WhitePaper

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How Organizations and Systems Use Supports Intensity Scales

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Authors' Note

The purpose of this white paper is to describe how organizations and larger systems can use Supports Intensity Scale (SIS) information such as that obtained from the *Supports Intensity Scale—Adult Version (SIS—A)*™ and the *Supports Intensity Scale—Children's Version (SIS—C)*™ to enhance their effectiveness and efficiency. The material and exhibits in this paper describe and demonstrate how SIS information can be used to facilitate knowledge on demand, implement continuous quality improvement, align service delivery system components, determine whether an individual should be reevaluated prior to the recommended 3-year interval between SIS assessments, use SIS scores to inform subgroup classification, and provide information for research.

Five exhibits are incorporated into this white paper. These exhibits are provided by individuals and organizations that have used supports intensity information for the enhancement purposes listed above. We are indebted to the following contributors for their willingness to share their insight, creativity, and hard work.

- Exhibit A. A Knowledge Library
  - » Jos van Loon: Arduin Foundation, the Netherlands (jloon@arduin.nl)
  - » Kees Swart: Arduin Foundation, the Netherlands (kswart@arduin.nl)
- Exhibit B. Using SIS Information for Continuous Quality Improvement
  - » Tim Lee: CEO, Qi Zhi Vocational Training Center, Taipei (Taiwan): tim.lee@atcidd.org
- Exhibit C. Aligning Supports Planning Within a Quality of Life Framework
  - » Marco Lombardi: Ho Gent University (Belgium) and Catholic University of Sacred Heart (Italy): marco.lombardi@hogent.be
  - » Luigi Croci: President, ANFASS Scientific Committee (Italy) and Joint Professor, Child Neuropsychiatry, Catholic University (Brecia, Italy): Luigi.croci@unicatt.il
- Exhibit D. Annual Review Protocol (James R. Thompson, Karrie A. Shogren, Robert L. Schalock, Marc J. Tassé, and Michael L. Wehmeyer)
- Exhibit E. The Use of the *SIS—C* in Research Studies in Spain
  - » Miguel A. Verdugo, Professor, University of Salamanca-INICO-Spain (verdugo@usal.es)
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Introduction and Overview

The white papers published by AAIDD in 2008 (Buntinx, Cobigo, et al., 2008; Buntinx, Croce, et al., 2008; Fortune, et al. 2008; Ivey, et al., 2008) responded to the need of organizations and larger service delivery systems nationally and internationally to operationalize the supports paradigm through the standardized assessment of peoples' support needs, and to describe strategies for how the profile and intensity of an individual's support needs can be used for supports planning and resource allocation. Since 2008, the use of AAIDD's two Supports Intensity Scales (i.e., the adult version [*SIS—A*] and children's version [*SIS—C*]) by organizations and systems has been framed by two additional factors—the increased emphasis on evidence-informed decision making, and the need to enhance an organization or system's effectiveness and efficiency.

Thompson, Schalock, & Tassé (2018; in press) summarize the research evidence that establishes the *SIS—A* and *SIS—C* as psychometrically valid measurement tools that can be used for multiple purposes. Thompson, Schalock, & Tassé (2018), in "How Support Needs Can Be Used to Inform the Allocation of Resources and Funding Decisions," discuss considerations for using standardized support need assessment to inform the allocation of public funding and individualized budgeting. Schalock, Thompson, & Tassé (2018) describe changes in the field regarding personal support plans. In this white paper, we focus on how organizations and systems can use Supports Intensity Scales (SIS) to enhance their effectiveness and efficiency by: (a) facilitating knowledge on demand, (b) incorporating SIS information into continuous quality improvement, and (c) aligning service delivery system components. Additionally, this white paper describes an annual review protocol that can be used to determine whether an individual's support needs should be reassessed prior to the recommended 3-year time period, the potential use of support intensity scores to inform classification, and research involving the *SIS—A* and *SIS—C*.

Facilitating Knowledge on Demand

As used in this white paper, the term "knowledge on demand" refers to providing those involved in supports planning and implementation with ready access to the individual's pattern and intensity of support needs and to specific support strategies that can be used to enhance the individual's functioning and personal well-being. The need to facilitate knowledge on demand is directly related to three contextual factors impacting current service/ supports providers and the larger service delivery system. First, multiple people are often involved in providing supports to people with intellectual and developmental disabilities (IDD), and communication with a person's support team and network is essential (Noordegraaf, 2007; Reinders, 2008; Reinders & Schalock, 2014; Schalock & Verdugo, 2013). Second, support teams have emerged as the primary vehicle for planning, implementing, reviewing, and evaluating personal support plans (Schalock & Luckasson, 2014; Schalock & Verdugo, 2012). Third, the effectiveness and efficiency of support teams is enhanced through their empowerment and involvement in supports

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planning and implementation (Buntinx, 2008; Reinders & Schalock, 2014). These three contextual factors underscore the importance of readily available information (i.e., "knowledge on demand") regarding the individual's support needs and specific support strategies that address those needs. Examples of how the pattern and intensity of support needs based on SIS assessment information and the understanding of specific support strategies can be used in organizations and systems to facilitate knowledge on demand are described in the following section.

