

Supports Intensity Scale

INFORMATION

(Publication date: January 2004)

Discover a unique, new assessment tool designed to plan meaningful supports for persons with an intellectual disability.

See p.17 for how to order.

American Association on Mental Retardation

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Overview of the *Supports Intensity Scale (SIS)*

What is SIS?

The *Supports Intensity Scale (SIS)* is a unique, scientific assessment tool *specifically designed* to measure the level of practical supports required by people with intellectual disabilities (i.e., mental retardation) to lead normal, independent, and quality lives in society.

The *Supports Intensity Scale* system has **two components**. A comprehensive **Manual** explains how to administer, score, and interpret the scale as well as how to use the instrument to create individualized supports plans. A **set of pre-printed interview forms**, part of a dynamic scoring system, is designed to measure support needs of the respondent in medical, behavioral, and life activity areas. The *SIS* scoring system is **paper-and-pencil based** and is meant to be administered by a **qualified interviewer** with feedback from one or more persons who know the respondent well.

The *Supports Intensity Scale* was developed over a period of five years by a **team of national experts** endorsed by the American Association on Mental Retardation (AAMR), a leader in the developmental disabilities field since 1876. The creation of *SIS* included: (a) an **extensive literature review** to identify initial items (i.e., candidate indicators of support needs); (b) a **Q-sort by 50 professionals** working in the field of intellectual disabilities to establish the content validity and initial grouping of items; and (c) **three field tests** where data were collected on over **1,700 persons with intellectual disabilities**. Apart from being empirically based and field tested, *SIS* has **excellent psychometric properties** and the Manual discusses these properties in detail.

What does SIS measure?

The *Supports Intensity Scale* is divided into **3 sections**, each of which measures a particular area of supports needs of the respondent:

Section I: The Supports Needs Scale

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

Section II: Supplemental Protection and Advocacy Scale

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

Section III: Exceptional Medical and Behavioral Support Needs

This section measures supports needs in **15 medical conditions** and **13 problem behaviors** commonly associated with intellectual disabilities. An underlying assumption is that certain medical conditions and challenging behaviors predict that a person will require increased

levels of support, regardless of her or his relative intensity of support needs in other life areas. For example, people with high support needs in terms of respiratory care need maximum support in their daily life regardless of their level of support needs in specific activities associated with home living, community living, and so forth. When completing this scale, the support needs for each life activity are examined with regard to three measures of support need: **Frequency, Daily Support Time, and Type of Support**. *Frequency* is concerned with how often “extraordinary support” (i.e., support beyond that which is typically needed by most individuals without disabilities) is required for each targeted activity. *Daily Support Time* assesses the amount of time that is typically devoted to support provision on those days when the support is provided. *Type of Support* reflects the nature of support that would be needed by a person to engage in the activity in question.

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

How the Supports Intensity Scale Can Help You

The *Supports Intensity Scale* is a unique assessment tool **dedicated exclusively** to identifying and measuring the supports needs of persons with intellectual disabilities in order to help them lead a regular, independent life. If you are a caregiver to a consumer or have a family member with an intellectual disability, here’s what *SIS* can do for you:

- ◆ Gives you a **direct, reliable, and valid measurement of supports** requirements in **57 life activities**.
- ◆ Provides a **clear ranking of support needs in 15 medical and 13 behavioral conditions**.
- ◆ Presents an **overall supports needs** score and a **percentile ranking** of persons needs based on national field test data.
- ◆ Gives you a **graphic plot** of information recorded so that you have a **visual display** of areas of high intensity vs. low intensity of supports needs.
- ◆ **Supplements adaptive behavior measures** by telling you *exactly* what practical supports are required to perform a task (Adaptive measures identify the *skills* an individual has to do a task).
- ◆ Allows feedback from respondent and those most close to him/her so that **you have a clear picture of person’s needs, preferences, and goals for life**.
- ◆ **Empowers persons with intellectual disabilities** by giving them an opportunity to plan a life of *their* choice.
- ◆ Provides a **solid knowledge base** on respondent to **develop individualized, person-centered plans**.
- ◆ Helps **make clinical judgments** regarding an individual’s support needs.
- ◆ Assists with **resource allocation** and **financial planning**.
- ◆ Leads to long-term **independence** and **enhanced quality of life** of persons with intellectual disabilities.

