • | | |
| Use AAIDD training | • | • | | • | | • | | | | | | | • |
| Use AAIDD interviewers | | | | | | | • | | | | | | |
| Use for resource allocation | • | • | • | | | | • | | | | • | | |

* P = Pilot, C = Entire Caseload, W=Waiver only

as of January 2008



SIS Licensing Costs

The ultimate cost to implement the SISOnline assessment instrument is determined by the following: the basic cost of the SISOnline Enterprise software license; custom programming to the system which can include integration into a client management system; and training.

"Our experience with the Supports Intensity Scale has been very positive in that it does not measure a person's deficits but the kind and intensity of supports needed for a person to participate more fully in the life of the community. Although New Horizons has been using this tool for only a few months with people being introduced to our agency, we have found it user-friendly and comprehensive. "The SIS provides an easy-to-read and clear set of expectations for those involved with providing supports."

> Regis Obijiski, Executive Director, New Horizons Resources, Inc., New York

AAIDD SISOnline Pricing

The ultimate cost to implement the SISOnline assessment instrument is determined by the following: the basic cost of the SISOnline Enterprise software license; custom programming to the system which can include integration into a client management system; and training.

The SISOnline Enterprise software license fee is determined by how many people (Users) will use the system to complete assessments or otherwise manipulate the data within the contracted year and how many Assessments are contracted for within the year. The SISOnline Enterprise license fee is an annual cost.

Custom programming can include supplemental questions that can be added to the basic SISOnline assessment as well as customized reporting, programming, and client management system integration required meet specific state and local requirements

Training is highly recommended. Pricing for training depends on the training model, the number of people trained and travel considerations. This is covered more extensively in the Training Services section of this document.

AAIDD SISOnline Enterprise basic software license costs, without any customization, integration or training can be estimated based on the following:

Cost per User contracted for each year (10–10,000), depending on number = \$250.00-\$90.00

Cost per Assessment contracted for each year (100–250,000), depending on number = \$16–\$8



"Finally, we have an assessment tool that provides a foundation for real, person-centered planning. By design, the SIS encourages discussion in all major life areas. As a result, person centered plans more accurately reflect individual interest and goals, and quality of life is improved."

> Robin Baker, Developmental Disabilities Consultant for The Durham Center in North Carolina.

SIS Service Initiatives

AAIDD is committed to individualized planning for people with intellectual disabilities and developing further resources to enhance the use of tools such as the Supports Intensity Scale. Following are some of the initiatives geared to ensure the longevity and efficiency in the use of SIS.

"Instead of the usual summer camp, our pilot program with SIS gave kids a chance to explore real career opportunities and pick up valuable employment and social skills in real life situations. Further, we found that skill levels acquired also spilled over into the areas of independence and home and family living."

> Dr. Herm Fishbein of the Children's Services Council, Florida

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SIS for Children

A children's version of SIS is under development for use for children ages 5-15 with intellectual disabilities. Committee members include experts in intellectual disability, special education, program administration, and psychometrics. Five of the committee members are authors of the current adult version of SIS. It is anticipated that the children's SIS will contain items that are applicable universally to life activities of all children in the age range specified. The anticipated launch of SIS for Children is 2009.

Teleconference for SIS users

A teleconference series for SIS users at the state level will begin in 2008. The teleconferences will provide a forum to states to discuss experiences with SIS and learn from each others' experiences.

Multiple Languages Supported by SIS

SIS has been or is in the process of being translated in 10 languages, including Spanish, French, Chinese, Catalan, Italian, Dutch, Croatian, Hebrew, Japanese, and Portuguese.

SIS Administration and Scoring Guide and White Papers

AAIDD is working with the SIS authors and trainers to publish in early 2008, a booklet encapsulating updates on the administration and scoring of the Supports Intensity Scale based on the growing knowledge from the use of SIS in the field. This Guide will complement the existing SIS User's Manual. Also, a series of electronic white papers on issues such as resource allocation, international implementation, and developing individual service plans will be available in 2008 on the SIS website at www.siswebsite.org.

SIS User Forums at Annual Meetings

The 2007 annual meeting of AAIDD featured several sessions on SIS by state leaders as well as invited guests from the Netherlands and Italy to discuss experiences of these early adopters. These presentations are part of the commitment of AAIDD to provide a forum for early adopters of SIS to share experiences for the benefit of future SIS users. AAIDD will continue to hold strategic meetings such as these to facilitate dialogue among users of SIS.

AAIDD SIS Interviewers Services

AAIDD can provide trained SIS interviewers to states interested in seeking help in conducting SIS assessments with clients. As an integral part of this service, comprehensive "look-behind" supports are offered by AAIDD through its senior SIS trainers. This quality assurance component is to facilitate data collection; ensure data integrity, particularly data reliability; and open communication between the client, field staff, and SIS interviewers. This service also includes help with logistics of interview arrangements as well as data entry. AAIDD provides a detailed final report to the state after completion of the project. If you are interested in an integrated system to incorporate the use of SISOnline, we also offer wide ranging technical consultation and support services.

Other Services Upon Request

AAIDD can consult with states to create and maintain effective and efficient systems of assessing individual support needs and implementing person centered planning by offering customized services in determining pilot protocols; developing system infrastructure strategies; and designing quality assurance systems.



Data Analysis Services

AAIDD can work with organizations on summarizing SIS assessment data into useful information such as reports comparing data to other states; looking at trends, averages, and profile of support needs; and helping evaluate and improve the quality of programs. The goal of these efforts is often to ensure high quality assessment data to support the assessment program's objectives. Assistance is available to develop a sound research study process with a clear rationale and purpose, employing appropriate methods and measures with tabled results. A variety of descriptive and exploratory data analyses can be used towards this end to monitor outcomes and ensure quality requirements. Sample analyses include these objectives or answering these questions:

- Are interviews being conducted as scheduled and is all the data complete and accurate?
- Are the ratings for an individual's assessment consistent and robust (Automating review of the ratings using data integrity tests that correlate typical rating pairs)?
- What data quality issues can be solved by adding validation and business rules to prevent errors when the data is entered?
- How are the support needs different for new individuals as compared to individuals currently receiving services? Does the current rate of change compare to the historical trend?
- Are there differences between subgroups on key variables?

In addition to formal testing to compare groups, descriptive statistical graphics are often important for reporting results to consumers and policy makers. A variety of graphic display options are possible, such as variable histograms, scatter plots, stem-leaf displays, box-whisker plots, and fitted curves. Apart from group comparison analyses, research questions can also explore relations between variables. These analyses can range from simple descriptive correlation studies to more complex multivariate models that identify the best combinations of variables for predicting certain outcomes or dependent variables (e.g., multiple regressions) from other independent or predictor variables. "Data mining" techniques are particularly helpful in discovering relations between variables and, more importantly, in developing practical applied tools like CART-based decision-trees. Furthermore, in such formative data collection exercises the preliminary screening for potential "outlier" data points, and how to handle them in statistical analyses, should be part of any data analysis plan.

"We hope that by implementing the Supports Intensity Scale, we will gradually change people's perceptions about disability in Taiwan."

> Susie Chang, Adult Services Supervisor, Syinlu Social Welfare Foundation.

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SIS User Support and Contacts

AAIDD is committed to ensuring best practices and communication within the community of SIS users. With these resources, help and information on SIS is just a phone call or click away.

"SIS is what we have been waiting for. In Italy, the Supports Intensity Scale is not merely an assessment instrument, but it is part of a national movement developed by a group of experts and advocates to create best practice standards in quality of life for people living with an intellectual disability."

