



Attachment: In Depth Feedback Related to SIS™ Specific Items and Intent (July 2008)

The purpose of this document is to provide information about how to respond to common feedback from families and respondents regarding the SIS™ and the SIS™ interview.

The Office of Developmental Programs (ODP) chose the SIS™ because they believe that measuring supports to be successful will help individuals and planning teams develop support goals that promote growth, independence, and engagement in an everyday life in the community. Every day people with developmental disabilities face people who underestimate them. The SIS™ encourages us to think about what supports would help each person become as engaged and as successful in all aspects of living an everyday life as possible. The SIS™ helps us talk about the kinds of support that a person with developmental disabilities would need to do a range of activities that are a part of an everyday adult life. It looks at individual's potential rather than his/her deficiencies. It assesses supports that are needed to help individuals successfully function in their communities. It encourages respondents and the planning team to see the person as a full-fledged participant of their community who wants the same opportunities and choices as all other members. The SIS™ represents a huge leap forward for the field.

It is a whole new way of measuring the supports a person needs.

Because of the different way in which the SIS™ looks at the individual's support needs, the initial experiences of some families and respondents may be confusion about the focus of the SIS™ or the way in which the interview was conducted. The SIS™ is a deceptively complex tool that involves a prescribed format for administration that was developed by the AAIDD, the publishers of the tool.

The following topics are addressed in this document to explain common questions received from families and other respondents during their initial experiences with the SIS™.

<i>Issue #1: Querying.....</i>	<i>2</i>
'The assessor questioned several of our evaluations of support needs.'	2
'I do not understand how someone who only met my child briefly could possibly comment on her level of medical necessity.'	2
<i>Issue #2: Teaching, interpreting, and applying the rating scales.....</i>	<i>3</i>
'The meanings of 'total physical support', 'monitoring', 'partial', or 'total physical assistance' were unclear...'	3
'...the assessor was inconsistent in his application of these terms...'	4
'I firmly believe that there would be different results with different assessors.'	4
<i>Issue #3: Time and Frequency ratings</i>	<i>5</i>
<i>Issue #4: Balancing scores across support categories.....</i>	<i>6</i>
<i>Issue #5: With so many SIS™ special circumstances unscripted, assessors can struggle to explain each in a clear and sensitive way</i>	<i>7</i>
<i>Issue 6: I thought I knew what to expect from the interview.</i>	<i>9</i>
<i>Issue 7: Is the SIS™ equally appropriate and useful for all individuals?</i>	<i>9</i>
<i>Summary</i>	<i>11</i>

Issue #1: Querying

'The assessor questioned several of our evaluations of support needs.'

AAIDD's training and protocol require that interviewers ensure that they thoroughly understand the nature of supports reported by respondents. This is accomplished by querying or asking for examples. Querying itself does not imply that the interviewer does not "believe" or "trust" the respondents' report. Instead, querying is how interviewers ensure that they accurately understand what an individual's support needs look like day-to-day. This feedback cues us to emphasize that assessors let respondents know that they may ask many questions. We will also emphasize the importance of explaining to respondents that the intent of questions will always be to understand what successful supports would look like or to ensure that respondents understand the author's item or rating intent.

"I do not understand how someone who only met my child briefly could possibly comment on her level of medical necessity."

Interviewers must discuss exceptional medical supports to determine how current supports for the 16 medical items relate to the SIS® rating scale definitions. If the comments the interviewer made were meant to clarify his understanding of the supports being reported or were to clarify SIS™ rating scale definitions, they would be standard interview protocol. On the other hand, an assessor cannot presume to give medical opinions regarding treatment or medical necessity or make offensive comments regarding medical needs.

A second question within this statement is regarding the validity of results when the interviewer does not personally know the individual. The standardization and statistical norming of the SIS™ is what assures that questions asked of knowledgeable respondents by a trained interviewer (even one who does not know the individual personally) will yield valid and reliable results about the individual's support needs.

The third issue reflected here is that the assessor may appear to be questioning or challenging the respondents' ratings. According to AAIDD protocol, it is the express responsibility of the assessor to use the interview (questions and discussion) with respondents to come to understand which of the published ratings best describe the individual's support needs. To do this the interviewer must insure that: 1) they understand the individual's support needs as described by the respondents, and; 2) that each item is rated according to the authors' actual intent for that item and for that rating scale. Interviewers are trained at length on the authors' intent for each rating scale and each of the 87 SIS™ items. In this vein, AAIDD protocol forbids interviewers to ask each item and simply record respondents' ratings. Interviewers are

trained and required by AAIDD to use respondents' information in conjunction with their own professional judgment and knowledge of the authors' item and rating intent. This means the interviewer must ask questions to be sure that he/she understands the individual's supports needs and how those supports fit into the authors' item and rating definitions, and that the final rating fits with the interviewer's "professional judgment". (Note that consensus is expressly not part of the AAIDD or SIS® protocol, although both Ascend and ODP consider consensus a valuable goal.)

