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Relating Supports Intensity Scale™ Information to Individual Service Plans

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Editors' Note

The contributors to the AAIDD White Papers on the Supports Intensity Scale™ (SIS™) were sought out by the editors because of their demonstrated successful implementation of SIS, the quality of their application, and the fidelity of their work to the conceptual and application model of SIS. It is important to realize that each implementation example reflects the initial phases of a long-term process of using and evaluating the efficiency, effectiveness, and impact of the Supports Intensity Scale. Thus, the implementation examples presented should be considered as current efforts, best practices, and benchmarks for evaluating future implementation efforts based on the judgment of the editors.

There is no intent on the part of the editors to suggest that the examples presented here regarding the use of SIS information to the development and evaluation of individual support plans are the only examples available; nor should they be considered as program standards. Knowledge is cumulative, and our primary intent is to share with the reader the current status of the multiple uses of SIS, including individual supports planning. It is our hope that the examples in the AAIDD SIS White Papers will serve as the basis for our increased understanding of how multiple entities can use SIS for the assessment of individual support needs and that we may use this information for multiple purposes, including individual support plans, staffing patterns, resource allocation, monitoring, and evaluating personal outcomes.

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Introduction

From its inception, individual supports planning was the major anticipated use of information related to the Supports Intensity Scale (SIS). We are now beginning to see the realization of this goal. The general experience to date is that SIS-related data need to be combined with other information to link person-centered planning with individual supports planning. This is to be expected because SIS, like all standardized, norm-based assessments wherein scores are derived by comparing the individual's score with the scores of other people with disabilities, does *not* provide information about the person's desired life experiences and goals. Thus, person-centered information regarding what settings the person most enjoys, what activities the person wishes to participate in, and what life experiences the person desires and envisions needs to be used in conjunction with SIS-related information. This White Paper presents four approaches to integrate SIS-related data into person-centered planning. The first example shows how the four-component assessment and planning process described in the 2004 *Supports Intensity Scale Users Manual* (Thompson et al., 2004, p. 79) can serve as a model for individual support plan (ISP) development and monitoring. The second example, from the state of Utah, demonstrates how one can develop enhancements to the standard SISOnline™ to address comment 1 (“identify desired life experiences or goals”) of the four-component assessment and planning process. The third example shows how one agency in the Netherlands has aligned quality of life (QOL) domains and indicators with the support areas assessed on SIS. The fourth example describes how SIS can be used to stimulate creative planning.

Using the Four-component Assessment and Planning Process in ISP Development and Monitoring

by James R. Thompson

Because Supports Intensity Scale (SIS) does not provide the same type of information person-centered planning processes offer, SIS should be used in conjunction with person-centered planning. The SIS authors recommend the four-component assessment and planning process depicted in Figure 1.

Each component of this process will be described on the subsequent pages along with an example from a case study based on a middle-aged gentleman (Mel) from the suburban Chicago, Illinois, area who has an intellectual disability.