Mauro Leoni, member of Editorial Board and Rights Manager, Vannini Editrice, Italy 0

SIS HELP DESK

For SISOnline users, a Help Desk accepts calls 24 hours a day, 7 days a week and an application specialist is available during business hours to provide assistance in using the system, understanding features, help with registration, passwords, and other similar service support needs. Registered SISOnline users are given a phone number to call in as well as an email contact.

SIS WEBSITE

A comprehensive website on the Supports Intensity Scale at <u>www.siswebsite.org</u> contains information on the Scale in addition to new items designed to keep you up-to-date on major developments with the Scale.

SIS VANTAGE NEWSLETTER

SIS Vantage, a free electronic quarterly newsletter, contains stories on user experiences with SIS and general news items of interest on the Scale. You can sign up at <u>www.siswebsite.</u> org/Newsletter.

SIS DISCUSSION BOARD

A discussion board at www.siswebsite.org has been in active use for end users of the Supports Intensity Scale to discuss issues and pose questions on the Scale.

SIS LISTSERV

An invite-only listserv for states was developed for the purposes of discussion the use of SIS for resource allocation purposes.

SIS EARLY ADOPTER TELECONFERENCE SERIES

These calls provide an update on recent modifications and additions to SISOnline features and services.



SIS CONTACTS

AAIDD welcomes emails at any time at <u>books@aaidd.org</u> from current or prospective SIS users, and someone will respond to you within 24 hours. Following are your contacts for specific areas related to SIS implementation.

Government Relations

Gary Slattery gary@sis-online.org

Tom Mooshegian tom@sis-online.org

Technical James Anderson help@sis-online.org

SIS training

Jula He jula@aaidd.org

Product Manager Angela Rapp Kennedy angela@aaidd.org

General queries

books@aaidd.org



Supports Intensity Scale Authors

Ten years ago, a group of disability experts started out with a passion and a commitment to promote greater participation by people with intellectual disability in a complex society. The result was a breakthrough tool that now allows disability professionals to provide supports and services as unique as the individual with the disability himself.

"This tool is in line with the basic principles of self-determination, individual choice, and the supports people need. The focus of supports is now looking at individual personal outcomes."

> Cathy Ficker-Terrill, CEO, Ray Graham Association of Persons with Disabilities, IL

Dr. James R. Thompson

Professor and Chairperson Department of Special Education Illinois State University

Dr. James R. Thompson is the lead author of the Supports Intensity Scale and has been teaching students with special needs since 1980, when he realized that his true calling was in special education. In addition to writing over 50 book chapters, monographs, and articles, Dr. Thompson has directed numerous research and development projects in special education and related fields, and has held offices within the American Association on Intellectual and Developmental Disabilities (AAIDD), the Council for Exceptional Children, and The Arc of the United States. Among other achievements, Jim is proud of his proficiency at playing 3rd base on a softball team. "Few handle the "hot corner" as well as I can!" he says.

"What has pleased me the most about the Supports Intensity Scale since its publication is the number of people who have told me that completing SIS has challenged planning team members to envision individuals with disabilities in a broader array of community settings and activities than those in which they are currently participating. It is easy to settle for the "status quo", and I'm delighted that SIS is promoting thoughtful consideration of ways that individuals can be supported to more fully participate in and contribute to society."

Dr. Brian R. Bryant

President, Psycho-Educational Services

Dr. Brian R. Bryant lives and works in Austin, Texas and has served in many professional capacities, including Director of Research at Pro-Ed, Inc., an adjunct faculty member at The University of Texas at Austin, and Research Fellow at the University's Vaughn Gross Center for Reading and Language Arts. Author of over 100 articles, tests, professional development guides, and books, Dr. Bryant's research interests include individuals with learning disabilities and mental retardation, particularly with regards to reading, mathematics, and assistive technology applications throughout the lifespan.

"I am glad people are finding the Supports Intensity Scale of value. Truth be told, there are a number of scales that are technically sound, yet never see any use. For a scale like SIS to be viable, someone has to find the scale to be of sufficient value as to be worth the time and effort to change what they are currently doing, sometimes dramatically. That is happening, and the practical focus on supports assessment and provision is good to see."

Dr. Ellis M. (Pat) Craig Consultant

After 36 years of service, Dr. Ellis M. (Pat) Craig retired from the Texas Department of Mental Health and Mental Retardation in 2003. Dr. Craig currently consults as a psychologist for mental retardation programs, conducting diagnostic assessments and behavior programming. In addition to authoring 22 book chapters and articles in professional journals, Dr. Craig has made presentations at numerous conferences. He has served as AAIDD's Psychology Division President as well as President of state and regional AAIDD chapters.

"The relatively slow rate of adoption by service agencies is a concern, but not unexpected. Nevertheless, the potential benefits of SIS for directly, rather than inferentially, assessing support needs and financial costs should eventually lead to wide-spread use."

Dr. Edward M. Campbell

Founder, E=MC2 Consulting, Inc.

Dr. Edward M. Campbell worked for the South Dakota Department of Human Services for 30 years before retiring in 2004. Dr. Campbell developed South Dakota's "SBR," a system which generates individual reimbursement amounts (IRAs) to assure the equitable distribution of resources keyed to the needs of the consumer. Dr. Campbell also developed a similar system for Wyoming ("DOORS") and participated in the development of the Supports Intensity Scale. Currently, he owns a company, E=MC2 Consulting, Inc., specializing in human services research applications.

"Several states have plans to develop systems to generate Individual Reimbursement Amounts (IRAs) or individual budgets from the Supports Intensity Scale data. While the SIS's ability to explain actual expenditure amounts remains to be seen, it can be anticipated that SIS data will significantly contribute to this process. I am looking forward to learning how SIS relates to other instruments, and how it enhances the ability to assure the equitable distribution of resources."

Dr. Carolyn Hughes

Professor, Department of Special Education Vanderbilt University

In addition to teaching courses in special education at Vanderbilt University in Nashville, Tennessee, Dr. Carolyn Hughes is also a research investigator in the John F. Kennedy Center at Vanderbilt. Dr. Hughes' research interests are in the areas of transition to adult life for high poverty youth, self-determination and support strategies for at-risk students and students with disabilities, and social interaction among general education high school students and their peers with disabilities. She has managed several federally-funded projects, including the



Metropolitan Nashville Peer Buddy Program and Project OUTCOME, a program for high school students with disabilities from high poverty backgrounds.

"Working together to develop the Supports Intensity Scale and trying to anticipate and address challenges that would come up with its use was a wonderful experience. It is very rewarding now to see its growing widespread adoption and how it is providing a systematic process for building more supportive environments and lives for people with intellectual disabilities."

Dr. David A. Rotholz

Associate Professor of Clinical Pediatrics University of South Carolina, School of Medicine

Dr. Rotholz is Clinical Associate Professor and Project Director for the Center for Disability Resources at the University of South Carolina's School of Medicine. Dr. Rotholz works with the Center's staff and the state mental retardation and developmental disability agency to direct system change effort in behavior support, provide technical assistance, and train staff on evaluation, research, and training projects related to research and training in developmental disabilities. Dr. Rotholz is also Director of the Behavior Support Team with the South Carolina Department of Disabilities and Special Needs. Dr. Rotholz has served as editor on highranking journals and has written more than 20 publications, including the best selling Positive Behavior Support Training Curriculum published by AAIDD.

"Seeing an increasing number of states adopt the Supports Intensity Scale is quite gratifying. The contribution of SIS to a meaningful planning process for successful community living for people with intellectual and developmental disabilities is one practical example of our actions accomplishing our mission."