Issue #2: Teaching, interpreting, and applying the rating scales

"The meanings of 'total physical support', 'monitoring', 'partial', or 'total physical assistance' were unclear..."

Although AAIDD and the SIS™ authors feel that definitions for each rating on each Rating Scale (as printed on the Rating Scale Handouts) are unambiguous and adequate for respondents to understand the intent of each rating; we have found that many respondents do struggle to understand distinctions between ratings. The "Type of Support" category in particular, has sometimes required a good deal of interviewer explanation and querying to insure that respondents consistently interpret the authors rating intent throughout the interview.

Interviewers have participated in extensive multi-week and multimodal training to learn the author's item and rating intent and strategies to communicate intent. Each interviewer has passed stringent in-vivo reliability testing to insure their competence at consistently understanding and applying rating definitions as AAIDD and the author's intend. Additionally, Ascend continuously reviews each assessor for fidelity to AAIDD SIS™ training protocol. This takes the form of in-person interview observations, monitoring via recorded interviews, internal consistency reviews of SIS™ documentation and thorough follow up of all potential concerns reported.

Ascend and ODP have noted that important aspects of AAIDD-approved SIS™ protocol are not covered in the one day "Introduction to the SIS" workshops.

The rating category "Type of Support" is sometimes difficult for respondents. This scale intends to capture the *nature* of actions that a support giver must do for/with the individual to be successful at an activity. We have found that some parents and provider staff inadvertently respond to "Type of Support" ratings with an indication of the *intensity* of the individual's need for support rather than the *nature* of the individual's need for support.

For example, when an individual always needs support for a given activity to be successful, they may be referred to in everyday language as "needing *total support or full support* for the activity". That is, someone may always need to provide support for that person to do that activity well. When an individual needs such support, some

respondents are tempted to automatically choose rating #4 “Full *Physical Support*” for the “Type of Support” category. In these situations, the *nature* of the support needed and the *intensity* of the support needed have been blended. It is important for interviewers to clarify this with respondents, as the terms “*total support/ full support*” and “Full *Physical Support*” can easily be inadvertently blended.

Type of Support is getting at what the support giver must do to help the individual be successful. The SIS™ “Type of Support” rating captures the nature of the activities the support person must do to help the individual be successful.

If the support person always needs to be present to give step by step coaching, a rating of #2, “*Verbal or Gestural Prompting*” could be best. If the support person always needs to be present to physically do some steps of the activity (while perhaps coaching the individual to do other steps) a rating of #3 “*Partial Physical Support*” could be best. In either of these scenarios the individual might be said in everyday language to require “*total support or full support*”, because the support person must be there for the individual to be successful. Yet neither example would correctly be scored on the SIS™ as requiring “Full *Physical Support*”.

“...the assessor was inconsistent in his application of these terms...”

ODP and Ascend are committed to maintaining the highest level of consistency between assessors and over time. Whenever there is a report of potential inconsistency, Ascend investigates interviewers’ understanding and application of SIS™ protocol. Ascend monitors and observes the assessor’s interviews. Targeted coaching and continued training are provided to ensure common methodology is used.

Two assessor attributes are of prime importance to ODP and Ascend. The first is interviewer fidelity to SIS™ protocol, and the second is the ability to flexibly yet clearly explain the SIS™ author’s item and rating intent in ways that accommodate the various language, communication and learning styles of respondents. Many SIS™ users look forward to further AAIDD publications to assist interviewers with explaining SIS™ items, ratings, and intent in ways that accommodate respondents’ wide variety of communication styles.

“I firmly believe that there would be different results with different assessors.”

The standardization and norming of the SIS™ is what assures that questions asked of knowledgeable respondents by an interviewer who has passed AAIDD approved training and testing will yield valid and reliable results about the individual’s support needs. Both ODP and Ascend are mindful of the need to assure continuity and consistency between assessors and over time. This is accomplished through selection and training of qualified individuals as assessors, by the project’s rigorous

quality review program, by targeted interviewer training, and by soliciting respondent feedback to inform the training process.