Mel

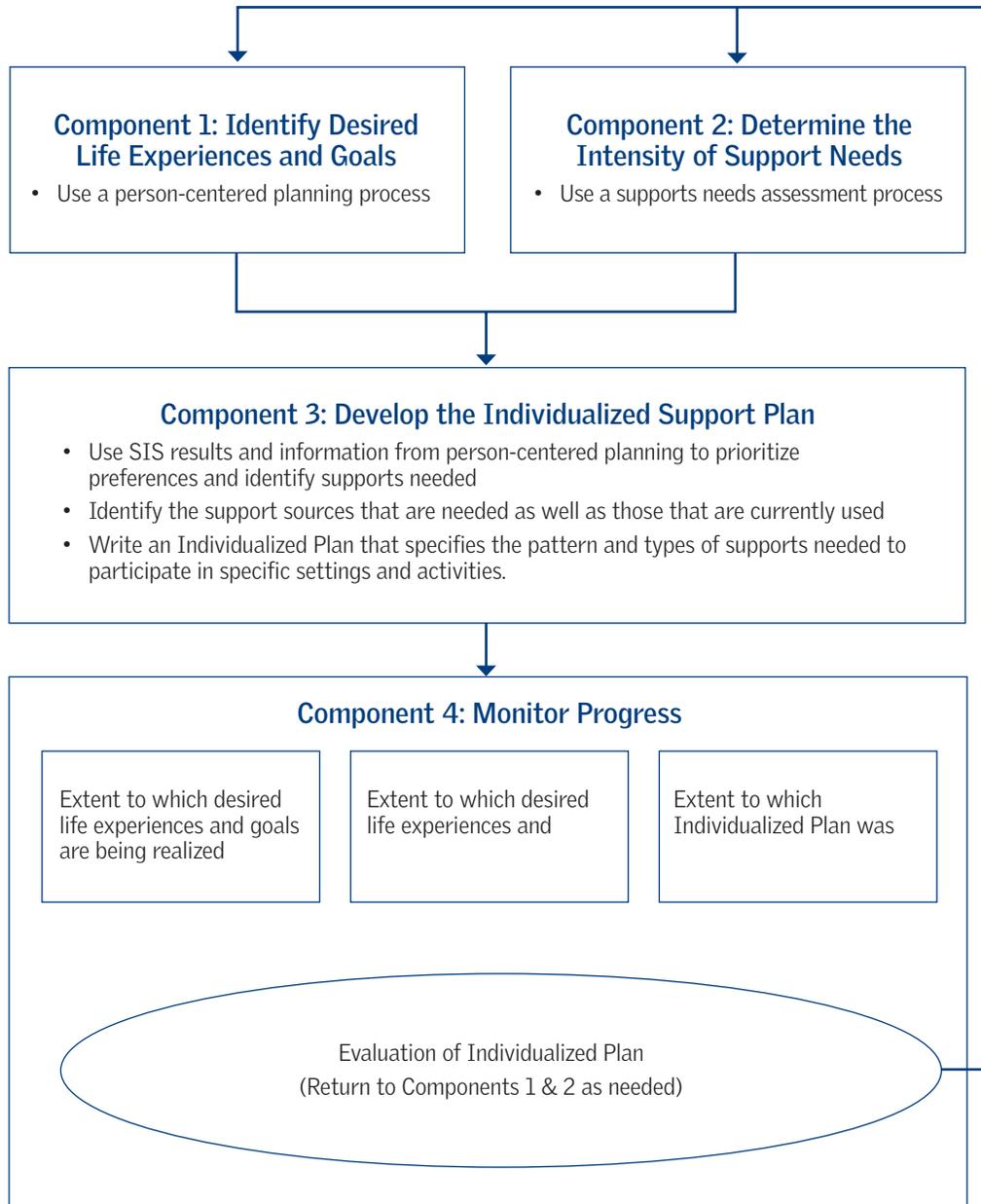
For purposes of illustration, here is some background information on Mel:

- He is a 36-year-old male with an IQ between the mild and moderate ranges. His adaptive behavior is in moderate range.
- His parents are getting older but are still very involved in his life and committed to his care and happiness. He also has siblings in the area who are very interested in his well-being.
- He has been living with four other men in a house in a residential neighborhood for the past 3 years.
- He displays some out-of-the-ordinary “autistic like” behaviors (e.g., self-stimulation, strange vocalizations), but these are not terribly problematic in that they are not overly distracting and people who know Mel get used to them.
- He is very trusting of others and takes an “I don’t see why not” attitude toward life when asked to do something, go somewhere, and so on.
- He works at a “sheltered workshop” type of program during the day.
- He enjoys routines: he comes home and rests, eats dinner, watches television, likes to go out to the mall, and so on, and is always ready for bed at 9:00 p.m.
- He enjoys going to see family; he visits his parents’ and siblings’ homes quite a bit and sometimes stays overnight.
- He enjoys eating. He can eat anything he wants without gaining weight, and his health is good.
- He is a bit indifferent to others. He is always pleasant but does not get very excited to see anyone.

Component 1

A person-centered planning process is needed to identify any discrepancies between an individual’s current life experiences and conditions and their preferred or desired life experiences and conditions. This process involves the consideration of the need

FIGURE 1
Four-component Support Needs Assessment, Planning, and Monitoring Process



Adapted from: Thompson et al. (2004, p. 79).

to maintain or change a person's life experiences as well as the prioritization of desired outcomes.