The *Supports Intensity Scale* is the first scale to align conceptually with the AAMR definition of mental retardation published in the 10th edition of *Mental Retardation: Definition, Classification, and Systems of Supports* (2002).

Five Trends that Created the Need for the Supports Intensity Scale

Trend 1: Changes in Expectations for Persons with Disabilities

The expectations for people with intellectual disabilities have changed dramatically over the last 50 years. Prior to the 1950s it was accepted as inevitable that adults with intellectual disabilities who lacked the skills needed to live independently and maintain employment would live life on the margins of society.

Times have changed. Today people with intellectual disabilities receive supports that enable them to live in the same communities as their loved ones. Moreover, since it has been demonstrated that **all people, including people with very significant functional limitations, can do meaningful work in community settings**, it is expected that people with intellectual disabilities are able to work at paid jobs for community-based employers. Further, it is now a person's legal right to access public settings and services, including community transportation services and recreational facilities (Americans with Disabilities Act, 1990). It is not only realistic to expect people with intellectual disabilities to live their lives as full-fledged members of a community, many consider it to be a failure of the system when this does not occur.

Multiple factors have contributed to the changes in society's perception of what is possible for people with intellectual disabilities to achieve and experience during their lives. Perhaps the **most important factor** was that people from different walks of life **successfully challenged prevailing assumptions** and questioned why things could not be done differently. In the words of George Bernard Shaw, "Some people look at things as they are and ask 'why'? I dream of things that never were, and ask 'why not'?" As more people began to dream and ask "Why not community houses? Why not real jobs? Why not recreational opportunities that the rest of society seems to enjoy? Why not?", efforts were made to provide greater opportunities for community integration and participation. As time went on, **more positive expectations for the lives of people with intellectual disabilities gained prominence.** *The high expectations were incorporated into policies and practices that necessitated the need for practical tools and strategies that provided for the accurate identification and meaningful provision of individualized supports.*

Trend 2: Functional Descriptions of Disabilities

The discipline of medicine provided the earliest descriptions of intellectual disabilities based on biological anomalies. Sometimes these descriptions were useful. For example, at one time mental retardation always occurred in children born with the amino acid disorder, phenylketonuria (PKU), but newborn screening and special dietary restrictions are now very effective in preventing intellectual disabilities resulting from PKU. **However, most medical descriptions have proved to be of limited usefulness in assisting people with intellectual disabilities to reach meaningful life goals.** The medical model's emphasis on "curing"

conditions was not particularly relevant when working with people whose disabilities could not readily be treated by medical means.

Functional descriptions of disabilities do not focus solely on biological characteristics, but rather on indicators of a person's performance on tasks that are required for successful functioning in contemporary society. Although medical and functional descriptions can each provide useful information (e.g., the fact that a person has strabismus is a *medical* description; the fact that a person cannot distinguish figures on a standardized computer screen is a *functional* description), **functional descriptions have proven to be extremely useful** to those seeking answers to questions such as: "What support does this person need?" "What skills does this individual need to learn?", and "How can the environment be modified to better accommodate this person's abilities and needs?"

Because functional descriptions provide information regarding ways in which a person's current level of skills is matched (or mismatched) with the demands of the environment, **functional descriptions are useful when identifying and creating supports that assist an individual in participating in a variety of settings and activities** (World Health Organization, 2001). For example, if a person's competence limits their ability to do something that he or she wants to do, such as riding the bus to work, functional descriptions may lead to identifying: (a) the specific skills a person needs to acquire and the strategies needed to teach the individual these skills; (b) tools (i.e., assistive technologies) that an individual might use to enhance his or her performance in particular settings or activities; (c) strategies for modifying the design or the demands of settings and activities so that individuals of differing abilities can be accommodated; or (d) a combination of these supports. *The focus on functional descriptions of disabling conditions has led to a focus on identifying supports that enhance a person's participation and successful functioning in community life.*