Issue #3: Time and Frequency ratings

According to AAIDD SIS™ training, *time* and *frequency* are rated according to the time and frequency of support needed to assist the individual to be successful at that particular activity. The time and frequency ratings should vary in accordance with the typical time and frequency needed to accomplish each activity successfully. This would be true even if “*total support*” is required for that activity (meaning “support is always needed during this activity”). Support given for some activities will occur more frequently (eating, toileting, communicating needs, perhaps). Support for other activities may occur less frequently (obtaining legal services, for example). Similarly, the daily support time that an individual would need for some activities may be quite significant, while the amount of time a day that would need to be devoted to other tasks may be less intense for that individual.

The AAIDD SIS™ manual and training adds a layer of complexity to the determination of support needs in one section. In the *Life Long Learning* section, the SIS™ asks not only: “*What supports would be needed to help this individual be as successful as a typically developing adult in the community?*” but also instructs respondents to consider: “*What level of support would give the individual the maximum opportunity to learn and be successful at the activity?*” Thus, in this section, interviewers are trained to query: “*Will that (time or frequency) of support be enough to give the individual the maximum opportunity to learn and apply this skill?*” This can be confusing for some because support needs are measured with a different emphasis than other sections of the interview. To some degree AAIDD trainers also encouraged this emphasis in discrete health and safety and protection and advocacy items as well (e.g., avoiding safety hazards, protecting self from exploitation).

The AAIDD SIS™ manual and training both emphasize that assessors are to “round up” if respondents feel a rating is between two support intensity levels. Thus, if a respondent says that the typical support time each day was in a range that spanned two levels, the interviewer would need to query which level *best represented the support needed in a typical day*- while explaining that the SIS™ instructs the interviewer to “round up” if the respondent feels the best rating falls exactly between two rating levels. For example, if the respondent thought daily support time for an activity was “about 2 hours to 2 hours and fifteen minutes a day”, the interviewer would need to ask the respondent whether they felt a score of 2, “30 minutes to less than 2 hours”, or a 3, “2 hours to less than 4 hours”, best represented his/her support needs. The interviewer would also explain the SIS™ philosophy to “round up” if a rating seems to be between or to span two levels. The SIS™ philosophy of rounding such ratings up is to ensure that support needs for that activity are not under-represented.

Issue #4: Balancing scores across support categories

Interviewers are not in the business of “keeping the score down”. Rather, their job is to keep the ratings reflective of the person’s typical support needs given the author’s intent for each item. The SIS® sometimes requires respondents to balance scores across categories when more than one type of support rating applies to discrete parts of an overall activity.

We can think of two situations in which an assessor might use terms suggesting the need to ‘balance’ scores.

In the first situation, AAIDD trainers taught that some items could be correctly scored in more than one way. There are times that respondents accurately point out that, for an individual to be successful at a particular activity, support might be given in either of two ways. Successful support might be given either in small ‘doses’ more frequently, or in larger ‘doses’ less frequently. In these cases, the interviewer may query about which pattern of supports would work best for or be preferred by the individual. Either answer would accurately capture the individual’s support needs and would result in a similar overall support needs score.

In the second scenario, active balancing and weighing of scores across rating categories is important for activities in which the individual needs an intense Type of Support for some parts of an activity yet is able to successfully do other parts of the activity with a much less intense Type of Support.

For example, if an individual could be successful doing two of three steps of an activity with simple *Prompting*, but required *Full Physical Support* to be successful at the third step, the respondents would need to decide what rating best captures the individual’s overall *Type of Support* for this whole activity. If the third step was incidental to the overall activity, the respondents and interviewer might feel comfortable rating the *Type of Support* as “*Prompting*”. If the third step was just as important to the success of the overall activity as the other steps, but required the *Full Physical Support* of the support giver, the respondents and interviewer may rate the *Type of Support* as “*Partial Physical Support*” (a blend of the *Prompting* and *Full Physical Support* levels of intensity). However, if the third step were seen as critical to the success of the entire activity, while the other steps were not seen as being critical, the respondents and interviewer may even rate the *Type of Support* as “*Full Physical Support*”. This would be relatively infrequent.