In Mel's case, the person-centered planning process identifies the following priorities: (a) to shift from working only at rehabilitation facility (sheltered workshop) to working for a community employer; (b) to start gardening and home decorating as a regular hobby; and (c) to maintain his current living arrangements. The privacy as well as the comradery with housemates that his current living situation provides are positive; also, his current living situation allows him to maintain close contact with his family, which is viewed as a high priority.

Component 2

The second component requires an assessment of support needs. Component 2 is accomplished in parallel with or shortly after person-centered planning (component 1). As Table 1 shows, Mel has a SIS Support Needs Index score of 111. He has relatively less intense support needs in the area of home living and relatively more intense support needs in the area of lifelong learning.

TABLE 1
Mel's support needs profile

%tile	Home Living	Community Living	Life Long Learning	Employment	Health & Safety	Social	SIS Support Needs Index	%tile
99	17-20	17-20	17-20	17-20	17-20	17-20	>131	99
	15-16	15-16	15-16	15-16	15-16	15-16	124-131	
90	14	14	14	14	14	14	120-123	90
	13	13	13	13	13	13	116-119	
80							113-115	80
	12	12	12	12	12	12	110-112	
70							111	70
		11						
60	11	11	11	11	11	11	105	60
	10						102-104	
50	10	10	10	10	10	10	100-101	50
							98-99	
40	9	9	9	9	9	9	97	40
							94-96	
30							92-93	30
	8	8	8	8	8	8	90-92	
20							88-89	20
	7	7	7	7	7	7	85-87	
10	6	6	6	6	6	6	82-84	10
	5	5	5	5	5	5	75-81	
1	1-4	1-4	1-4	1-4	1-4	1-4	<74	1

In examining SIS items related to areas of priority for change (employment and hobbies) for Mel, the following is evident:

- Based on information from the employment subscale, Mel is going to need more support in employment than most other individuals with intellectual and developmental disabilities.
- Completing work with acceptable speed and quality; coping with changes in job routines and assignments; and seeking information and assistance from an employer are areas where Mel will need the most intense supports.
- Mel's gardening and exploration of hobbies are going to require thoughtful support based on support needs identified in the community living, lifelong learning, and social subscales
- He is going to need very intense assistance if he participates in a community education or recreation class. A small-group setting (two to four people) is probably better than a large-group setting; he would need so much support in large groups that activities in such settings might be less meaningful.
- Communication skills will be a major barrier to Mel's participation in social activities.

Component 3

The third component requires the development of an individualized support plan in which the sources of support are identified based on a team process that considers personal priorities as well as practical issues such as finite resources. Information from components 1 and 2 inform the development of the plan. The plan should be "optimistically realistic" in the sense that it should be well thought through, workable, and action-oriented, focusing on the most important priorities. Here are the primary outcomes from Mel's ISP meeting:

- Mel should maintain his home life and connections with extended family. People in his house should continue to respect his desire for privacy and routines.
- Mel needs to start a part-time job in the community. A job developer on the planning team was aware of a hotel chain that needed maintenance help and pledged to assist Mel in exploring the possibility of working there. Wherever Mel eventually finds work, he will need to use picture prompting to help with communication.
- Residential direct support staff members are going to work with Mel on identifying gardening and home decorating opportunities each week that he can do alongside a support person. Additionally, staff members are going to explore different community leisure activities with Mel so he can try out a least two new things per month.
- The planning team will meet again in 60 days to evaluate the success of the plan.

Component 4

The component 4 entails follow-up and monitoring of an individual's quality of life and the implementation of the support plan. A key aspect of the fourth component is the planning team's examination of the progress that was made in assisting the individual in realizing the desired conditions and experiences that were specified during person-centered planning. Also, it is important for the planning team to determine whether the conditions and experiences originally specified as priorities should be maintained or revised. Finally, the team needs to assess the extent to which the support plan developed in component 3 was actually implemented.