Pattern and Intensity of Support Needs

For users of SIS Online, a *Family Friendly Report* for each assessed individual is generated and provided to users for supports planning. For Section 2 of the *SIS—A* and *SIS—C,* activity area scores are rank-ordered on the basis of total scores. For Section 1A and 1B, the specific medical conditions or challenging behaviors are similarly rank ordered. This ranking identifies the specific items/conditions/behaviors that require the provision of ongoing supports. The Supports Need Profile figure provided as part of the *Family Friendly Report* clearly summarizes the profile and intensity of needed supports in specific life activity areas, providing a clear and understandable profile of the individual's needed supports. Finally, the *Family Friendly Report* summarizes how the information presented in the individual's profile can be used to inform supports planning. In addition, SIS Online users can customize their reports to provide additional knowledge on demand, such as providing answers to the supplemental questions, including interviewer notes, and creating different data field names. The *Family Friendly Report* is currently available in both English and Spanish for *SIS—A*.

Specific Support Strategies

Even when a support team has information from the SIS Online *Family Friendly Report* regarding the pattern and intensity of support needs, they often lack knowledge of—and ready access to—specific support strategies that they can align with specific support needs. Effective support strategies promote the development, independence, interests, and well-being of a person, and enhance the individual's functioning, participation within society, and engagement in life activities. By having ready access to what specific support strategies are, and their anticipated effect(s), support teams can align assessed support needs with specific support strategies and use this information as an essential part of supports planning and implementation.

In Table 1 we provide a summary of seven widely used specific support strategies, along with a description of their components and purpose. This table is based on the international Delphi work of Lombardi, Chu, Schalock, & Claes (2017).

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TABLE 1
Specific Support Strategies and Their Components and Purposes

Strategy	Components and Purpose
Natural Supports	Building and maintaining support networks (e.g., family, friends, peers, colleagues), and fostering self-advocacy, friendships, community involvement, and social engagement.
Technology	Using assistive and information devices to enhance an individual's ability to communicate, maintain health and well-being, and to function successfully within his or her environment. Examples include communication aids, smart phones, electronic tablets/devices, medication dispensing devices, medical alert monitors, and speech recognition devices.
Prosthetics	Providing sensory aids and motoric assistance devices that support the body to undertake functions it cannot. Examples include wheelchairs, robotic arms or legs, special glasses/visual aids, hearing aids, and orthotic devices.
Education Across the Lifespan	Developing new skills and behaviors through behavioral techniques (e.g., modeling, manipulation of antecedents and consequences), task analysis, and education and training strategies such as Universal Design for Learning.
Reasonable Accommodation	Ensuring physical accessibility of buildings, transport, and work spaces; creating secure and predictable environments; and providing physical and other accommodations that allow individuals to negotiate their environments and carry out daily tasks.
Dignity and Respect	Enhancing social role status through community involvement, equal opportunity, recognition, appreciation, financial security, honors, personal goal setting, empowerment, and control of an individual supports plan.
Personal Strengths/Assets	Facilitating individual preferences, personal goals and interests, choice and decision making, motivation, skills and knowledge, positive attitudes and expectations, self-management strategies, and self-advocacy skills.

The information presented in Table 1 can be provided on demand to support teams through a number of platforms. Exhibit A provides an example of how a large community-based supports provider in the Netherlands has provided specific support strategy information (i.e., knowledge on demand) via an information technology (IT)-based platform.

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Exhibit A
A Knowledge Library

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Overview

The Knowledge Library is an application filled with information on support strategies and interventions that is searchable via different IT platforms. Its application is person-centered and consistent with the individual's personal goals and assessed support needs. A knowledge library needs to: (a) be based on evidence-based support strategies; (b) reflect a logic model of input (i.e., the pattern and intensity of the person's support needs), throughput (i.e., elements of a system of supports), and outcome (i.e., measures of personal outcomes such as quality of life [QOL] domain scores; van Loon, van Hove, Schalock, & Claes, 2008); and (c) implemented within a values-based framework such as that provided by the United Nations Convention on the Rights of Persons With Disabilities (Verdugo, Navas, Gomez, & Schalock, 2012).

The Knowledge Library

Example Content

Table 2 provides an example of how the Knowledge Library is formatted. The example is built around two (of eight) quality of life domains that are used frequently as personal support plan outcome categories: social inclusion and emotional well-being. As depicted in Table 2, each quality of life domain is related to components of a system of supports, exemplary support strategies, and anticipated effects.

Application

While all the support strategies listed in Table 1 have an evidence base, they should be implemented for the individual only after critical consideration/validation by a team of experts. The system has a structure of four components: the eight QOL domains; a list of of supports; a list of anticipated effects; and a table with the support strategies that also includes citations, URLs, and explanatory notes.

Teams of Experts

Several teams of experts are involved in developing a Knowledge Library. Each team has expertise on certain support profiles, such as people with multiple profound disabilities, elderly people with IDD, adults with IDD and challenging behavior, and children with IDD. These teams have several tasks, including searching for adequate support strategies, evaluating published support strategies, framing these support strategies in the model for

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evidence-based supports and interventions in a support methodology described in the Overview, putting these in the library, and evaluating the application.

Filling the Library with Support Strategies

After evaluation by the experts, the relevant citation and URLs are inserted into the system and marked with: (a) anticipated effect of this strategy (selecting a list of expected effects), (b) suitable components of the system of supports (selecting from a list), and (c) QOL domain(s) (selecting from a list). The explanatory notes are written according to the model for evidence-based supports and interventions in a support methodology by stating the underlying values and the environmental conditions that need to be met.