In each of these scenario’s, the “*Type of Support*” rating finally chosen may influence the way the team considers “*Frequency*” or “*Daily Support Time*” ratings. If “*Prompting*” was all that was needed and it was needed very often, a high rating for *Frequency* might be chosen. If prompting was needed frequently but for steps not considered critical to overall success at the activity, while full physical support was

needed less frequently but was considered critical to success at the activity, the interviewer and respondents would need to discuss and select a Frequency rating that best captures the overall essence of the individual's support need. In these situations, it would be correct for an interviewer to explain that respondents can consider the balance between the *Type of Support* thought to best capture the individual's need with the *Frequency* rating. It may sound something like "Since some steps are successful with frequent (e.g., many times a day) prompting and one critical step is successful with (weekly) full physical support, we have a choice to make. If we rate the *Type of Support* "*Partial or Full Physical Support*" in order to capture the critical steps a support giver must occasionally do for the individual to be successful at the overall activity, then we would want to let the *Frequency* rating reflect that this higher level of support is not needed many times a day, but rather is needed weekly."

Allowing *Frequency* or *Daily Support Time* categories to reflect the relative blending of *Type of Support* an individual may require for discreet steps involved in an activity as a whole is consistent with AAIDD training.

This was quite a long explanation of certain rating situations as taught by AAIDD SIS® master trainers. The important thing is that this feedback is helpful for the Pennsylvania project and potentially for the SIS® publishers, as well. Interviewers need more guidance in how to articulate to respondents the task of rating items when discrete sub-parts of an activity require very different types/ frequencies/ and times for support. This guidance is not currently part of the SIS® manual, but we pass on a request that the publisher consider adding it to the SIS® manual. Until then, Ascend will work to develop aids for assessors to help them work through these rating conundrums with respondents with less confusion or potential for misunderstanding.

Issue #5: With so many SIS™ special circumstances unscripted, assessors can struggle to explain each in a clear and sensitive way

One conundrum with the SIS™ is that it is an instrument that is designed to be conducted in both a highly individualized manner and with strict fidelity to SIS™ overarching principles, protocol, and rules. Add to that challenge the variability and uniqueness of the individuals and families for whom the SIS™ was designed, and the result is that it is not infrequent for special interview circumstances to arise that require interviewers to articulate SIS™ objectives in a different way or manage responses to sensitive issues triggered by the SIS™. In the absence of written examples in the SIS™ manual, Ascend has and will continue to develop sample scripts to which assessors can refer for a variety of these special circumstances.

One example where training materials are needed is for helping interviewers talk about the SIS™ or adapt the interview when questions about supports needed to help an individual "be as successful as a typical adult in the community" seem to trigger painful



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responses for a parent. Ascend is currently developing guides for assessors and other stakeholders in response to this need. See Issue 7 for more about this issue.

Another example comes from the *Life Long Learning* section of the SIS™. Here the SIS™ asks interviewers to introduce a somewhat different way for respondents to consider supports. Here the SIS™ asks interviewers to introduce a modification in the way respondents consider supports. It would be helpful for the SIS™ manual to explicate ways an interviewer might articulate these rating modifications. Ascend has documented for interviewer reference the most common to explanations used by national trainers. For example: *“we do not have to limit amount of support needed to an amount that seems practical or realistic, instead we want to capture the intensity of support that would give the individual the maximal opportunity to successfully learn and apply this skill”*, or, *“you do not need to limit your responses to supports that could realistically be provided in a typical day”*.

Issue 6: I thought I knew what to expect from the interview.

Ascend and ODP have noted that important aspects of AAIDD-approved SIS™ protocol are not covered in the one day “Introduction to the SIS” workshops. ODP, AAIDD and Ascend agree that it is important to help individuals, families and other respondents prepare for the SIS™ interview. Educating folks about the SIS™ purpose and what it actually requires and feels like is important in order for individuals, families, and other respondents to have the best possible experience. ODP has organized provider workshops and sponsored parent led workshops for parents through organizations like Acheiva (www.achieva.info). Ascend and AAIDD have both developed and posted educational materials on their websites (available at: www.ascendami.com or www.siswebsite.org). Through ODP’s Consulting program (www.odpconsulting.net), Support Coordinators have been trained in the Commonwealth’s use of the SIS™. Support Coordinators have the important task of contacting each individual and family prior to the SIS™ interview and helping them understand the SIS™ experience, its uses, and benefits.

Helping find ways to better prepare respondents is, indeed, an important response to issues raised. We continue to work with AAIDD, families, assessors, and with other states using the SIS™ to develop tools helpful to families and individuals.

Issue 7: Is the SIS™ equally appropriate and useful for all individuals?

The SIS™ offers some important advantages in the way in which inquiries are structured. These same advantages, however, can also lead to one potential difficulty with some SIS™ interviews. One of the fundamental rules of the SIS™ is its requirement that the definition of “success” be explained and consistently applied. The goal of each item is to measure the supports that would be necessary for the individual to do each activity successfully. The SIS™ defines success as: *doing an activity “as well as a typically developing adult in the community”*. One could imagine that some parents and caregivers supporting individuals with profound physical or cognitive involvement may experience significant emotional response to being asked to name the supports that would help their loved one do each activity “as well as a typically developing adult in the community”. This is especially true when one considers that the SIS™ requires interviewers to ask all 87 questions.

