Supports Intensity Scale

INFORMATION

/Publication date: December 2003/

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

See p.14 for how to order.
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American Association on Mental Retardation
444 North Capitol Street, NW • Suite 846
Washington, DC 20001
Ph: 202.387.1968 • Fax: 202.387.2193 • www.aamr.org
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: Exceptional Medical and Behavioral Support Needs
This section measures supports needs in 16 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.

Sections II and Section III: The Support Needs Scale and the Supplemental Protection and Advocacy 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. 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. 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 16 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 unpleasantries; 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 caregivers 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

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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 16 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.

**Who are the authors of the SIS?**
The *Supports Intensity Scale* was developed over a 5-year period by a team of ten experts and
researchers in the area of mental retardation, disabilities, and measurement. See back of this
document for complete list of authors.

**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 SIS helps achieve this end by providing a clear and scientific
assessment of the unique needs of the individual with the disability.

**Who should buy SIS?**
The *Supports Intensity Scale* can be used by agencies and individuals who provide services for
people with mental retardation and related developmental disabilities.

**To obtain a copy of SIS, call 301-604-1340 or email aamr@pmds.com**
*Questions on content? Email books@aamr.org*

**Product Information**
*Title:* *Supports Intensity Scale*
*Authors:* Dr. Jim Thompson, Ph.D. et al
*Sale price (till December 31, 2003):* $99.95 (Manual and 25 interview forms)
*Regular set price: *$125
*Regular Manual price: *$95
*25 interview forms: *$38.75
*100 interview forms: *$147.25
James R. Thompson, Ph.D.
Chairperson, Department of Special Education
Illinois State University, Campus Box 5910
Normal, IL 61790-5910

Brian Bryant, Ph.D.
President, Psycho-Educational Services
5114 Balcones Woods Dr., #307-163
Austin, TX 78759

Edward M. Campbell, Ph.D.
Management Analyst, State of South Dakota Department of Human Services
Hillsview Properties Plaza
C/o 500 East Capitol
East Highway 34
Pierre, SD 57501-5070

Ellis M. (Pat) Craig, Ph.D.
Research Specialist, Texas DMH/MR
PO Box 12668
Austin, TX 78711

Caroyln Hughes, Ph.D.
Professor, Department of Special Education
Box 328, Peabody, Vanderbilt University
Nashville, TN 37203

David A. Rotholz, Ph.D.
Project Director, Center for Disability Resources (UAP)
University of South Carolina School of Medicine
Columbia, SC 29208

Robert Schalock, Ph.D.
Professor Emeritus, Hastings College
P.O. Box 285
Chewalah, WA 99109-0285

Wayne Silverman, Ph.D.
Research Scientist, Institute for Basic Research in Developmental Disabilities
1050 Forest Hill Road
Staten Island, NY 10314
Marc Tassé, Ph.D.
Clinical Associate Professor of Psychiatry
Center for Developmental Learning
University of North Carolina at Chapel Hill
Chapel Hill, NC 27599-7255

Michael Wehmeyer, Ph.D.
Beach Center on Disability
Haworth Hall
1200 Sunnyside Ave., Room 3136
Lawrence, KS 66045-7534
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Integrating Supports in Assessment and Planning

James R. Thompson, Carolyn Hughes, Robert L. Schalock, Wayne Silverman, Marc J. Tassé, Brian Bryant, Ellis M. Craig, and Edward M. Campbell

Abstract

A systematic approach for addressing the support needs of persons with mental retardation and related developmental disabilities is presented and a new scale to measure individual differences in support needs described. The process employed in developing the scale is explained, including the establishment of a typology of support areas that was drawn from a review of the professional literature, a validation process using Q-sort methodology, and a pilot field test. Critical issues and practical challenges associated with efforts to measure and address the support needs of individuals are discussed.

We are experiencing a change in the way people with mental retardation and closely related developmental disabilities are viewed and served. A “supports paradigm” has been gaining prominence in recent years, evolving from the philosophy of normalization (Nirje, 1970; Wolfensberger, 1972), the community-based movement (Bruininks, Meyers, Sigford, & Lakin, 1981), and the contemporary emphasis on quality of life (Schalock, 1996, 1997). The paradigm shift involves a movement away from a principal focus on individuals’ deficits to one concerned primarily with self-determination and inclusion. The major focus is on the question, What supports are needed to help people participate in their community, assume valued social roles, and experience greater satisfaction and fulfillment? We propose that supports be defined as resources and strategies that promote the interests and welfare of individuals and that result in enhanced personal independence and productivity, greater participation in an interdependent society, increased community integration, and/or an improved quality of life. Although still emerging, the supports paradigm is gaining acceptance across disciplines, including education, health care, and social services/habilitation (Schalock, 2001).