Using the Knowledge Library

The Knowledge Library is meant to be the first resource for staff responsible for the development of a personal support plan. If they are in communication with the person and use the SIS (Thompson et al. 2004), they know what the person wants in his or her life, what their life goals are, and their support needs. And if they use an outcome measurement like The Personal Outcomes Scale (van Loon, et al., 2008), they know about the person's quality of life. To enhance the QOL of the person, the user can search for support strategies within QOL domains, within the components of the system of supports, and those best aligned with the anticipated effects (goals important *to* and *for* the person). An important feature here is the framing of these support strategies in the model for evidence-based supports and interventions in the support methodology previously outlined, which makes this library more than a mere overview of methods and interventions.

The system interface also allows the user to search and filter the library contents with a search phrase, anticipated effect, system of support, and QOL domain. This means that every query result can be refined using these four parameters. The explanatory notes, shown by the search results, offer the ability to determine the usability of the support strategy by recognizing the stated values as important to the individual and the environmental conditions that need to be in place.

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TABLE 2
Interventions Aligned to the QOL Domains of Social Inclusion and Emotional Well-Being

QOL Domain	Related Components of a System of Supports	Exemplary Support Strategies	Anticipated Effects
Social Inclusion	Natural supports Reasonable accommodation Professional services	Access/interface with natural supports Ensuring physical accessibility of buildings, transport, and work spaces; creating secure and predictable environments; and providing physical and other accommodations that allow individuals to negotiate their environment and carry out daily tasks Use of social media Facilitate transportation Use prosthetics (sensory or motor devices) Active support	• Increased community access, participation, and involvement • Enhanced personal development, community living, integrated employment • Increased social inclusion, interpersonal relations, social-emotional well-being • Make sure that people who need support have the chance to be fully involved in their lives and receive the right range and level of support to be successful
Emotional Well-Being	Natural supports Professional services Dignity and respect	Building and maintaining support networks Provide safe and predictable environments Access professional services Maximize incentives (e.g., rewards, opportunities to be successful) Use positive behavioral supports Gentle teaching Enhancing social role status through community involvement, equal opportunity, recognition, appreciation, financial security, honors, personal goal setting, empowerment, and control of an individual supports plan	• Reduce fear and anxiety • Increase motivation and satisfaction • Reduce challenging behaviors and increase positive interactions • Maximize mental/behavioral health • Increased motivation and achievement • Safety, security, engagement, being unconditionally valued

Note. QOL = Quality of Life

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Incorporating SIS Information Into Continuous Quality Improvement

For those organizations that engage in continuous quality improvement (CQI) to enhance their effectiveness and efficiency, SIS data can be incorporated into the CQI process. As discussed by Lee (2016) and Schalock et al. (2014), CQI: (a) is an internal, collaborative, and transformative process that involves a Plan-Do-Check-Act cycle; (b) focuses on enhancing personal outcomes and increasing an organization/system's effectiveness and efficiency; (c) combines the emphasis on effectiveness and efficiency of a business mindset with the values and mission of not-for-profit organizations; (d) is a parallel process at the individual, organization, and system level; and (e) incorporates best practices based on information obtained from credible sources that used reliable and valid methods and/or information based on a clearly articulated and empirically supported theory or rationale. A description of how SIS information is incorporated into CQI is presented in Exhibit B.

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Exhibit B
Using SIS Information for Continuous Quality Improvement

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What Is Continuous Quality Improvement (CQI)?

Continuous quality improvement (CQI) is a system of thinking, principles, and approaches. At the center of a CQI system is the Deming Cycle, also known as the Plan-Do-Check-Act Cycle (PDCA). The cycle and its components are shown in the following figure.