This is important to us and will be an important issue for AAIDD to address. During the initial training and through ongoing discussions with AAIDD, Ascend did confer with AAIDD national trainers about this issue. Our specific interest was whether there were ways to soften the impact of asking every question or of explaining the SIS™ definition of success. Their response was to reinforce that, to ensure reliability, every question must be asked and the definition of success must be fully explained and understood.

AAIDD agreed with our concerns that this key tenet of the interview sometimes can cause distress, especially for parents of individuals with significant or profound medical or developmental disabilities. AAIDD added that it may be helpful for assessors to explain the rationale for SIS™ questions: e.g., *“The SIS™ respects that all individuals have the right to have their needs measured in all areas that are a part of an everyday life. The SIS™ doesn’t want assessors to decide which support needs are appropriate to measure and which can be skipped. So the SIS™ requires that we ask all the questions for every individual.”* AAIDD also thought that it may be helpful for assessors to explain to parents that the SIS™ will help document the extent of supports needed by the individual.

Ascend does train our assessors in both of these approaches. However, these statements are not ‘sure-fire remedies’ to take the sting out of 87 questions rating specific supports needed by the individual to be able to do activities of everyday living *“like typically developing adults in the community”*. It has been our experience that this explanation often helps caregivers realize the assessor isn’t trying to be insensitive. Importantly though, the explanation doesn’t address the depth and reality of their emotional response.

When assessors bump up against a parent or loved one’s very real, and at times very powerful, grief or anger response, it can be difficult to keep “on protocol” and require that respondents verbalize each of the 3 support ratings for every item. Assessors need to ask each question and respondents must rate each of the 3 support categories for each item. However, assessors are trained to know that they do not need to further query ratings that they feel are clear and for which they feel they have enough information to be confident of the scores.

While many respondents feel buoyed by the SIS™ focus on possibility and positive support, the fact remains that for some parents a properly conducted SIS™, even when done sensitively and with compassion, can be an experience that evokes a profound sense of loss and injustice. The resolution to this difficulty will be found in our combined best judgments. Ascend and ODP have requested AAIDD develop training materials addressing this matter. In lieu of that, Ascend is writing a module for all assessors use in navigating these important but difficult situations. We are actively exploring ways to maintain overall SIS™ reliability and yet allow for minor modifications of querying methodology that may be helpful specifically for support givers for individuals who have very significant physical and cognitive involvement. It’s very important that all Ascend and state SIS™ staff be equipped to talk with individuals and families about these issues.

The SIS™ was designed to identify the intensity and pattern of supports needed by all persons with developmental disabilities, regardless of an individual’s specific disability, medical condition or intellectual ability. The sample of individuals that were included in the SIS™ norms included individuals with a wide range of disabilities and at least

some individuals representing each level of functioning included in the AAIDD definition of intellectual disability. Some individuals have combinations of characteristics and needs for support that is so unique that it is not possible to have an assessment instrument that includes people just like them in the normative sample. The SIS™ Users manual describes how the SIS™ norms were developed. The SIS™ website: www.siswebsite.org lists articles describing reliability studies conducted to date.

Summary

It is important to Ascend to be responsive to that for which we have impact and can effect: the professionalism and reliability of our assessors. We work diligently to have all interviewers consistently and reliably apply AAIDD and SIS® instructions. We aim to be respectful of and sensitive to each individual and parent while meeting ODP's requirement that our assessors abide by SIS® protocol. Working together and using feedback will help ODP and Ascend to ensure that interviews are respectfully and consistently conducted.

The protocol, structure, definitions, approach and items that are part of the SIS® tool we are not empowered to change. Refinements of these are the purview of AAIDD and the SIS™ authors, although both ODP and Ascend have committed to working with AAIDD to give feedback and to assist them to explore next steps. In particular we look forward to a greatly expanded and enhanced manual that addresses issues such as those outlined above.

Overall, we believe the SIS™ represents a huge leap forward for the field. The SIS® emphasizes on supports rather than deficits, person-centered rather than program-centered thinking, success rather than status quo, inclusion in the life of the community rather than inclusion in segregated programs, and on exploring a full range of typical life activities rather than limiting expectations about an individual's possibilities, are all steps in the right direction when it comes to measuring the needs of individuals with developmental disabilities.