Utilizing the Supports Intensity Scale with Direct Links to Individual Supports Planning

by Alan Tribble and Steve Wrigley

General Approach

Utah's Department of Human Services—Division of Services for People with Disabilities was among the first state programs to adopt the Supports Intensity Scale (SIS) as the primary assessment tool for people receiving supports through Medicaid waiver programs for people with intellectual disabilities, related conditions, and acquired brain injuries. Unlike other states that adopted SIS primarily for resource allocation, Utah's plan was to initially use SIS exclusively for individual supports planning. The *Supports Intensity Scale Users Manual* (Thompson et al., 2004) outlines a four-component assessment, planning, and monitoring process for ISPs utilizing SIS to determine the pattern and intensity of support needs (component 2) while relying on person-centered planning processes to identify desired life experiences and goals (component 1). Utah developed enhancements to the standard SISOnline to also address component 1.

In collaboration with AAIDD, SISOnline was modified to Utah's specifications, including the ability to mark each item as important *to* the person or important *for* the person and to add specific item notes. Section 4 was also added to SISOnline, providing additional risk screening items that were derived from a review of existing risk assessments used in other states and that we determined could be used to identify additional health and safety issues. A special report was developed that provides a separate list of all items marked as important *to* and *for* the person with notes and SIS item scores in addition to the standard information included in the SIS Scoring Form and Profile.

Balancing What Is Important *To* and *For* the Person

Relying on the work of Michael Smull, Utah adopted the planning goal of achieving a balance of what is important *to* the person and what is important *for* the person. The list of activities considered most important *to* and *for* provides information to assist in the identification of the unique interests and goals of the person as well as the identification of specific health and safety issues. The item selection process used in the development of SIS resulted in a broad sample of activities representing major life domains, so it was logical to use this as one of the methods to identify desired life experiences and goals as a component in the individual supports planning process.

Criteria for Importance *To* and *For* the Person

Before the annual planning meeting, SIS is administered using the standardized process for administration and scoring while simultaneously rating items as important *to* and *for* the person and adding notes as needed. The criterion for marking an item as

important *to* the person is that it must be an activity that the person tells us verbally or by their behavior is very important to his or her life. Such activities include the person's passions, values, interests, preferences, and personal goals. The criterion for marking an item as important *for* the person is that it is something we need to know to provide appropriate supports for the person. Such items include health and safety concerns as well as habilitation and training needs that are barriers to the person's desired life and are typically noted by others as important. Adding item notes is critical because we need to know specifically what about the activity is important. When rating an activity as important *to* and *for* the person, we do not limit the scope of the activity to the Expanded Item Descriptions: anything related to the activity may be rated as important *to* or *for* the person as long as it is explained in a note. Any item in SIS, including Section 4 that we added, may be indicated as important *to* or *for* the person; both *to* and *for* can be indicated for the same item; and items can be marked as neither *to* nor *for*.

The Role of the Support Team

Based on all available formal and informal assessments and sources of information, the support team adds to the important *to* or important *for* lists generated from SIS. This is a critical step, emphasizing the importance of using other assessment information and not relying solely on SIS. Because many of the same support team members involved in SIS are developing the supports plan, we are finding that SIS is an excellent tool for documenting information gleaned from other assessments, including informal methods such as just spending time with the person, which is highly valued in person-centered planning. After the *to* and *for* lists are complete, the items are categorized by the team according to how they will be used in the supports plan focusing on the identification of personal goals. The *to* items are each categorized as one of the following: (a) Important Information, which includes preferences, values, and things that are critical quality of life issues but are not goals for the person; (b) Future Goals; (c) Current Goals, which includes the personal goals that are the focus for the person at this time; and (d) Not Applicable, which indicates that the team has determined the item is no longer relevant or is something that does not need to be addressed at this time. The *for* items are each categorized as one of the following: (a) Important Information, which includes ways to successfully support the person but not issues that need to be addressed directly in supports and services; (b) In-the-Plan, which includes health, safety, and habilitation issues that need to be addressed in the ISP; and (c) Not Applicable, which indicates that the team has determined the item is no longer relevant or something that does not need to be addresses at this time.