Dr. Robert L. Schalock

Founder, Bob Schalock & Associates

Dr. Robert Schalock is Professor Emeritus at Hastings College in Nebraska where he chaired the Psychology Department and directed the Cognitive Behavior Lab from 1967 to 2000. Dr. Schalock is a prolific writer and is arguably most known for his work on quality of life in planning and delivering individualized services and supports. He has published numerous books and articles on personal and program outcomes, the supports paradigm, adaptive behavior, clinical judgment, and quality of life, and travels across the world consulting on human service issues. Dr. Schalock and his wife Susan are "semi-retired" and live in the mountains of northeast Washington State. His hobbies include gardening, camping, and fishing.

"I have been amazed at both the national and international interest in the Supports Intensity Scale and its increasing use at the individual, agency, and systems levels. To me, the most impressive aspect of SIS has been and is its international relevance as agency and systems-level personnel implement the supports paradigm. Over the last two years, my observation has been that SIS is truly 'the right instrument at the right time'."

Dr. Wayne P. Silverman

Director, Intellectual Disabilities Research Kennedy Krieger Institute in Baltimore

Dr. Wayne Silverman was head of the Department of Psychology at the New York State Institute for Basic Research in Developmental Disabilities before moving to the Kennedy Krieger Institute in 2006. During his 33-year career, Wayne has conducted both basic and applied research focused on many issues relevant to intellectual impairment and developmental disabilities. Wayne is a Fellow of AAIDD, the American Psychological Society, the International Association for the Scientific Study of Intellectual Disabilities, and the American Psychological Association. He is also the current President-Elect of The Academy on Mental Retardation.

"I'm very happy to see how well-received the Supports Intensity Scale has been, and I'm hopeful that it is having its anticipated positive impact in supporting the goals and aspirations of people with disabilities."

Dr. Marc J. Tassé

Assistant Director Florida Center for Inclusive Communities

Dr. Marc J. Tassé is Associate Professor at the University of South Florida (USF) in addition to being the Assistant Director of the Florida Center for Inclusive Communities, a University Center for Excellence in Developmental Disabilities. Before joining USF, Dr. Tassé was Associate Professor of Psychiatry and Community Education Director at the UNC-CH Center for Development at the University of North Carolina at Chapel Hill. Dr. Tassé is a clinical psychologist who enjoys working with individuals with developmental disabilities who also present co-occurring mental health problems and/or complex behavior problems. Originally from Québec, Dr. Tassé's previous positions include a postdoctoral fellowship at the Ohio State University Nisonger Center and a faculty position in the Department of Psychology at the Université du Québec à Montréal. He has over 60 publications in peer-reviewed journal articles, book chapters, and books in the area of developmental disabilities.

"I'm excited to see the broad interest in the Supports Intensity Scale. This interest is illustrated in the hard work that people from around the world have put forth to translate and adapt SIS into several languages/cultures. I am also most excited to see that folks correctly understand SIS as being a new standardized instrument/approach that makes us focus on what it takes to help the individual with developmental disabilities be successful in his or her life activities rather than focus once again on what the person can and cannot do."

Dr. Michael L. Wehmeyer

Senior Scientist and Associate Director University of Kansas

Dr. Michael L. Wehmeyer is with the University of Kansas where he is Professor of Special Education; Director of the Center on Developmental Disabilities; and Associate Director of the Beach Center on Disability. Dr. Wehmeyer is engaged in teacher personnel preparation in the area of severe, multiple disabilities and directs several federally-funded projects on research and model development in the education of students with intellectual and developmental disabilities. He is the author of more than 180 articles and book chapters and has written 19 books on issues from self-determination and technology use for people with cognitive disabilities to universal design for learning and access to the general curriculum for students with significant disabilities.

"What has struck me in the two years since the publication of the Supports Intensity Scale is the importance of conceptualizing the constructs of 'supports' and 'support need' in our field, and the potential of an instrument like SIS to enable the delivery of supports to be made based upon support need and not simply proxies for need, like IQ."



Appendices

APPENDIX 1: SISOnline System Design

APPENDIX 2: SISOnline Security

APPENDIX 3:

SISOnline Reports

AAIDD can customize assessment items and reports based on each entreprise's particular needs. SISOnline reports are available in HTML, Word, and Excel formats using Crystal Reports. Enterprises can also create or modify their own reports by uploading Crystal report documents to SISOnline as needed.

APPENDIX 1: SISONLINE SYSTEM DESIGN

The SISOnline system design follows industry best practices, including an architecture that separates the user interface and logic/business rule layers. The system architectures underlying the application are sound, using a common 3-tier architecture, a web browser to pass data to the middle (or application) tier, and rendering responses from the middle tier visually. An application (middle) tier consists of code executed both on demand from clients, and separately to service other needs (e.g. calling a web service to retrieve data). The third is the storage tier, responsible for keeping, sending and retrieving data. The central repository uses Microsoft's SQL Server. This architecture simplifies maintenance, providing flexibility for future requirements. To ensure the application scales with hardware the application is as lean as possible so all resources are effectively utilized (database connection pooling, identifying and removing bottlenecks, et cetera).

Integrating SISOnline with Existing Information Systems

SISOnline can be integrated into existing enterprises information management systems in two distinct ways: a SIS Web Functions (HTTP posting) vs. SIS Web Service (XML based).

SIS Web Functions

The SIS web functions are used when a user needs to be "transferred" from an application to the SISOnline website. The SIS Web functions will allow for pre-population of data or loaded assessment data based on the information passed into the SIS website. Below are examples of when to use these SIS Web Functions:

- You would like a user to enter certain information in your system, and then have the data appear when the user enters the SIS web site from a redirection from your application.
- You would like to have a certain assessment loaded when the user enters the SIS web site from a redirection from your web site.

SIS Web Service

The SIS web service is used to perform tasks that a user may not need to see. Below you will find examples of when to use the SIS Web Service:

- You would like to export all the assessments from the SIS system into your application for reporting purposes.
- You would like to delete assessments based on a deletion criteria the SIS system does not provide
- You would upload batches of demographic data for new assessments (a more secure means of exchanging demographic transmitting data.)

The Web Service users multiple means of security. Besides SSL encryption, the server to server communication is authenticated by the ensuring the servers are at predefined static IP addresses. Both servers could have encryption certificates to validate the authenticity of both the sending and receiving servers. Large



Figure 1.



Figure 2.

amounts of data can be transmitted well ahead of time, before users need to access the data, possibly shortening a user's session time.

Alternative norms for an enterprise can be customized to allow for alternative normative data rather than the normative transformations provided in the SIS Manual. These alternative norms (based on based on local research, state standards, or other sources of normative information) can be provided as a table similar to the one found in Appendix 6.3 (i.e. Total Scores, Support Needs Index Scores, and Percentile Ranks.) Meaning, for each Total Score the user may enter different values based on alternative norms.

System Customization Approach

As the assessment is often considered the heart of a human services program, it is crucial to set clear overall intent and objectives of an enterprise's SIS program as early as possible, usually well before technical support plans are defined. If the objectives are to improve staff planning to quantify the frequency and intensity of support needs, additional data on living situation and what time of day the supports are needed are important. If integrating multiple assessments into one interview, adding items

Functions

- Export Single Assessment
- Export all Assessments
- Delete Assessment
- Load batch data

within a particular section may be helpful. Work flow issues arise with managing resource allocation. Another common goal is to ensure an objective assessment of the support needs of the individuals and use that as a basis for distributing available funds fairly. To ensure the customization work meets the enterprises requirements, a detailed requirements document is recommended that can be reviewed, adjusted, and approved before beginning the implementation work. A requirements document defines the functionality of the systems, including security, administrative control, reporting, business rules, and data models that define the types and lengths of fields to provide rigorous data validation during data entry.