Trend 3: Chronologically Age Appropriate Activities

Previously, many assumed that people with intellectual abilities had "minds" similar to those of children. The "developmentally age appropriate assumption" resulted in tailoring life activities and experiences to people's "mental ages." For example, adults might be encouraged to engage in childlike activities (e.g., playing with toys designed for young children) as opposed to adult activities. Because they were considered to be "eternal children," an overriding value of the service delivery system was to provide protection from life's unpleasantness; therefore, adults with intellectual disabilities were not encouraged to take risks in their lives.

In contrast, the "chronologically age appropriate" perspective holds that people, regardless of intellectual abilities or limitations, should have the opportunity to have life experiences and engage in activities consistent with their chronological ages. As this view gained prominence, it became evident that the life experiences, attitudes, and behaviors of adults with intellectual disabilities were very different from those of children. Moreover, interacting with people consistent with one's chronological age reduced stigmatization and

afforded individuals greater personal dignity and respect. It was also found that individuals with intellectual disabilities were capable of successfully fulfilling adult roles in society when provided with proper support. *The importance that has been placed on meeting chronologically age appropriate needs has focused attention on developing and delivering supports in age-appropriate settings.*

Trend 4: Consumer-Driven Services and Supports

As services to persons with intellectual disabilities expanded during the past 50 years, national, state, and local systems of service delivery emerged. Although these systems provided new opportunities to people with disabilities and their families, often, “consumers” had to fit in with the “programs” that were offered in order to receive assistance. For example, if a person with a disability wanted assistance in finding and keeping a job, he or she was compelled to participate in a service organization’s vocational “program.” In the best cases, people had some options regarding various facets of a program (e.g., options about types of work, where to work, which coworkers and supervisors with whom to work). However, in far too many situations there were no such options and people with disabilities had to participate in the pre-determined program or forfeit eligibility with the sponsoring organization.

In contrast, the consumer-driven approach requires support providers to tailor supports to the needs and preferences of the person and his or her family. In this approach, each person determines the types of settings and activities in which he or she wants to participate, and the onus is on the support provider to collaborate with people with disabilities and their families to identify and arrange needed supports. Although many question the extent to which the consumer-driven approach has truly gained prominence in today’s world, the rapid growth of person-centered planning processes provides evidence that practices are changing. Person-centered planning processes (e.g., Personal Futures Planning, MAPS, Essential Life-Style Planning, Whole Life Planning) focus on identifying a person’s preferences, skills, and goals to establish a vision of life experiences and conditions that the person would like to have.

Another indication of the strength of the consumer-driven approach is the movement toward providing funding directly to people with disabilities and their families as opposed to funding “programs” that are administered by service provider organizations. It has been argued that direct funding of organizations invariably leads to forcing people to fit into existing programs offered by the organizations. An alternative being used in many states is to have funds (e.g., cash or vouchers) go directly to people, who then have real leverage to influence the types and intensities of supports provided because they can shop for supports that meet their needs.

It is difficult to address effectively an individual’s support needs unless these needs are clearly identified and communicated. *The movement toward consumer-driven services and supports is directly related to the need for tools such as the SIS that reliably and validly measure individual support needs.*

Trend 5: Support Networks that Provide Individualized Supports

A change in thinking has also occurred with respect to the people who provide supports to individuals with intellectual disabilities and how to best provide them. The traditional “caregiver approach” assumed that due to limitations in adaptive skills, people with intellectual disabilities needed paid care givers to help with dressing, grooming, cooking, etc. Although some people require personal care, the role of “caregiver” is now perceived as too narrow to meet the full needs of individuals. That is, there are many other critical support needs across a broad range of settings and activities that should not be ignored.