Despite its conceptual appeal, the transition to a supports paradigm presents a number of clear challenges. First, people with disabilities, as consumers of supports, must be described on the basis of their personal needs and aspirations. Such a description would supplement, or perhaps supplant, an orientation that is focused on deficits; such a reconceptualization requires the development of new systems of classification. Second, the traditional focus on supports that addresses basic personal care and maintenance must be expanded to include the enhancement of personal development, empowerment, inclusion, and valued social roles. Systems of support implementation, in order to meet these challenges, need to be designed to assess a wide range of support needs, be person-centered, be sufficiently flexible to accommodate substantial variation in individual priorities, and provide a means to regularly evaluate each individual’s changes in status and needs over time.

In this article we describe a four-component approach for determining support needs and developing plans that meet these needs. The four components are depicted in Figure 1 and involve (a) identifying a person’s desired life experiences and goals, (b) determining an individual’s intensity of support needs across a wide range of environments and activities, (c) developing an individualized support plan, and (d) monitoring outcomes and assessing the effectiveness of the plan. We also describe how a new scale was developed to measure the intensity of an individual’s support needs. Each phase of the scale’s development are presented, including findings from an initial field test.
Figure 1 Four-component support needs assessment and planning process.
The four-component approach and the development of the scale were based on five assumptions about the nature of support needs of persons with mental retardation and related developmental disabilities. Each assumption is discussed below.

**Five Assumptions Regarding the Nature of Support Needs**

**Assumption 1: Types of Support Must be Tailored to Individual Needs and Preferences**

According to the American Association on Mental Retardation’s (AAMR’s) *Definition, Classification, and Systems of Supports* (Luckasson et al., 1992), mental retardation is a product of interactions between a person’s skills and the nature and demands of the person’s environment. Thus, mental retardation is typically reflected in a poor fit between what a person can do without any extraordinary assistance or support and what the environment expects. Because there is considerable variance among the demands in different environments, the levels of personal competence across individuals, and the goals and desires of different individuals, it is unlikely that any two people will have the exact same support needs or require the same support plan. Truly personalized support plans and practices will match the provision of different types of supports to individual needs and circumstances.

**Assumption 2: The Provision of Support Must be Flexible**

People’s support needs are dynamic (i.e., they change across settings, across situations, and over time). Therefore, a support assessment, planning, and provision process should identify an array of supports that is sufficiently flexible to respond to changing circumstances. In addition, periodic re-evaluations are needed to review an individual’s current supports and determine whether the supports are meeting the person’s needs. It is also important to identify circumstances that might call for short-term intensive supports in hopes of reducing the need for long-term supports. For example, buying an electric wheelchair and teaching someone how to operate it is an intensive support that could reduce future needs in regard to personal mobility. In much the same way, providing education to young children at risk for developmental delays is an intensive support that might lead to prevention of the need for any extraordinary support later in life.

**Assumption 3: Some Supports Are More Important to Individuals Than Others**

A support needs assessment and planning process must allow for the prioritization of support needs. Because many supports consume resources and because the financial resources to fund supports will always be finite, there is a great need to distinguish between supports that are priorities and those that are relatively less critical. Factors guiding the prioritization of support needs include the individual preferences of the person who is being supported and consideration of primary human needs that society is expected to provide for all citizens (e.g., safety, shelter, nourishment). The individual with the disability and his or her family should make final decisions regarding support priorities.


A support needs assessment process should produce information that maximizes awareness among planning team members as to what an individual wants in his or her life in both present and future contexts. This should promote creative problem-solving among planning team members to identify, structure, and coordinate supports. A support plan should emerge that, at a minimum, identifies (a) different sources of support that can either garner and/or directly provide the assistance the individual needs, (b) the purposes or functions of each type of support to be provided, and (c) the intensity of the support provision to most effectively meet the individual’s needs.

**Assumption 5: The Assessment of Support Needs Must Consider Multiple Factors**

As noted by Luckasson et al. (1992), failure to consider factors related to an individual’s cultural, ethnic, linguistic, and economic background or communication and behavioral characteristics might seriously compromise or invalidate the process of developing a support plan. When assessing needs, support teams must be sensitive to and respectful of differences in values, expectations, and beliefs that influence the lives of all people. Including family and friends as members of the team can
ensure that cultural and other factors are being considered in the process of support plan development. In addition, using multiple methods of obtaining information, such as informal interviews and direct observation, will increase the likelihood that the perspectives of all interested parties are included when identifying an individual’s support needs.

A Four-Component Approach to Support Needs Assessment and Planning

Addressing the support needs of persons with disabilities requires a systematic analysis of what they want to do (e.g., interests, preferences) in their daily lives and the types of assistance they need to participate in the settings and activities they desire. Such assistance includes both extraordinary assistance that most other people in society do not require and typical assistance that many people in society need on a regular basis. Based on this needs analysis, a plan for providing individualized supports across a wide range of environments can be developed, implemented, and evaluated. We propose a four-component approach (Figure 1) to guide the support needs assessment and planning process. Each component is described below.