The ISP Action Plan

Items categorized as Important Information and Future Goals are included in the ISP as part of a Person-Centered Profile to be used by people developing specific support strategies and by direct support staff. The *to* items categorized as Current Goals are used to develop personal goals that are the central focus of the ISP Action Plan. Other *to* items can also be addressed in the action plan because they may address quality of life issues not directly related to one of the personal goals. The "*for*" items categorized as In-the-Plan must be addressed somewhere in the ISP. Most of these issues are addressed as formal or informal action steps because they relate to addressing barriers to personal goals; however, they can also be addressed as non-goal-related supports or tied to broad waiver services covered by contracts that do not require detailed strategies.

Integrity Checks

To provide integrity checks in the system, all items categorized as Current Goals need to be addressed by a personal goal in the ISP, and all items categorized as In-the-Plan need to be addressed somewhere in the ISP Action Plan or tied to a specific service. All paid or waiver services must also be tied to a *for* item to document that it is a necessary service.

Web-based Case Management System

Utah has developed a Web-based case management system that electronically links SIS with the ISP. This allows SIS items marked as important *to* and *for* the person to be added to, categorized in, and written into the ISP in one fully integrated process. This not only maximizes efficiency but also ensures no data are lost or important issues unaccounted for.

Implementation to Date

Over the past two years, we have completed this enhanced version of SISOonline with all 4,000 consumers in our waiver program with approximately 150 state employee case managers as interviewers. Initially, *to* and *for* lists were used more informally in our existing ISP process; however, we have now transitioned to using the more comprehensive process outlined here. The direct link from assessment to plan has proven to be very beneficial in documenting good supports already in place, has expanded discussions to new activities previously not considered, and has helped us differentiate what is really important to each of our consumers from what others think is important for him or her.

The ability to use SIS standard scores and percentiles, information about a person's support needs on individual activities, *and* what people say is most important *to* and *for* him or her has resulted in a truly unique and powerful assessment tool. We have acknowledged our future interest in assessing SIS's role in resource allocations; however, initially focusing on the practical applications of SIS for supports planning rather than funding has reduced the pressure to prove scoring reliability and has provided the opportunity for stakeholders to see the positive benefits of SIS. Although we acknowledge that SIS is not a replacement for other person-centered assessment tools or processes, it has been shown to be an effective structured method to document what has been learned about the person, and most importantly it directly bridges the gap between assessing and planning.

Aligning Quality of Life Domains and Indicators with SIS Data

by Jos van Loon

Arduin, which is a service provider for persons with intellectual and developmental disabilities in the Netherlands, has a strong commitment to both the supports paradigm and the concept of quality of life. Over the last 3 years, Arduin has implemented the four-component process for the supports assessment, provision, and monitoring referenced in the *Supports Intensity Scale Users Manual* (Thompson et al., 2004, Figure 4.1, page 79) based on the person's identified desired life experiences and goals (component 1). They have also interfaced this four-component process with the assessment and evaluation of quality of life-related outcomes based on the eight core quality of life domains and indicators suggested by Schalock and Verdugo (2002) and validated in a number of cross-cultural studies (for example, Schalock et al., 2005). Additionally, they have stressed a quality improvement process by emphasizing a firm relationship between what is asked and needed, what is done, and an evaluation of the resulting outcomes. Thus, they have stressed a three-component logic program model: input, throughput, and output.

Input

The input is the goals and perspectives of the person, his or her support needs as assessed on the Supports Intensity Scale (SIS), and a current assessment of his or her quality of life. Personal values and aspirations determine the priorities of the individual and are referenced by core quality of life domains. The component 1 interview incorporates information from both SIS and a quality of life assessment instrument regarding the person's dreams, perspectives, and priorities. Specifically, the psychologist first does a structured interview with the person and his or her parents or relatives requesting information about the person's desired life experiences and goals. In this interview the person is asked on each domain of SIS (Sections I–III) what the present situation is, what he or she thinks about the present situation, and what his or her ideal situation would be. This is written in a form on the Internet program of the Regional Support Office (RSO). Thereafter, SIS is administered and scored electronically, with the primary respondents being the person and his or her family. The data from the interview and SIS are combined electronically to produce a report that gives an overview of the goals of a person and the supports that he or she needs to achieve those goals. This report is used by both the service provider and the RSO as the basis for the development and implementation of the person's ISP.