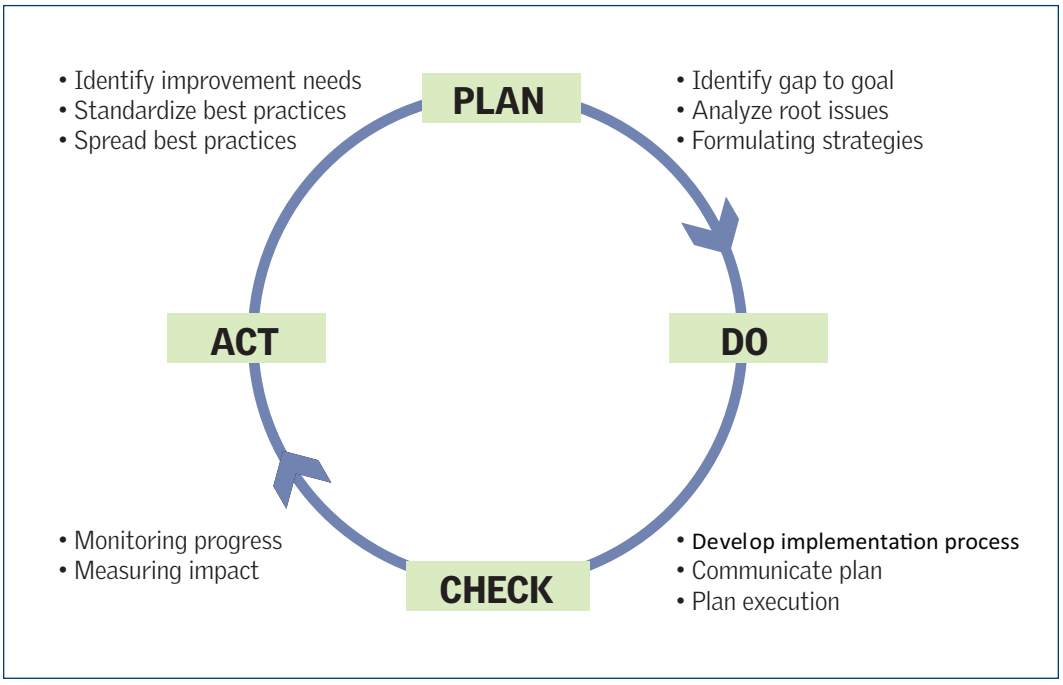

Figure 1. **The Plan-Do-Check-Act (PDCA) cycle and its components.**

The Importance of CQI at Qi Zhi Vocational Training Center

In order to reap the benefit of CQI and the core PDCA process, this system of thinking and doing needs to saturate an organization on three levels: the customer level (continuous improvement of client's quality of life), the team level (continuous improvement of team performance), and the organization level (continuous

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improvement of organization effectiveness and efficiency). The SIS plays an important role in all three levels. On the customer level, the SIS provides the basis for supports strategies that improve the clients' quality of life. On the team level, the SIS scores and data from the evaluation of the effectiveness of SIS-based supports strategies allow the team to best utilize their limited resources and improve team performance. On the organization level, aggregate SIS scores and data from related supports strategies provide insightful information that aid in organizational-level decisions on how to create more customer impact and organizational growth, be more financially efficient, and have less operational waste.

SIS as an Integral Part of Improving Clients' Quality of Life

PDCA is the foundational process of providing supports to a client and improving his or her quality of life, and SIS is an integral part of the quality of life improvement process. The key is that each of the SIS items are aligned with a specific quality of life domain, which include—personal development, self-determination, interpersonal relationships, social inclusion, rights, emotional well-being, physical well-being, and material well-being. Table 3 summarizes how SIS information is used in the CQI process to improve clients' quality of life.

TABLE 3
Using the SIS in the CQI Process

	Process	Timing/Frequency	Purpose	Role of SIS
PLAN	Personal Outcome Scale interview	Annual	Assessment of individual's current quality of life	Each item of the SIS is associated with a specific domain of quality of life
	Supports Intensity Scale interview	Every 3 years or major life change	Assessment of individual's support needs	Assessment tool
	Goals and dreams interview	Annual	Identify personal goals and dreams that are important to him or her	The most important goal and supporting objectives are aligned with specific quality of life domains and SIS items
	Develop individual supports plan (ISP)	Annual	Formulating supports strategies based on assessed needs and personal goals	Each support strategy is based on a specific SIS item and score

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	Process	Timing/Frequency	Purpose	Role of SIS
DO	Visually communicate supports plan	As needed	Use clear and easy to understand charts and pictures to communicate supports plan to all relevant stakeholders	SIS items provide information on support type and frequency
	Implement supports	As needed	Implement supports strategies and procedures	SIS items-based supports strategies provide information on support type and frequency
	Track support plan implementation	As needed	Track and record support plan implementation progress	Provides data on the effectiveness of each SIS item-based supports strategy and status of their implementation
CHECK	Monitor support implementation	As needed, at least monthly	Monitor whether support is provided according to plan	
	Personal Outcome Scale interview	Annual	Assessment of individual's quality of life after receiving support services.	Each item of the SIS is associated with a specific domain of quality of life
	Evaluate support strategies	As needed, at least quarterly	Evaluate effectiveness of support strategies	Tracks information on whether a support strategy that is associated with a specific SIS item is effective
ACT	Identify major improvement needs	Annual	Identify major quality of life improvement needs based on quality of life domains and related SIS items	Identify important quality of life domains and related SIS items
	Share effective strategies	Annual	Record effective strategies and procedures in to organization implicit and explicit knowledge base	Build knowledge of effective SIS items based support strategies
	Start PDCA cycle again	Annual	Go to the Plan stage of the PDCA cycle and start the process again.	

Note. SIS = Supports Intensity Scales; CQI = continuous quality improvement; PDCA = Plan-Do-Check-Act.

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SIS as an Integral Part of Improving Team Performance

SIS scores, associated support strategies, and related aggregate data provide valuable information that allow direct support teams to increase their impact and performance over time. Direct support teams can utilize SIS items-based data and adjust their supports strategy and refocus their efforts on the high impact approaches. Table 4 details some of the ways SIS items-based data can be used to improve team performance, though the process covers much broader application of the PDCA process.

TABLE 4
Using SIS Data to Improve Team Performance

	Process	Timing/ Frequency	Purpose	Role of SIS
PLAN	Identify short-term support team targets	Weekly to quarterly	Identify team's short-term goals and targets as the team members tackle their work responsibilities	May involve SIS items-based support strategy goals to be implemented
	Identify ineffective action steps or barriers to targets	Weekly to quarterly	Identify and analyze root causes of ineffective action steps and barriers to team goals	May involve SIS items-based support strategy implementation details to be implemented
	Develop specific action plans	Weekly to quarterly	Develop specific action steps and tasks based on strategies in goal and growth plans	May involve team actions required for specific SIS items-based support strategies
DO	Visually communicate action plans	Weekly to quarterly	Use clear and easy to understand charts and pictures to communicate action plans with team members and foster mutual support and accountability	Communicate actions related to implementation of SIS items-based strategies
	Implement action plans	Weekly to quarterly	Implement personal and team goal and growth action steps	Implement actions related to implementation of SIS items-based strategies
	Track plan implementation	As needed	Track and record goal and growth action steps implementation progress	Track progress related to implementation of SIS items-based strategies