Strong rollout strategies involve all stake holders in developing the program, and hence need strong communication plans to ensure clear understandings of all aspects of the program. Assigning a clinical person to address questions regarding how to rate particular situations is also helpful to be done early. It is also important to decide early is who will do the interviews (case workers, assessment specialists, contractor or state employees, or intake and evaluation staff). This will affect how to handle training and reliability testing for interviewers.

APPENDIX 2: SISONLINE SECURITY

SISOnline ensures security requirements are met, including: administrative processes, physical (e.g., data center) security, patch management (to operating systems, network equipment, and other data application services), data backup and recovery processes, virtual private networks management, and firewall protection. These security measures are part of our processes to assure compliance with the US Government's Privacy Rule (45 CFR Parts 160 and 164) that implemented the Health Insurance Portability and Accountability Act (HIPAA) of 1996. The focus of the Privacy Rule was the management of protected health information (PHI). By April 20, 2005 all covered entities should have been compliant with the Security Rule (45 CFR Parts 160, 162 and 164). HIPAA defines electronic protected health information (ePHI) as any electronic information that is created or received by a health care provider that relates to the past, present, or future physical or mental health of an individual and that identifies the individual. The definition of PHI in the Privacy and Security Rule excludes education records covered by FERPA and employment records. The Security Rule covers electronic creation, transfer, storage and receipt of PHI/ePHI and was issued in its final form in April 2003.

HIPAA implementation specifications are either *required* (*R*) or *addressable* (*A*). A covered entity must implement the *required* implementation specifications. For addressable implementation specifications, the following options are available:

 Assess whether each implementation specification is a reasonable and appropriate safeguard in its environment, when analyzed with reference to the likely contribution to protecting the entity's electronic protected health information;

- (ii) As applicable to the entity
 - (A) Implement the implementation specification if reasonable and appropriate; or
 - (B) If implementing the implementation specification is not reasonable and appropriate
 - Document why it would not be reasonable and appropriate to implement the implementation specification; and
 - (2) Implement an equivalent alternative measure if reasonable and appropriate.

References to standards and specification in the following recommendations will indicate if the specification is required (R) or addressable (A).

Facility Access Controls—164.310(a)(1)

Implement policies and procedures to limit physical access to its electronic information systems and the facility or facilities in which they are housed, while ensuring that properly authorized access is allowed.

- Contingency Operations (A)—Establish (and implement as needed) procedures that allow facility access in support of restoration of lost data under the disaster recovery plan and emergency mode operations plan in the event of an emergency.
- 2. Facility Security Plan (A)—Implement policies and procedures to safeguard the facility and the equipment therein from unauthorized physical access, tampering, and theft.
- Access Control and Validation Procedures

 (A)—Implement procedures to control and validate a person's access to facilities based on their role or function, including visitor control, and control of access to software programs for testing and revision."

4. Maintenance Records (A)— Implement policies and procedures to document repairs and modifications to the physical components of a facility which are related to security (for example, hardware, walls, doors, and locks).

The SISOnline Server is housed in a professionally managed secure location that is monitored and staffed 24 hours a day, 7 days a week. Onsite video surveillance and key card access assures that only authorized personnel will be allowed to enter onto the server room floor. Unescorted access must be first authorized by specific SISOnline Server system administrators.

There is a backup of data and software systems that is taken off-site nightly to protect against data losses that would require a remote system restoration in the case of a disaster.

Workstation Use—164.310(b) (R)

Workstations may only be used for authorized business purposes. Place workstations in secure areas away from regular patient traffic and position display screens to minimize unauthorized viewing and/or access. All users are responsible for practicing precautions to protect the confidentiality, integrity, and availability of ePHI in the information systems at all times. Workstations may not be used to engage in any activity that is illegal or is in violation of organization's policies.

- 1. Access may not be used for transmitting, retrieving, or storage of any communications of a discriminatory or harassing nature or materials that are obscene or "X-rated". Harassment of any kind is prohibited. No messages with derogatory or inflammatory remarks about an individual's race, age, disability, religion, national origin, physical attributes, sexual preference, or health condition shall be transmitted or maintained. No abusive, hostile, profane, or offensive language is to be transmitted through organization's system.
- 2. Information systems/applications also may not be used for any other purpose that is illegal, unethical, or against company policies or contrary to organization's best interests.

Messages containing information related to a lawsuit or investigation may not be sent without prior approval.

- 3. Solicitation of non-company business, or any use of organization's information systems/ applications for personal gain is prohibited.
- 4. Participation in chain letters and other such activities is also prohibited.
- 5. Transmitted messages may not contain material that criticizes organization, its providers, its employees, or others.
- 6. Users may not misrepresent, obscure, suppress, or replace another user's identity in transmitted or stored messages.

Information in 164.310(b) is provided as guidelines for recommended workstation usage.

Workstation Security—164.310(c) (R)

Workstations are the property of organization and must always remain on the premises, unless prior authorization by the Technical Security Officer has been granted for removal of workstations from the premises.

Workstations utilized off organization's premises are protected with security controls equivalent to those for on-site workstations.

Users may only access and utilize workstations as assigned by their supervisor.

Supervisors are responsible for monitoring use of workstations.

All users report unauthorized workstation use to the Technical Security Officer.

The organization installs on all workstations anti-virus software to prevent transmission of malicious software. This software is regularly updated.

Portable workstations (e.g. workstations (e.g., PDAs, laptops, etc.) are also subject to the same safeguards and protections. Portable workstations are maintained in a safe and secure manner when transported.

Networks are secured with a Firewall.

- Network access is limited to legitimate or established connections. An established connection is return traffic in response to an application request submitted from within the secure network.
- 2. Firewall console and other management ports are appropriately secured or disabled and are located in a physically secure environment.
- 3. Mechanisms to log failed access attempts are in place.
- 4. The configuration of firewalls used to protect networks are approved by the Technical Security Officer and maintained by the IS Department.

Servers are located in a physically secure environment and are on a secure network with firewall protection.

- 1. The system administrator or root account is password protected
- 2. A security patch and update procedure are established and implemented to ensure that all relevant security patches and updates are promptly applied based on the severity of the vulnerability corrected.
- 3. All unused or unnecessary services are disabled.

Information in 164.310(c) is provided as guidelines for recommended workstation security.

"For years, I begged for a tool that wasn't deficitsdriven, and now we have one...SIS causes providers of services to look at people with developmental disabilities as being genuine parts of the general population, rather than less than the general population."

Greg Kirk, Director of Professional Counseling Services for Americus, Inc., GA

Device and Media Controls— 164.310(d)(1)

Policies and procedures that govern the receipt and removal of hardware and electronic media that contain protected health information into and out of a facility, and the movement of these items within the facility.

- Disposal (R)—Implement policies and procedures to address the final disposition of electronic protected health information (ePHI), and/or the hardware or electronic media on which it is stored.
- Media Re-use (R)—Implement policies and procedures to address the final disposition of electronic protected health information, and/or the hardware or electronic media on which it is stored.
- 3. Accountability (A)—Maintain a record of the movements of hardware and electronic media and any person responsible
- Data Backup and Storage (A)—Create retrievable, exact copy of electronic protected health information, when needed, before movement of equipment.

SISOnline has an equipment disposition policy for the disposition of equipment and electronic media which has be used with ePHI. Such systems are destroyed or scrubbed of data, as appropriate. The standard systems management process includes the creation of data backups before moving equipment.