Throughput

The developed ISP sets out in detail which supports are given (and their priority) on which quality of life-related support areas. This process is depicted in Table 2.

Individualized supports are delivered through one or more of the following support strategies: personal empowerment, advocacy, skill training, environmental modification accommodation, assistive technology (i.e., prosthetics that reduce the mismatch between the person's capabilities and the environment's requirements), and personal assistance such as befriending, employee assistance, in-home living

TABLE 2
Key Components of an ISP Process (Arduin)

QOL domain	QOL domain indicators	SIS area	Goals on QOL indicators and/or SIS areas	Priorities	Individualized supports*
I. Emotional Well-being	1. Contentment 2. Self-concept 3. Lack of stress	<ul style="list-style-type: none"> • Health and safety • Protection and advocacy • Exceptional behavioral support needs 	1. 2. 3.		
II. Interpersonal Relations	4. Interactions 5. Relationships 6. Supports	<ul style="list-style-type: none"> • Social activities 	4. 5. 6.		
III. Material Well-being	7. Financial status 8. Employment 9. Housing	<ul style="list-style-type: none"> • Employment activities 	7. 8. 9.		
IV. Personal Development	10. Education 11. Personal Competence 12. Performance	<ul style="list-style-type: none"> • Home living activities • Lifelong learning 	10. 11. 12.		
V. Physical Well-being	13. Health and health care 14. Activities of daily living 15. Leisure	<ul style="list-style-type: none"> • Health and safety • Exceptional medical needs 	13. 14. 15.		
VI. Self-determination	16. Autonomy/personal control 17. Personal goals 18. Choices	<ul style="list-style-type: none"> • Protection and advocacy 	16. 17. 18.		
VII. Social Inclusion	19. Community integration and participation 20. Roles 21. Supports	<ul style="list-style-type: none"> • Community living activities • Social activities 	19. 20. 21.		
VIII. Rights	22. Human (respect, dignity, equality) 23. Legal	<ul style="list-style-type: none"> • Protection and advocacy • Health and safety 	22. 23.		

*These supports can be activities in the areas of personal empowerment, advocacy, skill training, environmental modification/accommodation, assistive technology (i.e., prosthetics that reduce the mismatch between the person's capabilities and the environment's requirements), and personal assistance such as befriending, employee assistance, in-home living assistance, transportation, and the provision of legal counsel.

assistance, transportation, and the provision of legal counsel. These support strategies, which are the basis of person-centered planning, can focus on either SIS-based activity areas and exceptional needs, one or more of the core indicators associated with each of the eight core quality of life domains, or both.

- Focusing on SIS-based activity areas and exceptional medical and behavioral support needs is accomplished best by incorporating the respective (and specific, as listed in SIS) life activity area(s) or exceptional medical or behavioral support

need(s) as specific objectives within the ISP. In the case of life activity areas, the goal is to enhance the identified activity; in the case of exceptional medical/behavioral support needs, the goal is to improve the individual's medical/behavioral functional status.

- Focusing on the indicators of each of the quality of life domains is best accomplished by providing support strategies to enhance the respective indicator. In this case, the goal is to improve the individual's status on the respective core indicator.