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	Process	Timing/ Frequency	Purpose	Role of SIS
CHECK	Monitor goal and growth plan implementation	Weekly to quarterly	Monitor whether plans are implemented and supported	May need to monitor actions related to implementation of SIS items-based strategies
	Evaluate strategies and action steps	Weekly to quarterly	Evaluate whether particular strategy and/ or action is effective in reaching personal and team goals and targets	May need to evaluate whether SIS items-based strategies are effective
ACT	Identify ineffective strategies, processes, and barriers to goals	Weekly to quarterly	Identify ineffective strategies, processes, and barriers to goals that require immediate adjustment	Identify ineffective SIS items-based strategies
	Share effective strategies	Weekly to quarterly	Record effective strategies and procedures into organization's implicit and explicit knowledge base	Record effective SIS items-based strategies and incorporate into team know-how
	Start the PDCA cycle again	Weekly to quarterly	Go to the Plan stage of the PDCA cycle and start the process again	

Note. SIS = Supports Intensity Scales; PDCA = Plan-Do-Check-Act.

SIS as an Integral Part of Improving Organizational Effectiveness and Efficiency

Although not discussed in this exhibit, aggregated SIS scores and information on associated support strategies can also provide valuable insights that allow management teams to make decisions that increase organizational performance over time. Management teams can utilize SIS items-based aggregate data to better allocate resources, streamline processes, develop high impact programs, and better serve the customers. In this process, the plan-do-check-act components are used analogously to their use in the above two charts.

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Aligning Service Delivery Components for Increased Effectiveness and Efficiency

Alignment involves placing or bringing critical organization- and system-level functions into the logical sequence of inputs, throughputs, outputs, and outcomes. By using these four logic model components, organizations and systems become more effective and efficient in integrating and synthesizing considerable information obtained from the assessment of support needs (Schalock & Verdugo, 2012; Thompson, Schalock, Agosta, Teninty, & Fortune, 2014; Verdugo, Jenaaro, Calvo, & Navas, 2017).

The challenge faced by organizations and systems who want to use SIS and support-related information in the alignment process is to integrate assessed support need information with specific support strategies both horizontally (i.e., across input, throughput, output, and outcome components) and vertically (i.e., across the system, organization, and individual). Since SIS and support-related information is applicable primarily at the "input" and "throughput" component levels, Table 5 summarizes how service delivery components can be aligned vertically across the system, organization, and individual, and horizontally across input and throughput components.

TABLE 5
Aligning Service Delivery Components

Alignment Component	Input Component	Throughput Component
System	• Policies consistent with person-centered planning and the supports paradigm • Standardized assessment of support needs • Resource allocation based in part on the pattern and intensity of assessed support needs	• Service delivery framework that aligns support need data with support planning, implementation, review, and evaluation
Organization	• Policies consistent with person-centered planning and the supports paradigm • Use of data resulting from the standardized assessment of support needs for supports planning and implementation and support team training	• Use of support teams who incorporate person-centered planning and the supports paradigm into personal support plans • Resources devoted to implementing individualized support strategies; creating environments that enhance growth, development, and inclusion; reducing the mismatch between what is an what can be; and enhancing personal goals
Individual	• Assessment of support needs • Identification of personal goals	• Receipt of individualized supports based on prioritized personal goals and support needs that are important both to and for the individual

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Aligning a service delivery system both vertically and horizontally is an essential technique in systems-level planning, especially for those jurisdictions that want to integrate the supports paradigm with outcomes evaluation. Both organizations and systems are increasingly expected to evaluate the results of the services and supports they provide. Doing so requires not just aligning input, throughput, output, and outcome components, but also identifying, defining, and quantifying the specific support strategies employed and the personal outcomes assessed.

Two outcome frameworks commonly used in developing personal support plans are life activity areas (such as those assessed on the *SIS—A* and *SIS—C*) and quality of life domains. Exhibit 3 describes the approach used in Italy to align supports planning that includes using SIS data within a quality of life framework. The input and throughput matrices presented in Figures 2 and 3 are complimentary to the alignment activities summarized in Table 5.

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Exhibit #C
Aligning Supports Planning Within a Quality of Life Outcomes Framework

Marco Lombardi and Luigi Croce

Overview

Information from the SIS is employed by service providers throughout Italy as a major component in aligning supports planning within a quality of life framework. The approach is described here using two matrices that help organizations integrate a significant amount of information that impacts the development and monitoring of personal support plans. Figure 1 is an *ecological matrix* that provides the framework for aligning significant input factors (referred to as "input categories" in Figure 1) to quality of life domains. Figure 2 is a *support matrix* that provides the framework for aligning support objectives and strategies to the same eight quality of life domains. Major aspects of each matrix are described in the following section.