TECHNICAL SAFEGUARDS

Access Control—164.312(a)(1)

Implement technical policies and procedures for electronic information systems that maintain electronic protected health information to allow access only to those persons or software programs that have been grated rights.

- 1. Unique User Identification (R)—Assign a unique name and/or number for identifying and tracking user identity.
- Emergency Access Procedure (R)—Establish (and implement as needed) procedures for obtaining necessary electronic protected health information during an emergency.
- Automatic Logoff (A)—Users are required to make information systems inaccessible by any other individual when unattended by the users (ex. by using password protected screen saver or logging off the system).
- 4. Encryption and Decryption (A)—Implement a mechanism to encrypt and decrypt electronic protected health information.

Part 1 of 164.312(a)(1) can apply on the client side and sever side. From a client perspective all SISONLINE workstation accounts are unique and trackable on their respective local network. From a server perspective, all SISONLINE accounts and web site administrative accounts are unique and login activity is being logged.

Part 2 and 3 of 164.312(a)(1) are provided as guidelines for SISOnline users.

Part 4 of 164.312(a)(1) from a client perspective recommends that any health information saved locally from SISOnline is properly encrypted and safe guarded whether it's information stored on a hard disk or transferable media. On the SISOnline server, SSL is used to encrypt the data connection across the internet to the SISONLINE web site. Passwords are encrypted when stored or transmitted in the SISOnline system.

Audit Controls—164.312(b) (R)

Implement hardware, software, and/or procedural mechanisms that record and examine activity in information systems that contain or use electronic protected health information.

All SISONLINE login activity is logged by the system. SISOnline will log the user name and date anytime a user accesses any PHI record in SISOnline or views a record in the user administration module.

Integrity—164.312(c)(1)

Mechanism to Authenticate Electronic Protected Health Information (A) - Implement electronic mechanisms to corroborate that electronic protected health information has not been altered or destroyed in an unauthorized manner.

Information in 164.213(c)(1) is provided as guidelines for an integrity information system.

Person or Entity Authentication— 164.312(d) (R)

Implement procedures to verify that a person or entity seeking access to electronic protected health information is the one claimed.

SISOnline employs unique user identifiers and passwords to authenticate users.

Transmission Security—164.312(e)(1)

- Integrity Controls (A)—Implement security measures to ensure that electronically transmitted electronic protected health information is not improperly modified without detection until disposed of.
- 2. Encryption (A)— Implement a mechanism to encrypt electronic protected health information whenever deemed appropriate.

SISOnline directs all traffic through an encrypted SSL connection through which all data passes between the web server and the users' web browser. There is a way for end users to access the system without an SSL connection and this problem is being addressed in a new SIS design.

ADMINISTRATIVE SAFEGUARDS

Security Management Process— 164.308(a)(1)

Implement policies and procedures to prevent, detect, contain, and correct security violations.

- 1. Risk Analysis (R)—Conduct an accurate and thorough assessment of the potential risks and vulnerabilities to the confidentiality, integrity, and availability of electronic protected health information held by the covered entity.
- 2. Risk Management (R)—Implement security measures sufficient to reduce risks and vulnerabilities to a reasonable and appropriate level to comply with 164.306(a)
- Sanction Policy (R)—Apply appropriate sanctions against workforce members who fail to comply with the security policies and procedures of the covered entity.
- Information System Activity Review (R)— Implement procedures to regularly review records of information system activity, such as audit logs, access reports, and security incident tracking reports.

In addition to security reviews as part of all SISOnline development, the technical staff conducts a security assessment (risk analysis and management planning) of SISOnline every 180 days. The results of the assessment are reviewed by program managers and resources allocated to approved plans of action. Our employees are aware of the importance of IT security and the need for security of privacy sensitive data. Each new employee is briefed on the privacy policies and are required to sign an agreement that details the importance of confidentiality. Employees who have failed to follow our confidentiality policies and procedures have been terminated.

Assigned Security Responsibility— 164.308(a)(2) (R)

Identify the security official who is responsible for the development and implementation of the policies and procedures required by this subpart for the entity.

The staff person who is responsible for the development and implementation of the policies and procedures required by HIPAA needs to be determined.

Workforce Security Responsibility— 164.308(a)(3)

Implement policies and procedures to ensure that all members of its workforce have appropriate access to electronic protected health information, as provided under paragraph (a)(4) of this section, and to prevent those workforce members who do not have access under paragraph (a)(4) of this section from obtaining access to electronic protected health information.

- Authorization and/or Supervision (A)— Implement procedures for the authorization and/or supervision of workforce members who work with electronic protected health information or in locations where it might be accessed.
- 2. Workforce Clearance Procedures (A)— Implement procedures to determine that the access of a workforce member to electronic protected health information is appropriate.
- 3. Termination Procedures (A)—Implement procedures for terminating access to electronic protected health information when the employment of a workforce member ends or as required by determinations made as specified in paragraph (a)(3)(ii)(B) of this section.

The staff are from time to time required to complete security clearances, authorizations, and other appropriate procedures to ensure the security and confidentiality of the information we manage for our clients. Our current project and business processes perform the necessary functions required to ensure access controls (availing and terminating access) for privacy sensitive and otherwise confidential information.

Information Access Management— 164.308(a)(4)

Implement policies and procedures for authorizing access to electronic protected health information

- 1. Isolating Health Care Clearinghouse Function (R)—If a health care clearinghouse is part of a larger organization, the clearinghouse must implement policies and procedures that protect the electronic protected health information of the clearinghouse from unauthorized access by the larger organization.
- Access Authorization (A)— Implement policies and procedures for granting access to electronic protected health information, for example, through access to a workstation, transaction, program, process, or other mechanism.
- Access Establishment and Modification

 (A)—Implement policies and procedures
 that, based upon the entity's access authorization policies, establish, document, review,
 and modify a user's right of access to a work station, transaction, program, or process.

Our current project and business processes perform the necessary functions required to ensure access controls (availing and terminating access) for privacy sensitive and otherwise confidential information. Item # 1 above does not apply.

Security Awareness Training— 164.308(a)(5)

Implement a security awareness and training program for all members of its workforce (including management).

- 1. Security Reminders (A)—Periodic security updates.
- Protection from Malicious Software (A)— Procedures for guarding against, detecting, and reporting malicious software.
- 3. Log-In Monitoring (A)—Procedures for monitoring log-in attempts and reporting discrepancies.

 Password Management (A)—Procedures for creating, changing, and safeguarding passwords.

Our current employee training and business procedures provide awareness training for employees who access privacy sensitive data. Our systems are protected behind two firewalls and have appropriate virus, spam, and spyware protections. Login, database activity, new security patches, backup, hard disk utilization, bandwidth utilization, and other system processes are continually monitored, as appropriate for our systems, with the capability to send automatic alerts (pages, cell phone calls, and secure email messages) to systems administrators 24x7x365. System logs are reviewed periodically by systems administration staff.

Security Incident Procedures— 164.308(a)(6)

Implement policies and procedures to address security incidents.

 Response and Reporting (R)—Identify and respond to suspected or known security incidents; mitigate, to the extent practicable, harmful effects of security incidents that are known to the covered entity; and document security incidents and their outcomes.

Our operations staff follow a "3 tier" response process to address system incidents, including help desk requests, security incidents, network problems, and other events that impact the quality of service provided by SISOnline. The first level person who receives a request (usually at our help desk or on the technical support team) will gather the information needed to investigate the problem. The second level of response is the Senior Systems Administrator, and the third level is the SIS Project Director. SISOnline processes for managing urgent requests have proven reliable and effective. An immediate response and follow-up activities are identified and resources allocated to correct our processes and systems and mitigate avoidable problems. Our team uses a secure request tracking system that identifies the requestor,

the severity of the problem, the source of the request, the system or service involved, the status of the resolution, progress towards resolution and related activity, the resolution, and other important items related to the request.