Component 1: Identify Desirable Life Experiences and Goals

A person-centered planning process is recommended for determining how a person’s current life experiences conform to or differ from his or her desired life experiences and goals. A variety of different person-centered planning processes have been described (e.g., Butterworth et al., 1993; Malloy, Cheney, Hagner, Cormier, & Bernstein, 1998; Mount & Zwernik, 1988; O’Brien & Lovett, 1993; Smull & Harrison, 1992; Vandercook, York, & Forest, 1989). A common theme is focusing on the development of “a vision of the life-style the individual would like to have, and the goals needed to achieve it, that is unrestricted by current resources or services” (Butterworth, Steere, & Whitney-Thomas, 1997, p. 7). Ideally, an outcome of person-centered planning is the identification of daily experiences and daily settings/environmental conditions that provide an individual with an improved quality of life.

An interview will typically provide the best means to identify the areas of support that are most important for an individual. The principles and techniques of “person-centered planning” should guide this interview process as well as subsequent team-planning activities. Through conversations with the person, and in many cases the individual’s advocates, those areas of the person’s life can be identified in which change is desired. In situations where the interview reveals that an individual does not desire any changes in his or her life (i.e., “everything is fine”), it is still important to understand what supports are needed to maintain these conditions and experiences. Types of supports that the individual may want to increase or decrease include natural supports (i.e., sources of support that are naturally present in settings and activities, such as family, coworkers, neighbors, or other community members), generic supports (i.e., supports used by people without disabilities, such as public transportation), supports provided by disability services organizations (i.e., formal services that involve paid staff), and technological supports (i.e., assistive technologies).

A standardized and highly structured interview would not have sufficient flexibility to tap the key information sought at this stage. Individual differences are simply too great to permit a rigid structure to be both valid and practical, given that the emphasis is on discovering what each individual uniquely values. Nevertheless, some general uniformity needs to be maintained, and guidelines for the initial interview are as follows:

1. A conversational style should be used versus a standardized structured interview.
2. Key content areas need to be addressed during this interview (see sample questions in Table 1).
3. Although the individual’s personal views are critical, it may be necessary to include caregivers or family members who are intimately familiar with the individual during this interview.
4. Avoid using questions that may be answered yes/no; open-ended questions will generally produce more detailed and useful responses.
5. Based on the person’s response to your probe question, you may need to follow-up with additional inquiry in that area.
6. If major themes/goals seem to emerge from the individual’s responses, confirm these issues by going over them again with him or her.
7. Confirm/validate the needed support areas with appropriate caregivers or family members.
8. Even a nonverbal individual can identify preferences when given options/choices; when a per-
## Table 1  Sample Questions for Initial Interview

<table>
<thead>
<tr>
<th>Domain</th>
<th>Sample questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Global—Life Goals</td>
<td>What are your hopes and aspirations, and what can be done to help you achieve these?</td>
</tr>
<tr>
<td>Global—Relationships</td>
<td>Who are the key people in your life, and what types of relationships do you desire?</td>
</tr>
<tr>
<td>Home Living</td>
<td>Tell me about where you are living. What do you like about living there, and are there any changes you might be considering? What kind of meals are you able to prepare by yourself and with what meals do you need help? What kind of help do you need with your daily personal care (such as bathing, toileting)?</td>
</tr>
<tr>
<td>Community Living</td>
<td>Tell me what kinds of things you do outside the home. Where do you go shopping? How do you get around the community? Tell me about some new things that you would like to do.</td>
</tr>
<tr>
<td>Education/Training</td>
<td>Tell me about your reading and writing skills. Tell me what you like to read. What kind of things do you want to learn?</td>
</tr>
<tr>
<td>Employment</td>
<td>Are you currently employed? What do you like about your job? Tell me about the jobs you’ve had in the past. Tell me about what kind of job you would like to have. What kind of special assistance do you need on a job?</td>
</tr>
<tr>
<td>Health &amp; Safety</td>
<td>How is your health in general? What medications do you take? What kind of exercise do you get? How safe do you feel in your neighborhood?</td>
</tr>
<tr>
<td>Behavioral</td>
<td>How do you get along with other people? What kind of help could you use in order to do the things you would like to do?</td>
</tr>
<tr>
<td>Social</td>
<td>What kind of things do you do with your family? What kind of new things would you like to do with other people? Tell me about your friends. Tell me about your boyfriend/girlfriend.</td>
</tr>
<tr>
<td>Protection &amp; Advocacy</td>
<td>How do you tell people when you want to do something new? Who helps you make decisions? What do you know about self-advocacy groups?</td>
</tr>
</tbody>
</table>

son’s preferences are not clear, consult with a family member or caregiver.