Input Matrix (Figure 2): From Assessment to Support Objectives

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Input Matrix: From Assessment to Support Objectives (INP-UT)

Input categories	Input variables	Quality of Life Domains							
		PWB	MWB	EWB	SD	PD	SI	IR	RE
What is important *to* the Person?	Personal Goals and Preferences General								
	Personal Goals and Preferences Specific								
What is important *for* the Person?	1. Home living								
	2. Community living								
	3. Life-long Learning								
Support Needs Items	4. Occupancy								
	5. Health and Safety								
	6. Social								
	7. Protection and Advocacy								
	8. Medical excp.								
	9. Behavioral excp.								
Intell. Abil. Adapt. Behav. Participation Inclusion	Functioning strengths								
	Functioning limitations								
Health	Physical Health								
	Mental Health								
Context	Facilitators								
	Barriers								
QOL level	QOL profile								
	Support Objectives								

Figure 2. Example of a simplified version of an Ecological Matrix. Each cell at the cross point between a specific quality of life (QOL) domain (PWB = physical well-being, MWB = material well-being, EMB = emotional well-being, SD = self-determination, PD = personal development, SI = social inclusion, IR = interpersonal relations, and RE = rights) and an ecological variable, identifies a classified information. That is the value of the specific ecological variable relevant and to be integrated to define specific support objectives. An electronic version of the Ecological Matrix is the core of the software "Matrici Ecologiche"® (Consorzio La Rosa Blu, 2017) used in the ANFFAS services.

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Important TO the Person

An interview in a conversational format is conducted with the client that focuses on their desired supports. General questions are asked of the person regarding the main support areas and which supports are valued as *important to* the individual. The support needs explored in the conversation are global goals in the these areas: relationships, home living, community living, education/training, employment, health and safety, behavior, social, and protection and advocacy. The interview can integrate material from the newly developed instrument, *A Guide for Planning Teams* (Thompson et al., 2017). The dialogue is framed and structured using quality-of-life items related to these eight domains: physical well-being (PWB), material well-being (MWB), emotional well-being (EMB), self-determination (SD), personal development (PD), social inclusion (SI), interpersonal relations (IR), and rights (RE).

Important FOR the Person

The support needs information collected using the SIS greatly contributes to the comprehension of what is important *for* the person. Having a standardized score for each support area (relationships, home living, community living, education/training, employment, health and safety, behavior, social, and protection and advocacy) gives a clear idea of the pattern and intensity of supports that a person needs to fulfill the demands of typical life activities. The reader is referred to Shalock, Thompson, & Tassé (2018) for a description of the alignment of SIS items to quality of life domains.

Description of Functioning

The individual's functioning is described to have a more complete understanding of the person and their ecological context. Having a picture of the different components (intellectual abilities, adaptive behavior, participation, health, and context) and their composition, in terms of strength and limitations or barriers and facilitators, is an important point to identify supports. This is accomplished by asking which supports are needed to bridge the gap between the user's actual functioning and the current demands of their environment. A standardized assessment instrument may be used to quantify the individual's current, actual functioning in these domains.

Quality-of-Life Profile

As depicted in Figure 2, the input information described above is organized around the eight quality-of-life domains previously described.

This great amount of information, typical of every individual supports plan (ISP), is collected in just one file called the" Ecological Matrix." This approach permits users to visualize all the relevant information in just one page: information relating to what is important to and for the individual, the supports needed, the description of the individual's functioning, and the actual quality-of-life profile of the person. Ecological balancing is accomplished by giving priority to those areas reflecting the person's goals and relevant supports for inclusive environmental participation.

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ISP Related Activities	QoL Domains	PWB	MWB	EWB	SD	PD	IR	SI	RE
Time ↓	Support Objectives								
	Indicators								
	Monitoring instruments								
	Support strategies								
	1. Natural supports								
	2. Technology								
	3. Prosthetics								
	4. Education across the lifespan								
	5. Reasonable accommodations								
	6. Dignity and respect								
	7. Personal strengths/assets								
	8. Professional services								

Figure 3. **Example of a simplified version of a Support Matrix; the domain (PWB = physical well-being, MWB = material well-being, EMB = emotional well-being, SD = self-determination, PD = personal development, SI = social inclusion, IR = interpersonal relations, and RE = rights) rows give a topographic criterion to embed specific categorized supports along the columns below. Any column accommodates the coordinated series of supports invested to improve QOL in that specific domain. An extended version of the Support Matrix is part of the software "Matrici Ecologiche"® (Consorzio La Rosa Blu, 2017) used in the ANFFAS services. ISP = individual supports plan.**

Support Objectives

The case manager, in collaboration with the individual and their team, defines the object of the intervention and the intended result. It is important that an optimistic and realistic plan of action is designed and implemented. This process is facilitated by using an action verb associated with an intended result from using the respective support strategy (see Shalock, Thompson, & Tassé [2018] Table 6 for examples). An operational definition increases the chances of having an optimally evaluable objective and a clear intervention focus for the supports provided. As the final step of this process, support objectives are associated with specific quality-of-life domains.

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Choose the Appropriate Support Strategies

The possible strategies to implement the support objectives include: natural supports, technology, prosthetics, education across the lifespan, reasonable accommodations, dignity and respect, personal strengths/assets, and professional services (Lombardi et al., 2017). The respective support strategies are then aligned with the quality-of-life domain.

There is a third component of the alignment process used in Italy, the evaluation of QOL-related outcomes that are anticipated to be enhanced with the input and throughput alignment processes summarized in Figures 2 and 3. The output process is realized by monitoring support implementation and support provision.

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SIS—A Annual Review Protocol

Information from a supports need assessment must reflect the reality of a person's current needs. Although a supports needs assessment scale can possess outstanding psychometric properties regarding its reliability and validity, changes in people's life circumstances and functioning might result in changes in their support needs since their prior assessment. Support needs are stable over time, but certainly not fixed.