It has also become clear that people with intellectual disabilities need support networks comprised of many individuals who provide many different types of support. Although natural supports (i.e., supports that are inherent in the environment such as coworkers, neighbors, classmates, bus drivers, and police officers) may not be sufficient to provide the full range of supports that many people with intellectual disabilities require, true community integration and inclusion will be unattainable as long as providing support remains the sole purview of paid staff.

The new “supports paradigm” shifts the focus from caregiving to investing time in creating and nurturing support networks; thus, this paradigm shift redefines, but does not eliminate the role of paid staff persons. Paid staff persons should place emphasis on identifying and developing the capacities of “natural supports” (i.e., persons who can provide assistance on a daily basis that is not particularly intrusive or time consuming, and who provide similar support to others in the environment). **Support networks offer several advantages over a caregiver model, including:** (a) enhanced opportunities for individuals to experience a sense of “social belonging” due to increased opportunities to establish meaningful relationships with others; (b) increased number of people who become committed to an individual’s success; and (c) increased capacity among the general population for including people with disabilities.

The “supports paradigm” holds that supports should follow a person to whatever settings the person wants and needs to be in. Supports should not only be mobile, but should also be individualized (i.e., tailored to the unique characteristics of the individual and the settings). A key premise of the supports paradigm is that assistance to people with intellectual disabilities should be provided in settings where the individual needs and wants to be. *Two key implications of the supports paradigm are: (a) the need to identify, describe, and understand people in regard to their pattern and intensity of support needs; and (b) focusing planning and service delivery on providing supports that reduce the gap between an individual’s level of personal competence and the demands of the settings in which the person participates.*

The Spirit of the Age: The Supports Paradigm

Zeitgeist is a German word meaning “the spirit of the age.” Based on the trends of the past several decades, today’s zeitgeist in the field of human services targeted to persons with intellectual disabilities can be summarized as follows:

Because of the mismatch between an individual's repertoire of skills and the demands of the environment, individuals with intellectual disabilities and closely related developmental disabilities need support in establishing networks that include a wide variety of family members, friends, acquaintances, and paid support staff. People in a person's network need to provide support that enables that person to engage in chronologically age appropriate activities in community settings that are consistent with his or her personal goals and preferences.

The five key trends that have been summarized above coalesce around the concept of supports. Therefore, there is a need for assessment and planning processes that: (a) allow for the reliable and valid assessment of individual support needs; (b) promote thoughtful identification of and planning for support provision; (c) encourage conscientious monitoring and revision of support plans; and (d) advance public policy and organizational structures that enable individual support needs to be addressed in an efficient and equitable manner.

Although today's zeitgeist is conceptually appealing, translating it into practice is challenging. For example, what if a person wants to be supported in settings and activities that are not chronologically age appropriate? In such cases the chronological age approach clashes with the consumer-driven approach, and complex issues must be weighed against each other to determine which approach takes precedence. What if resources are not sufficient to support a person in settings and activities consistent with his or her personal preferences? Can a consumer ever be told, "No, it's not in the budget" in a consumer-driven planning process? In a world of finite resources, how does a planning team decide which activities and settings are priorities and how does a team monitor itself to assure that certain settings and activities are not dismissed simply because they are relatively expensive or inconvenient? How can existing service delivery systems and structures be transformed to one providing consumer-driven, individualized supports?

While the *Supports Intensity Scale* and the planning procedures described in the accompanying manual do not provide definitive answers to these questions, **they can help planning teams and organizations better align resources and strategies that enhance personal independence and productivity.** The *SIS* and the related planning processes promote greater participation in a complex society by people with intellectual disabilities and ultimately, improve their quality of life.

How the *Supports Intensity Scale* Differs from Instruments that Measure Personal Competence

The constructs of personal competence and support needs are related, but are not the same thing. There is a growing consensus that intellectual disability (i.e., mental retardation) is best conceptualized as significant limitations in the multidimensional construct of personal competence. In addition to physical competence (which is not associated with conceptualization of mental retardation), personal competence is conceptualized to include the domains of conceptual, practical, and social intelligence.