Contingency Plans—164.308(a)(7)

Establish (and implement as needed) policies and procedures for responding to an emergency or other occurrence (for example, fire, vandalism, system failure, and natural disaster) that damages systems that contain electronic protected health information.

- Data Backup Plan (R)—Establish and implement procedures to create and maintain retrievable exact copies of electronic protected health information.
- 2. Disaster Recovery Plan (R)—Establish (and implement as needed) procedures to restore any loss of data.
- Emergency Mode Operation Plan (R)— Establish (and implement as needed) procedures to enable continuation of critical business processes for protection of the security of electronic protected health information while operating in emergency mode.
- 4. Testing and Revision Analysis (A)—Implement procedures for periodic testing and revision of contingency plans
- Applications and Data Criticality Analysis (A)—Assess the relative criticality of specific applications and data in support of other contingency plan components.

All critical SISONLINE data files are routinely backed up. An off-site copy of the data and software systems are saved nightly. In the case of a disaster that would require a recovery at a new facility, our team is experienced at setting up SISOnline systems for internal testing and development and would install the system on a server at another facility.

Evaluation—164.308(a)(8) (R)

Perform a periodic technical and non-technical evaluation, based initially upon the standards implemented under this rule and subsequently, in response to environmental or operational changes affecting the security of electronic protected health information that establishes the extent to which an entity's security policies and procedures meet the requirements of this subpart.

SISOnline completes periodic security and operations reviews of its systems as part of its processes, including quality improvement programs.

Business Associate Contracts & Other Arrangements—164.308(b)(1)

Written Contract or Other Arrangement (R)—A covered entity, in accordance with 164.306, may permit a business associate to create, receive, maintain, or transmit electronic protected health information on the covered entity's behalf only if the covered entity obtains satisfactory assurances, in accordance with 164.314(a) that the business associate will appropriately safeguard the information.

This standard does not apply with respect to:

- 1. The transmission by a covered entity of electronic protected health information to a health care provider concerning the treatment of an individual.
- 2. The transmission of electronic protected health information by a group health plan or an HMO or health insurance issuer on behalf of a group health plan to a plan sponsor, to the extent that the requirements of 164.314(b) and 164.504(f) apply and are met; or
- The transmission of electronic protected health information from or to other agencies providing the services at 164.502(e)(1)(ii)(C), when the covered entity is a health plan that is a government program providing public benefits, if the requirements of 164.502(e)(1)(ii)(C) are met.

A covered entity that violates the satisfactory assurances it provided as a business associate of another covered entity will be in noncompliance with the standards, implementation specifications, and requirements of this paragraph and 164.314(a).

Implementation specifications: Written contract or other arrangement (Required). Document the satisfactory assurances required by paragraph (b)(1) of this section through a written contract or other arrangement with the business associate that meets the applicable requirements of 164.314(a).

Business associates that work on systems that include privacy sensitive data are required to sign HIPAA compliance agreements and another confidentiality agreement.

Host Security

The overall security of the SISOnline web site, server and web site is excellent. Nessus found O issues with medium to high severity. The Microsoft security assessment only showed two minor weaknesses against the baseline recommendations.

Host Overview

The SISOnline website resides on a Dell Power-Edge 2850 server running Microsoft Windows 2003 standard edition.

Microsoft Baseline Windows 2003 Server Security Recommendations

For windows servers, Microsoft makes the following baseline security recommendations. Areas highlighted in red indicate areas in which SISONLINE and/or the SISOnline Server does not conform to these recommendations.

"The instrument allows you to see where a person has a lot of independence and has high ability and where a person would need supports to achieve a level of independence. To me, that is really important."

> Ellen Devorsetz, service coordinator at New Horizons Inc., Poughkeepsie, NY

APPENDIX 3: SISONLINE REPORTS

Area 1 (Standard SIS Scales Scores, Graphs, etc.)

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Supports Intensity Scale Report

Confidential Interview and Profile Results for the Supports Intensity Scale (SIS)

| Last Name: | Adams | Report Date: | 03/29/2006 |
|----------------|--------------------|-----------------|-----------------------|
| First Name: | Abigail | Interview Date: | 12/04/2005 |
| Middle Name: | A | Tracking Num: | 456321 |
| Date of Birth: | 08/01/1980 | Gender: | F |
| Address: | 5 Main Street | Age: | 26 |
| City: | Bluffton | Language: | Spanish |
| State, Zip: | SC, 29909 | Phone: | 8438367777 |
| Interviewer: | washington, George | Position: | Social Worker |
| Agency: | Red Cross | Phone: | 8438369999 12 |
| Address: | 1 Main Street | Email: | washingtron@yahoo.org |
| City: | Bluffton | State, Zip: | SC,29926 |
| | | | |

2

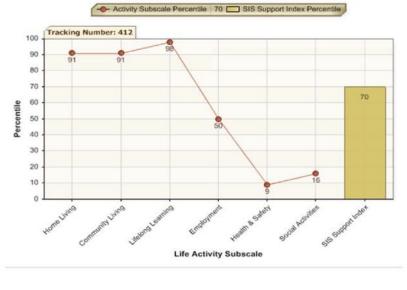
Information for the SIS ratings was provided by the following respondents: Name Relationship Language Spoken

| | Section 1: S | upport Needs So | cale | |
|----------------------------|----------------------|----------------------|------------|---------------------------|
| | Activity Subscale an | id Composite Score P | esults | |
| Activities Subscale | Total Raw Score | Standard Score | Percentile | Confidence Interval (95%) |
| A. Home Living | 75 | 14 | 91 | 13 - 15 |
| B. Community Living | 80 | 14 | 91 | 13 - 15 |
| C. Lifelong Learning | 98 10 | 16 | 98 | 15 - 17 |
| D. Employment | 52 | 10 | 50 | 9 - 11 |
| E. Health and Safety | 24 | 6 | 9 | 5 - 7 |
| F. Social | 24 | 7 | 16 | 6 - 8 |

Activities Standard Score Total: 67 SIS Support Needs Index: 108 Percentile: 70

(95% Confidence Interval: 111-105)

Activity Subscale and Composite Score Profile



| Protection and Advocacy Activities in Rank Order | Raw Score |
|---|-----------|
| | |
| Item 1: Advocating for self | 3 |
| Item 2: Managing Money and finances | 3 |
| Item 3: Protecting self from exploitation | 3 |
| Item 4: Exercising legal responsibilities | 3 |
| Item 5: Belonging to/participating in organization | 3 |
| Item 6: Obtaining legal services | 3 |
| Item 7: Making choices and decisions | 3 |
| Item 8: Advocating for others | 3 |

Note. Activities ranked 1-4 are examined to help in developing support plans. Attention should also be paid to activities that are tied for first and fourth positions.

| Se | ection 3: Exceptional | Medical and Behav | vioral Support Needs |
|---------------|-----------------------|-------------------|----------------------|
| Activity | Total Points | Total Points > 5 | Any Item Circled "2" |
| A. Medical | 30 | Yes 🗟 | Yes |
| B. Behavioral | 26 | Yes | *Yes |

Section 4: Most Important For The Person

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Note. *Indicates that it is highly likely that this individual has greater support needs than others with similar SIS Support Needs Index.