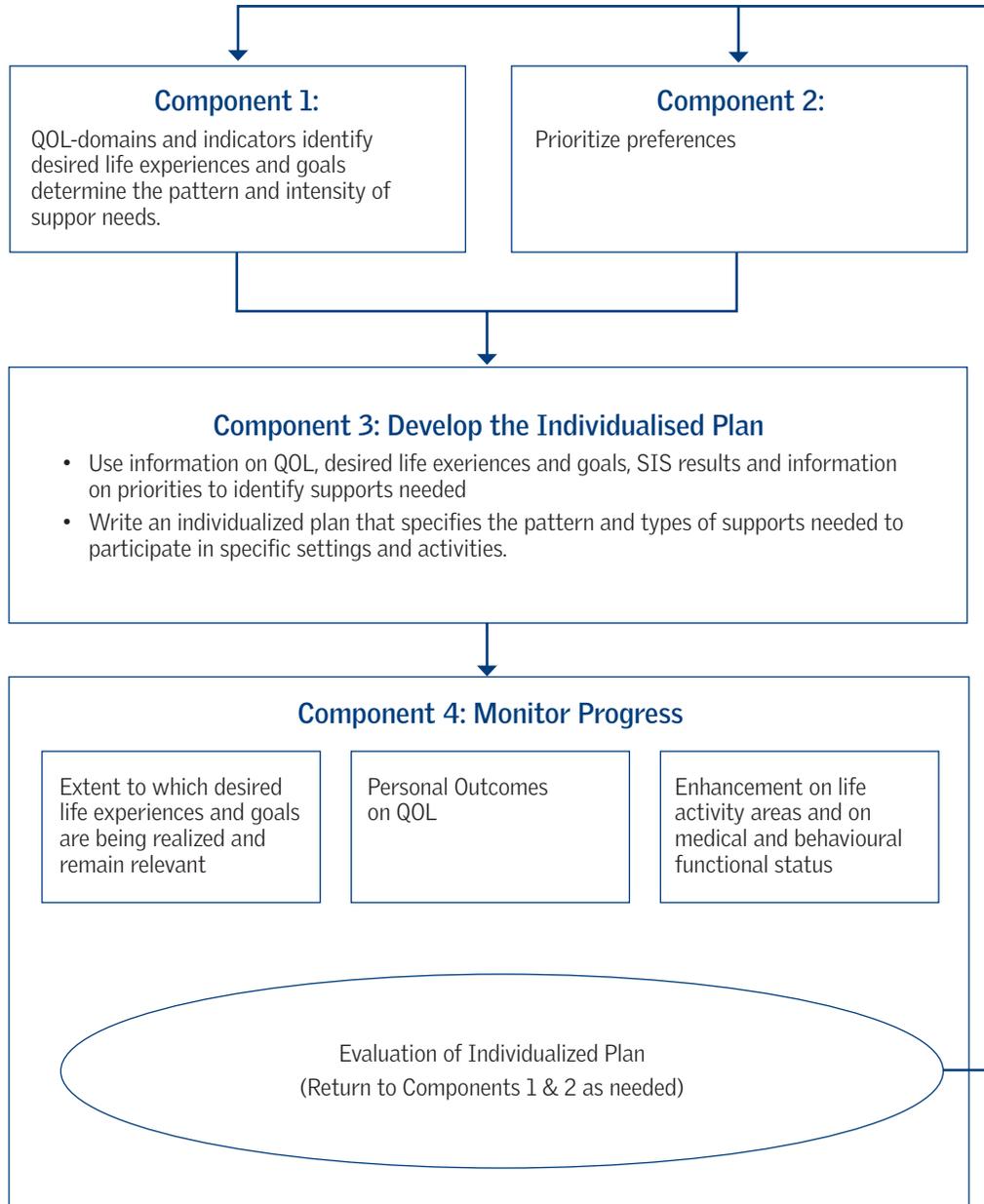
Based on the ISP process outlined in Table 2 Arduin has developed a computer program that generates an ISP after all the needed information is provided. In choosing the individualized supports provided, the person who writes the ISP is facilitated by being able to click on a database with a variety of methods.

Output

The outcome of an ISP for a person should be a better quality of life as measured on the basis of quality of life-related personal outcomes. Arduin and the University of Ghent are developing a Personal Outcome scale based on eight core quality of life domains. The new scale will replace the one currently used. Besides quality of life-related personal outcomes, improvement of the individual's medical or behavioral functional status is also an important outcome. These outcomes should be measured regularly and as part of a continuous process of quality improvement as shown in Figure 2, which is a slight modification to Figure 4.1 that is found in the *Supports Intensity Scale Users Manual* (Thompson et al., 2004, p. 79).

In summary, the alignment between SIS information, the individual's ISP, and personal, quality of life-related domains and outcomes creates an excellent opportunity to systematically support people in improving their quality of life. An important advantage for a service provider to aligning support needs and quality of life domains and outcomes is that it creates the conditions for a Management Information System in which the core business of the organization—to support people and to improve the quality of life of the persons it supports—is at the center.