For nearly 50 years the two cornerstones for diagnosing mental retardation have been IQ tests and adaptive behavior scales. Whereas IQ tests focus primarily on the *maximal* performance of an individual on tasks related to conceptual intelligence, adaptive behavior scales focus on the skill level a person *typically* displays when performing tasks in his or her environment. Adaptive behavior scales measure aspects of conceptual, practical, and social intelligence, even though performance on tasks requiring social intelligence are often underrepresented on adaptive behavior scales. In addition to diagnosis, adaptive behavior scales are useful in identifying educational or training related goals.

In contrast, the *SIS* focuses on the *pattern and intensity of supports needed to enable a person to participate in valued settings and activities*. There are five major influences on the support needs of people with intellectual disabilities and one of them is the level of personal competence. It is likely that the greater an individual's level of personal competence, the less the intensity of support needs. Conversely, the lower a person's level of personal competence, the greater the support needs. The other four other major influences on the intensity of a person's support needs are: (1) Exceptional medical support needs; (2) Exceptional behavior support needs; (3) The number and complexity of the settings in which a person participates; and (4) The number and complexity of the life activities in which a person participates. **Inferring a person's pattern and intensity of support needs from traditional measures of personal competence is unlikely to result in specific and practically useful conclusions because IQ scores and adaptive behavior measures do not provide a complete measure of personal competence, nor do they account for the other four influences on support needs.**

To summarize, the *SIS* is a support needs assessment scale, and is not a scale to measure personal competence. Whereas intelligence tests and adaptive behavior scales attempt to directly measure aspects of personal competence, the *SIS* attempts to directly measure support needs. The reason for developing a support needs scale is that it is assumed that a direct measure of support needs will provide more specific and direct information and therefore will be more useful for planning teams and those involved in systems-level supports management who are trying to determine how to best support an individual in community settings.

The Supports Intensity Scale and Adaptive Behavior Tests

Since both the *Supports Intensity Scale* and adaptive behavior scales are concerned with typical performance in everyday activities, there is a greater likelihood for the *SIS* to be confused with adaptive behavior scales as opposed to other standardized assessment measures. Because the *SIS* and adaptive behavior scales measure are related, but different constructs, **the scales should be used for different purposes. It is essential to understand that the *SIS*, as well as any other scale that is designed to measure support needs, does not supplant the need for adaptive behavior scales or other measures of personal competence that are essential for diagnosing the condition of intellectual disabilities.**

A key distinction between the two scales is that adaptive behavior stems are “skills” needed to successfully function in society, whereas the *SIS* stems are activities that a person does during the course of participating in everyday life. For example, take a daily activity such as preparing food. Whereas there are usually a number of more specific food preparation items on an adaptive behavior scale (e.g., cuts foods with knife, mixes and cooks simple foods, plans a meal for 4 people), the *SIS* is used to assess only *how much extraordinary assistance or support a person needs in order to prepare food that he or she consumes on a typical day*. Everyone has to eat, thus everyone must get food prepared – it is a regularly occurring part of life. **An adaptive behavior scale focuses on the skills a person has in regard to food preparation; the *SIS* focuses on the relative intensity of support the person needs to accomplish the food preparation.**

Although item stems on adaptive behavior and support needs scales are comparable, **the responses are extremely different.** Adaptive behavior responses deal with level of mastery or performance. Items are usually scored on a Likert scale ranging from “no skills” to “some skills” to “fully skilled.” The response on a support needs scale reflects intensity of supports needed to accomplish the task.

The *SIS* Manual discusses the differences between the two scales in greater detail.

Frequently Asked Questions on the *Supports Intensity Scale*

Publication date: January 2004

What is the AAMR *Supports Intensity Scale*?

The AAMR *Supports Intensity Scale (SIS)* is a unique, new assessment tool specifically designed to measure the pattern and level of supports required by an adult with mental retardation or a closely related developmental disability in order to lead a normal, independent life in society. The *SIS* has two components: a manual explains how to administer the instrument and a set of pre-printed forms rate the respondent on the intensity of supports required in medical, behavioral, and life activity areas.