Area 2 ("For's" – this lists only those items that were marked as "For's". The "For" items should be listed by the order they appear in the SIS.)

| Section 4: Most Important For The Person | | | | | | | |
|--|--|------|------|------|--|--|--|
| Sect 1, Part A, | Unsanitary / inappropriate living conditions (Sec 1-A-5: Housekeeping | Freq | Time | Туре | | | |
| | and cleaning) [Note: display notes here if any] | 1 | 4 | 0 | | | |
| | Financial/Money Management issues (Sec 2-2: Managing money and personal finances) Loaning money/indebtedness/financial exploitation by others/excessive gambling [Note: display notes here if any] | 2 | 3 | 2 | | | |
| | Pregnancy and parenting issues [Note: display notes here if any] | | 1 | | | | |
| 이 사람은 방법을 가지 않는 것이 같이 많이 | Criminal Justice Involvement not related to sexual activity [Note: display notes here if any] | | 0 | | | | |
| 10 J. 62 States | Refusal of critical services or treatment and medical [Note: display notes here if any] | | 0 | | | | |

Area 3 ("To's" – this lists only those items that were marked as "To's". The "To" items should be listed by the order they appear in the SIS.)

| | Section 5: Most Important To The Person | | | |
|----------------|---|------|------|------|
| Sect 1, Part A | Unsanitary / inappropriate living conditions (Sec 1-A-5: Housekeeping | Freq | Time | Туре |
| | and cleaning) [Note: display notes here if any] | 1 | 4 | 0 |

| Sect. 2, Item 2 | 2Financial/Money Management issues (Sec 2-2: Managing money and personal finances) Loaning money/indebtedness/financial exploitation by others/excessive gambling [Note: display notes here if any] | 2 | 3 | 2 |
|-----------------|---|---|---|---|
| Sect. 4, Item | Pregnancy and parenting issues [Note: display notes here if any] | | 1 | |
| Sect. 4, Item | | | 0 | |
| Sect 4, Item | Refusal of critical services or treatment and medical [Note: display notes here if any] | | 0 | |

Area 4 Detailed list of all items (the detailed list contains the scores, "To's", "For's", and Notes for each item in each Section).

| | SIS Item | | Scor | e | Important "To' or "For" | | | |
|---|---|-----------|-----------|-------|-------------------------------|--|--|--|
| | Section 1 Caretaker and Environmental Risk: | | | | | | | |
| | Part A – Home Living Activities | | | | | | | |
| 1 | Using the toilet [Note: display notes here if any] | Freq 1 | Time 2 | | "T" and/or "F" if selected | | | |
| 2 | Taking care of clothes [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| 3 | Preparing food [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| 4 | Eating food [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| 5 | House keeping and cleaning [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| 6 | Dressing [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| 7 | Bathing and taking care of personal hygiene and grooming needs [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| 3 | Operating home appliances [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| | Display the Note for Part A if any Part B – Community Living Activities | | | | | | | |
| 1 | Getting from place to place throughout the community [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| 2 | Participating in recreation/leisure activities in the community [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| 3 | Using public services in the community [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| 4 | Going to visit friends and family [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| 5 | Participating in preferred activities [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| 5 | Shopping and purchasing goods and services [Note: display notes here if any] | 1 | 2 | 10.00 | "T" and/or "F" if selected | | | |
| 7 | Interacting with community members [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| 3 | Accessing public buildings and settings [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| | Display the Note for Part B if any Part C – Lifelong Learning Activities | | | | | | | |
| 1 | Interacting with others in learning activities [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected | | | |
| 2 | Participating in training/educational decisions | 1 | 2 | 4 | "T" and/or "F" if | | | |

| | [Note: display notes here if any] | | | | selected |
|----|---|---|---|---|--|
| 3 | Learning and using problem solving strategies [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 4 | Using technology for learning [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 5 | Accessing training/education settings [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 6 | Learning functional academics [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 7 | Learning health and physical education skills [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 8 | Learning self-determination skills [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 9 | Learning self-management strategies [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| | Display the Note for Part C if any | | | | |
| | Part D – Employment Activities | | | | |
| 1 | Accessing/receiving job/task accommodations [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 2 | Learning and using specific job skills [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 3 | Interacting with co-workers [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 4 | Interacting with supervisors and coaches [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 5 | Completing work-related tasks with acceptable speed [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 6 | Completing work-related tasks with acceptable quality [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 7 | Changing job assignments [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 8 | Seeking information and assistance from an employer [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| | Display the Note for Part D if any | | | | |
| | Part E – Health and Safety Activities | | • | | "T" 1/ "T" : |
| 1 | Taking medications [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 2 | Avoiding health and safety hazards [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 3 | Obtaining health care services [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| | Ambulating and moving about [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 5 | Learning how to access emergency services [Note: display notes here if any] Maintalaina a putritious dist | 1 | 2 | 4 | "T" and/or "F" if selected "T" and/or "F" if |
| 6 | Maintaining a nutritious diet [Note: display notes here if any] Maintaining physical health and fitness | 1 | 2 | 4 | "T" and/or "F" if selected "T" and/or "F" if |
| 7 | [Note: display notes here if any] Maintaining emotional well-being | 1 | 2 | 4 | selected "T" and/or "F" if |
| 0 | [Note: display notes here if any] | | 2 | 4 | selected |
| | Display the Note for Part E if any | | | | |
| 1 | Part F – Social Activities Socializing within the household | 1 | 2 | 4 | "T" and/or "F" if |
| ۴. | [Note: display notes here if any] | | 2 | 4 | selected |
| 2 | Participating in recreation/leisure activities with others [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 3 | Socializing outside the household [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |

| 4 | Making and keeping friends [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
|--|--|------|---|------|--|
| 5 | Communicating with others about personal needs services [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 6 | Using appropriate social skills [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 7 | Engaging in loving and intimate relationships [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 8 | Engaging in volunteer work [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| | Display the Note for Part F if any | | | | |
| | Section 2 - Supplemental Protection and Advoc | cacv | Sca | le | |
| | Social activities | | | | |
| 1 | Advocating for self | 1 | 2 | 4 | "T" and/or "F" if |
| 8 | [Note: display notes here if any] | - 32 | | - 23 | selected |
| 2 | Managing money for personal finances activities and others [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 3 | Protecting self from exploitation [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 4 | Exercising legal responsibilities [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 5 | Belonging to and participating in self-advocacy/support organizations personal needs services [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 6 | Obtaining legal services [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 7 | Making choices and decisions relationships [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| _ | | | | | |
| 8 | Advocating for others [Note: display notes here if any] | 1 | 2 | 4 | "T" and/or "F" if selected |
| 8 | [Note: display notes here if any] | 1 | 2 | 4 | |
| 8 | [Note: display notes here if any] Display the Note for Section 2 if any | | | | selected |
| 8 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S | | | | selected |
| 8 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed | | | | selected |
| | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed Respiratory Care | | ort N | | selected |
| 1 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed Respiratory Care Inhalation or oxygen therapy [Note: display notes here if any] | | ort N | | selected |
| 1 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed Respiratory Care Inhalation or oxygen therapy [Note: display notes here if any] Postural drainage [Note: display notes here if any] | | ort N 1 2 | | selected "T" and/or "F" if selected "T" and/or "F" if selected |
| 1 2 3 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed Respiratory Care Inhalation or oxygen therapy [Note: display notes here if any] Postural drainage [Note: display notes here if any] Chest PT [Note: display notes here if any] | | 0 rt N 1 2 1 | | "T" and/or "F" if selected "T" and/or "F" if selected "T" and/or "F" if selected |
| 1 2 3 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed Respiratory Care Inhalation or oxygen therapy [Note: display notes here if any] Postural drainage [Note: display notes here if any] Chest PT [Note: display notes here if any] Suctioning [Note: display notes here if any] | | ort N 1 2 | | "T" and/or "F" if selected "T" and/or "F" if selected "T" and/or "F" if selected |
| 1 2 3 4 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed Respiratory Care Inhalation or oxygen therapy [Note: display notes here if any] Postural drainage [Note: display notes here if any] Chest PT [Note: display notes here if any] Suctioning [Note: display notes here if any] Feeding Assistance | | 0 rt N 1 2 1 | | selected "T" and/or "F" if selected "T" and/or "F" if selected "T" and/or "F" if selected "T" and/or "F" if selected |
| 1 2 3 4 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed Respiratory Care Inhalation or oxygen therapy [Note: display notes here if any] Postural drainage [Note: display notes here if any] Chest PT [Note: display notes here if any] Suctioning [Note: display notes here if any] Feeding Assistance Oral stimulation or jaw positioning [Note: display notes here if any] | | 1 1 2 1 2 0 | | selected "T" and/or "F" if selected "T" and/or "F" if selected "T" and/or "F" if selected "T" and/or "F" if selected |
| 1 2 3 4 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed Respiratory Care Inhalation or oxygen therapy [Note: display notes here if any] Postural drainage [Note: display notes here if any] Chest PT [Note: display notes here if any] Suctioning [Note: display notes here if any] Feeding Assistance Oral stimulation or jaw positioning [Note: display notes here if any] Tube feeding [Note: display notes here if any] | | 1 2 1 2 0 1 | | selected "T" and/or "F" if selected "T" and/or "F" if selected "T" and/or "F" if selected "T" and/or "F" if selected "T" and/or "F" if selected |
| 1 2 3 4 5 6 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed Respiratory Care Inhalation or oxygen therapy [Note: display notes here if any] Postural drainage [Note: display notes here if any] Chest PT [Note: display notes here if any] Suctioning [Note: display notes here if any] Feeding Assistance Oral stimulation or jaw positioning [Note: display notes here if any] Tube feeding | | 1 1 2 1 2 0 | | selected "T" and/or "F" if selected "T" and/or "F" if selected "T" and/or "F" if selected "T" and/or "F" if selected "T" and/or "F" if selected |
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| 1 2 3 4 5 7 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed Respiratory Care Inhalation or oxygen therapy [Note: display notes here if any] Postural drainage [Note: display notes here if any] Chest PT [Note: display notes here if any] Suctioning [Note: display notes here if any] Feeding Assistance Oral stimulation or jaw positioning [Note: display notes here if any] Tube feeding [Note: display notes here if any] Parental feeding [Note: display notes here if any] Parental feeding [Note: display notes here if any] Skin Care Turning or positioning | | 1 2 1 2 0 1 | | selected "T" and/or "F" if selected "T" and/or "F" if |
| 1 2 3 4 5 6 7 8 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed Respiratory Care Inhalation or oxygen therapy [Note: display notes here if any] Postural drainage [Note: display notes here if any] Chest PT [Note: display notes here if any] Suctioning [Note: display notes here if any] Feeding Assistance Oral stimulation or jaw positioning [Note: display notes here if any] Tube feeding [Note: display notes here if any] Parental feeding [Note: display notes here if any] Parental feeding [Note: display notes here if any] Skin Care Turning or positioning [Note: display notes here if any] Dressing of open wounds | | 1 2 1 2 0 1 2 | | selected "T" and/or "F" if selected "T" and/or "F" if selected |
| 8 1 2 3 4 5 6 7 8 9 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed Respiratory Care Inhalation or oxygen therapy [Note: display notes here if any] Postural drainage [Note: display notes here if any] Chest PT [Note: display notes here if any] Suctioning [Note: display notes here if any] Feeding Assistance Oral stimulation or jaw positioning [Note: display notes here if any] Tube feeding [Note: display notes here if any] Parental feeding [Note: display notes here if any] Skin Care Turning or positioning [Note: display notes here if any] Dressing of open wounds [Note: display notes here if any] | | 1 2 1 2 0 1 2 1 2 | | selected "T" and/or "F" if selected "T" and/or "F" if selected |
| 1 2 3 4 5 6 7 8 | [Note: display notes here if any] Display the Note for Section 2 if any Section 3 – Exceptional Medical & Behavioral S Part A – Medical Supports Needed Respiratory Care Inhalation or oxygen therapy [Note: display notes here if any] Postural drainage [Note: display notes here if any] Chest PT [Note: display notes here if any] Suctioning [Note: display notes here if any] Feeding Assistance Oral stimulation or jaw positioning [Note: display notes here if any] Tube feeding [Note: display notes here if any] Parental feeding [Note: display notes here if any] Parental feeding [Note: display notes here if any] Dressing of open wounds [Note: display notes here if any] Dressing of open wounds [Note: display notes here if any] Other Exceptional Medical Care | | 1 2 1 2 0 1 2 1 2 | | selected "T" and/or "F" if selected "T" and/or "F" if selected |

| 12 | Dialysis [Note: display notes here if any] | 2 | "T" and/or "F" if selected | | | | |
|----|---|---|-------------------------------|--|--|--|--|
| 13 | Ostomy Care [Note: display notes here if any] | 1 | "T" and/or "F" if selected | | | | |
| 14 | Lifting and/or transferring [Note: display notes here if any] | 2 | "T" and/or "F" if selected | | | | |
| 15 | Therapy services [Note: display notes here if any] | 1 | "T" and/or "F" if selected | | | | |
| 16 | Other(s) [Note: display notes here if any] | 2 | "T" and/or "F" if selected | | | | |
| _ | Display the Note for Part A if any | | ponotica | | | | |
| | Part B – Behavioral Supports Needs | | | | | | |
| | Externally Directed Destructiveness | | | | | | |
| 1 | Prevention of assaults or injuries to other [Note: display notes here if any] | 1 | "T" and/or "F" if selected | | | | |
| 2 | Prevention of property destruction [Note: display notes here if any] | 2 | "T" and/or "F" if selected | | | | |
| 3 | Prevention of stealing [Note: display notes here if any] | 1 | "T" and/or "F" if selected | | | | |
| | Self-Directed Destructiveness | | | | | | |
| 4 | Prevention of self-injury [Note: display notes here if any] | 2 | "T" and/or "F" if selected | | | | |
| 5 | Prevention of pica [Note: display notes here if any] | 1 | "T" and/or "F" if selected | | | | |
| 6 | Prevention of suicide attempts [Note: display notes here if any] | 2 | "T" and/or "F" if selected | | | | |
| _ | Sexual | | | | | | |
| 7 | Prevention of sexual aggression [Note: display notes here if any] | 1 | "T" and/or "F" if selected | | | | |
| 8 | Prevention of non-aggressive but inappropriate behavior [Note: display notes here if any] | 2 | "T" and/or "F" if selected | | | | |
| 1 | Other | | | | | | |
| 9 | Prevention of tantrums or emotional outbursts [Note: display notes here if any] | 1 | "T" and/or "F" if selected | | | | |
| 10 | Prevention of wandering [Note: display notes here if any] | 2 | "T" and/or "F" if selected | | | | |
| 11 | Prevention of substance abuse [Note: display notes here if any] | 1 | "T" and/or "F" if selected | | | | |
| 12 | Maintenance of mental health treatments [Note: display notes here if any] | 2 | "T" and/or "F" if selected | | | | |
| 13 | Prevention of other serious behavior problem(s) | 1 | "T" and/or "F" if | | | | |