Research findings strongly support the stability of *SIS—A* scores over the 3-year interval that has become the standard practice for reassessment in North America (Shogren, Thompson, Shaw, Grandfield, & Hagiwara, in press). Therefore, for most people, a reassessment every 3 years will be sufficient to assure the currency of their *SIS—A* assessment results. There is no way of knowing, however, if that re-assessment window is adequate to detect changes in support needs for any one individual. There are events in the lives of everyone, including people with IDD, that might trigger important, even sudden. changes in support needs.

Because of the importance of maintaining current assessment information, Thompson, Shogren, Schalock, Tassé, & Wehmeyer (2017; see also Thompson, Shogren, Seo, Wehmeyer, & Lang, 2016) created the *SIS—A Annual Review Protocol* to guide planning teams in evaluating the possibility that a person's support needs might have changed since their last assessment. The *Annual Review Protocol* is described in Exhibit D. Upon completion, support teams make the decision to pursue reassessment (because they believe a person's intensity of support needs may have changed) or conclude that a person's support needs are not meaningfully different than when previously assessed.

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Exhibit # D
Annual Review Protocol

There are four sections to the *SIS—A Annual Review Protocol*. Each section is completed by a reviewer in consultation with at least two respondents who know well the person being assessed. The critical question asked and answered in each section is, "Have there been meaningful changes since the last *SIS—A* assessment was completed?" The focus of Section 1 is on identifying whether the person may have experienced changes due to significant life events. In Sections 2 and 3, the focus is on whether the person has experienced significant changes due to changing health or behavior concerns. In Section 4, the reviewers are asked to consider if there have been changes in 21 *SIS—A* items since the prior *SIS—A* assessment. Through extensive statistical analyses (Thompson et al., 2016), these 21 items have been shown to be the best subset of items to understand the support need domains measured on the full version of the *SIS—A*.

Table 6 provides an overview of the *Annual Review Protocol*, including its major sections and their respective focus, the scoring metric used in reference to each section, and exemplary life events (Section 1) or SIS life activity items (Section 4) used to assess whether meaningful changes have occurred in the person's life since the last *SIS—A* assessment was completed.

TABLE 6
Overview of the *SIS—A* Annual Review Protocol

Section Number, Focus, and Scoring Metric	Exemplary Life Events (Section 1) or *SIS—A* Life Activity Items (Section 4)
1. Life event changes: Yes/no	• Loss of parent, spouse, or other close loved one • Changes in residential status • Involvement with the criminal justice system • Retirement
2. Medical issues: Yes/no	
3. Challenging behavior issues: Yes/no	
4. Life activity areas: Yes/no	• Housekeeping and cleaning • Interacting with community members • Learning and using problem-solving strategies • Taking medications • Maintaining a nutritious diet • Making and keeping friends • Protecting self from exploitation

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An Annual Review Summary is completed by the reviewer after the team has scored Sections 1-4. The summary specifies whether the pattern and intensity of this person's support needs (a) have not meaningfully changed since the prior *SIS—A* assessment or (b) may have changed in important ways since the prior *SIS—A* assessment.

> When the *Annual Review Summary* indicates that a person has experienced changes in the pattern and/or intensity of his or her support needs since the last *SIS—A* assessment, protocol users (e.g., service providers, jurisdictional decision makers) should consider a number of actions, including case review, re-administration of the full *SIS—A*, and/or conducting or accessing other broad-based clinical assessments.

For more information consult: Thompson, J. R., Shogren, K. A., Schalock, R. L., Tassé, M. J., & Wehmeyer M. L. (2017). *SIS—A Annual Review Protocol*. Washington, DC: American Association on Intellectual and Developmental Disabilities. (Product No. 357).

Classification Based on an Individual's Intensity of Support Needs

How an individual with intellectual disability (ID) is classified involves high-stake decisions about these persons and their families. What's at stake for these individuals is an improved understanding of the person; rationally linking subgroup classification to important actions such as planning supports, research, and outcomes evaluation; communication; fairness; and the equitable distribution of resources (Luckasson & Schalock, 2013). A classification system also affects the approach the field takes to answering the basic question in classification: How the total group that was defined as "in" the category (i.e., diagnosed as an individual with ID) is now to be subdivided or categorized into smaller groups on the basis of criteria that are relevant to a specific purpose?

As discussed by Schalock and Luckasson (2015), a classification system should be aligned with a clearly stated purpose, result from a logical and sequential series of steps, allow for multiple classification subgroups, and be useful to the individual. The availability of standardized supports need intensity scores such as those provided on the *SIS—A* and *SIS—C* permits an evidence-informed approach to classifying the level of an individual's support needs. Such an approach is consistent with the supports paradigm and a supports-based service delivery system. In reference to classifying on the basis of intensity of support needs, a systematic approach to subgroup classification involves specifying:

- *The purpose of classification*: Determining individual budget allocations, matching needs with resources, research, and outcomes evaluation.
- *What is to be classified* (i.e., the classification element): The intensity of support needs.
- *The information required for classification*: Standardized support intensity scale scores.
- *The specific terms used to categorize subgrouping*: Examples include support needs, substantial support needs, very substantial support needs (American Psychiatric Association, 2013, p. 52); mild, moderate, substantial, pervasive (Schalock & Luckasson, 2015).