What are supports?

Supports refer to an array of resources and strategies, including individuals, money or tangible assets, assistive devices, or environments that enable people with developmental disabilities live normal lives in regular community settings.

What support areas does the *SIS* measure?

The *Supports Intensity Scale* measures supports required by an individual in 57 life activities in the areas of home living; community living; life-long learning; employment; health and safety; social interaction; and protection and advocacy. Each activity is evaluated according to the frequency, daily support time, and type of support required by the person to participate in the activity.

The *Supports Intensity Scale* also measures 15 exceptional medical needs and 13 behavioral support needs of the individual being tested. The rationale here is that certain medical conditions and challenging behaviors predict that a person will require increased levels of support, regardless of his or her relative intensity of support needs in other life areas.

How is the *Supports Intensity Scale* administered and who can administer *SIS*?

The *Supports Intensity Scale* is conducted as a semi-structured interview by a qualified interviewer with preferably two or more respondents that know the individual well. The interviewer should be a professional who has completed at least a bachelor level degree. The respondents must have know the person being rated for at least three months and have had recent opportunities to observe the person function in one or more environments for substantial periods of time.

How is the *SIS* different from an adaptive behavior scale?

The *Supports Intensity Scale* fills a unique niche not covered by adaptive or other measurement scales. Adaptive measures identify skills that a person has learned, i.e., what the person can or cannot do whereas the *Supports Intensity Scale* identifies what supports it will take for the person to perform the task in question. While an adaptive behavior scale is used to diagnose mental retardation and identify relevant educational and training goals, the *Supports Intensity Scale* is used to determine a

person's support needs in different areas of life to develop individualized support plans. The *SIS* is a planning tool could be used no matter which adaptive or IQ test is administered.

Has the *SIS* been field tested?

The *Supports Intensity Scale* has been normed on a sample of 1306 people between the ages of 16 and 70+ identified with mental retardation or other developmental disabilities. The *SIS* sample was drawn from 33 states and 2 Canadian provinces and the data was collected between spring 1999 and fall of 2002.

What are the benefits of *SIS*?

- Provides direct, reliable, and valid measurement of supports requirements in 57 life activities.
- Ranks results by frequency, daily support time, and types of support needed.
- Evaluates impact of 15 medical and 17 behavioral conditions on overall support needs.
- Presents percentile ranking of persons needs based on national field test data.
- Provides graphic plot of information recorded, including visual display of areas of high intensity vs. low intensity of supports needs.
- Supplements adaptive behavior measures by revealing *exactly* what practical supports are required to perform a task (Adaptive measures identify the *skills* an individual has to do a task).
- Allows feedback from respondent and those most close to him/her to provide clear picture of person's needs, preferences, and goals for life.
- Empowers persons with intellectual disabilities by giving them an opportunity to plan a life of *their* choice.
- Provides solid knowledge base on respondent to develop individualized, person-centered plans
- Helps make clinical judgments regarding an individual's support needs.
- Assists with resource allocation and financial planning.
- Leads to long-term independence and enhanced quality of life of persons with intellectual disabilities.

What is the need for *SIS* today?

Contemporary society has moved away from viewing individuals with developmental disabilities as needy, to seeing them as people who have a life and need support, and the *Supports Intensity Scale* was developed in response to this change in society's view of the concept of disability. The *SIS* also reflects the shift we have seen over the past 50 years to the focus on *functional* rather than medical descriptions of disabling conditions. Disabling conditions like mental retardation can be enhanced with the provision of appropriate life strategies and resources, and the *SIS* helps achieve this end by providing a clear and scientific assessment of the unique needs of the individual with the disability.

Product Information

Title: *Supports Intensity Scale*; **Authors:** Dr. James R. Thompson, Ph.D. et al

Pages: Manual: 128 pp. Interview forms: 8pp.

Price: \$125 (Manual and 25 interview forms); 25 interview forms: \$38.75;
100 interview forms: \$147.25

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