FIGURE 2
Four-component Support Needs Assessment, Planning, and Monitoring Process (Arduin)



Stimulating Creative Planning with SIS

by James A. LeVelle, PhD, and Jan K. Ivey, LCSW

When planning individual supports, a great deal is expected of people with disabilities, plan facilitators, and the person's circle of support. This planning team is expected to recall large amounts of information about a person and then creatively form a meaningful support plan. The truth is that even the best planners, the most creative teams, and the most expressive people with disabilities can overlook important ideas that can improve a person's quality of life. However, there are many ways in which the Supports Intensity Scale (SIS) can facilitate the development of plans that are person-centered, complete, and creative. In general use, SIS provides important assessment information concerning a person's pattern and intensity of support needs that can be used to enhance person-centered planning. Additionally, SIS can be used to enhance planning by (a) identifying the person's preferred supports in relation to support needs that may be preferred by members of the planning team; (b) encouraging members to review SIS for support needs that may have been overlooked by the planning team; (c) directing team members to rethink support strategies that may have lost steam; and (d) stimulating team members to consider new ideas or activities.

Identify Preferred Supports

When conducting an interview using SIS, the interviewer has a great opportunity to ask participants whether an identified support need is a priority or preferred support to the person assessed or to members of the person's planning team. At times, a planning team prioritizes needs that are based on the concerns of team members, not the person receiving supports. This leads supports away from a person-centered perspective and weakens the value of the plan. For example, team members may prioritize bathing because a person is lax about his or her hygiene. However, if the person views social events as a priority, then supports necessary to participate in social events will be of greater value to the person. In this situation, the emphasis on social events could also help the person understand the social value of having good hygiene. This approach would be more meaningful to the person and is respectful of the person's right to make choices about his or her life.

Review for Missed Content

SIS can assist the planning team by prompting members to consider support needs across a broad range of life activities that can remind team members of areas in which a person may need support that could have otherwise been overlooked. In Louisiana, the importance of using SIS for this purpose became apparent when 20 individualized plans were randomly selected and then compared to SIS assessments conducted after the plans had been development. In all 20 plans, SIS identified support needs that would usually be important to a person but were not included in the plan. For example, one plan did not address the medical needs of a young woman with diabetes; another plan neglected to address needs associated with a man's desire for social activities; and another omitted transportation needs essential to participation in

activities that were identified in the plan. In each situation, SIS could have helped the planning team to create a more complete plan.

Rethink Past Supports

Reviewing items on SIS can prompt a planning team to rethink a person's support needs. This can be important in situations in which a person's needs have been addressed, but the planning team has become complacent about or desensitized to the importance of a person's support needs in a particular area. For example, a person may need physical assistance to take a bath because of difficulty getting into the bathtub or shower and the planning team has relegated this event to being "just" a routine support. By rehashing this support need, the planning team is more likely to consider alternatives such as purchasing a lift that could allow the person to bathe independently.

Stimulate New Ideas

Reviewing items on SIS can prompt members of the planning team to consider new support needs and activities that were not considered in the past. This goes beyond simply looking for needs that may have been overlooked. As different areas of life are discussed during the person-centered planning process, team members can review specific items and brainstorm ideas that may be attractive to the person. For example, one young woman with severe physical limitations was planning with her team and made some important discoveries: she and the team had never considered advocacy training because she found speaking difficult and did not like to use augmentative communications. However, after reviewing the Advocacy section of SIS, she became excited about what she could learn and the people she could meet, and soon the team was brainstorming possibilities. As a result, she enrolled in a state advocacy training workshop where she met new friends, learned new skills, and became a more active advocate for herself and her friends.

In conclusion, there are many ways in which SIS can be used to make ISPs more creative, more complete, and more meaningful to the person receiving supports. The results that can be achieved by taking a little extra time to be creative can mean the difference between a support plan that is simply functional and one that supports a rich life full of adventures.

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Useful Web Sites

Information on the Supports Intensity Scale www.siswebsite.org

Electronic *SIS Vantage* newsletter (Free sign-up)
..... <http://www.siswebsite.org/Newsletter/>

SIS presentation
..... <http://www.siswebsite.org/galleries/default-file/SISpresentation.pdf>

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