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If jurisdictions use SIS scaled scores as a part of their resource allocation formula, this systematic approach to subgroup classification is not inconsistent with the methodology described in Thompson et al., (2018)regarding resource allocation or the approach described in Thompson et al. (2014, pp. 93–95) to arrange preferred supports while applying disciplined fiscal management strategies. Using SIS-based data for subgroup classification is an evolving methodology. For example, current work is being done to empirically derive clusters of support needs that can be used to inform/generate subgroup classification (e.g., Shogren,Tassé et al., 2017).

Research Involving the *SIS—A* and *SIS—C*

To date, about 28% of the articles published using SIS data can be classified as addressing the measurement of support needs. This compares with 43% focusing on evaluating psychometric properties, 7% on assessing support needs, 7% on supports planning, and 15% on resource allocation. These studies about measurement of support needs (i.e., the 28%) have dealt with support needs and adaptive behavior, the impact of medical and behavioral support needs on community living, SIS scores vs. care weights, rater bias, the use of *SIS—A* with persons with severe mental illness, and translation and cultural adaptations. In the following exhibit, the authors discuss two lines of research in Spain in which scores from the *SIS—C* were used to compare support needs of students with and without ID, and to determine the support needs of children with cerebral palsy (CP) or autism spectrum disorder (ASD).

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Exhibit E
The Use of the *SIS—C* in Research Studies in Spain

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The *SIS—C* (Thompson et al., 2016) has been rigorously developed in Spain following the seven-step procedure proposed by Tassé and Craig (1999). Research to date on the *SIS—C* has obtained several evidences of the scale's validity and reliability (see for example Verdugo, Arias, & Guillen, in press; Verdugo et al., 2016; and Verdugo, Guillen, Arias, Vicente, & Badia, 2016). In this exhibit we summarize and discuss research we have conducted comparing support needs of students with and without ID in compulsory education, and determining support needs of children with CP or ASD.

Comparing Support Needs of Students With and Without Intellectual Disability

One of the applied contexts of *SIS—C* use is the educational system. In Spain, the education of students with ID is ensured by the Organic Law on the Improvement of Quality of Education, based on the principles of normalization and inclusion, the least restrictive environments, and the United Nation's Convention on the Rights of Persons With Disabilities (CRPD).

Using the *SIS—C* in Spanish schools has required research regarding the distinction between common and extraordinary support needs, because schools are places where both students with common development and students with ID attend. Thus, it has been necessary to compare and differentiate the support needs of students with and without ID, *based on criteria that distinguish between common and extraordinary support needs.* Establishing these criteria has involved providing information on the evidence of the construct and content validity of the list of indicators describing the support needs of children and adolescents without disabilities and those of students developing typically. This list describes the support needs that children and adolescents with common development have in the same activities, domains, and age groups as described in the *SIS—C*. The list is included as an Appendix within the *SIS—C* used in Spain. Research has shown evidence of the content validity of the list based on a sample of 222 teachers who acted as judges regarding the validity of the indicators. This determination has led to the provision of supports that meet the needs of students with ID within inclusive settings.

Ongoing research in this area is calculating receiver operative characteristics (ROC) curves with binomial confidence intervals to identify cut-off points that will lead to an

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accurate distinction between common vs. extraordinary support needs. Thus far, a total of 1036 participants have been assessed for this using the *SIS—C* (222 students without ID, 814 with ID).

Determining Support Needs of Children with CP or ASD

The purpose of this line of research has been to determine the support needs of children with CP or ASD. To date, 270 participants with a diagnosis of CP and 293 with a diagnosis of ASD have been assessed. Initial analyses indicate that the *SIS—C* can be used for individuals without a primary diagnosis of ID, with some important cautions. The first caution is that it may be necessary to adjust the daily time index, which is difficult to use in the Community and Neighborhood section of the *SIS—C* when it is applied to children with CP, and in the Social Activities domain in children with ASD. In addition, the Exceptional Support Needs section was shown as more relevant for these groups than in the group with ID.

The second caution is that it is very important that people who use the scale clearly understand its purpose, implications, and limitations. This is especially true for the families and professionals interviewed. Third, since the field tests were mainly conducted within special education schools, children scored higher on the scale than those special needs students enrolled in regular schools. Families interviewed often commented that there are some items that could be removed, and other items that should be added (specifically related to children with extensive and pervasive support needs).

The fourth caution concerns the actual assessment. It is important to highlight the fact that using the *SIS—C* as a semistructured interview makes more sense in young children with specific characteristics, making it necessary to be careful when asking some items. This is to say, items related to activities that require language or movement should be asked conscientiously when children have problems speaking or moving. The same logic can be followed with items related to avoiding abuse or exploitation situations or regarding self-care. To avoid uncomfortable situations, additional information should be asked before starting the interview.

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Conclusion

The supports paradigm has truly transformed the policies and the practices of organizations and systems providing services and supports to person with IDD. The transformation has involved significant changes in the conceptualization and measurement of an individual's support needs, the use of support needs data in resource allocation decisions, the provision of supports based on the elements of a system of supports, and the evaluation of the influence of individualized supports on valued outcomes. Each of these changes poses both a challenge and an opportunity for organizations and systems using supports intensity scales. The propose of this white paper has been to describe how such organizations can use SIS information to respond to those challenges and opportunities by facilitating knowledge on demand, incorporating SIS information into continuous quality improvement, aligning service delivery components, determining how often a complete SIS needs to be re-administered, and using SIS data to inform classification.

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