9. Have the individual, family members, and/or caregivers identify any significant health or safety issues.

The purpose of the initial interview is to identify the areas of special importance to the person with developmental disabilities. Some suggested questions for the interview are provided in Table 1. The first two questions are “big picture” questions that provide overall direction to the support planning process. The remaining questions are related to eight support areas (how these support areas were selected is discussed later in this article).

Some major themes likely will emerge from this discussion with the individual and his or her representatives. Even if there are significant limitations in verbal communication skills, an analysis of preferences and dislikes can often suggest important accommodations to make in the person’s environment. It is also essential to understand the person’s current level of functioning, strengths and talents, as well as any potential barriers to achieving desired changes. Health status, as well as behavioral and cognitive skills, must be taken into account.

A person’s lack of experience in expressing choices or lack of opportunity to participate in a variety of community-based and other activities may limit his or her ability to state personal goals or make informed choices. Obviously, informed choices can only be made when an individual is aware of the options available. Nevertheless, the information gleaned from this initial interview should help determine priority areas that need to be addressed by the team that develops the support plan (i.e., Component 3). This planning group’s primary task is to identify the necessary supports required to enable the person to achieve his or her stated goals to the maximum degree possible.
It is important that a person specifically trained to conduct person-centered planning facilitates this process. Because person-centered planning has achieved a grass-roots level of acceptance in recent years, it is likely that there is a great degree of variance in the way in which the approach is implemented. Training as a facilitator in one of the recognized approaches to person-centered planning helps ensure that the process is being used appropriately. In addition, it is critical to have the person who is actively participating in the process not be an employee of the organization that provides supports/services to the consumer. This addresses an inherent conflict of interest of all provider agency employees, who may be inclined to offer supports and services provided by their organization rather than utilize other appropriate supports and services to meet the individualized needs of the consumer.

Finally, although the content of the questions listed in Table 1 is important, it is most vital to discern the meaning behind the answers. For example, a consumer with a significant degree of cognitive and physical disabilities may respond that he wants to be a police officer. Although some other members participating in the planning session may view that as unrealistic, there might be some activities that the consumer associates with this goal that could be both satisfying and achievable. In this actual case, the consumer was eager to spend more time riding in a car in his neighborhood, a goal that was feasible, even though employment as a police officer was not. Although this example is a simple one, the point that it illustrates is essential. Interviewers must probe to be sure that the consumer’s true intent is discovered.

Component 2: Determine the Intensity of Support Needs

The Supports Intensity Scale—SIS (Thompson et al., 2002) is a multidimensional measure designed to determine the intensity of an adult’s support needs. The instrument was designed to assess support needs, determine the intensity of needed supports, monitor progress, and evaluate outcomes. Moreover, SIS results can be useful for projecting support costs and justifying access to certain types of funded services/programs (e.g., supported employment, supported living). The SIS, which is in its second stage of field development, assesses support needs according to:

- Eight support areas: home living, community living, education/training, employment, health and safety, behavioral, social, and protection and advocacy
- Four medical areas: respiratory care, feeding assistance, skin care, and “other exceptional medical needs”
- Four challenging behavior areas: externally directed destructiveness, self-directed destructiveness, sexual problem behavior, and “other challenging behaviors”

The SIS contains three separate 4-point Likert rating scales that allow users to evaluate the frequency and duration of daily support, as well as the type of support, for each specific item within the eight life areas (the selection of these areas is discussed later). It also enables the assessment of none to critical support needs in the medical and challenging behavior areas. The SIS is based on (a) a literature review of support functions to identify potential indicators of support, (b) an aggregation of potential support indicators into the support areas referenced above by a group of education and habilitation professionals, (c) an initial field test to determine the appropriateness of scale items and structure, and (d) an extensive field test on a large sample to determine reliability and validity (currently in progress). An expanded description of each of these activities is provided later in this article.

Although we are not aware of any other instruments that are comparable to the SIS in regard to scope or format, any psychometrically sound scale that includes measures of support needs could be used within the planning process that is outlined in Figure 1. It is also important to note that the SIS is appropriate to use anytime there is a need to assess an individual adult’s support needs. Therefore, it can be used independently of the four-component approach for addressing the support needs that is described in this article.

Component 3: Develop the Individualized Support Plan (ISP)

The evaluation of frequency, duration, type, and sources of supports needed for each of the eight support areas included in the scale will result in a support needs profile. This profile, in conjunction with information gleaned from Component 1 (the person-centered interview), will guide planning teams in developing an ISP that specifies what, when, where, how, and by whom supports will be
provided. The purpose of an ISP is to enable an individual to have life experiences and goals that mirror his or her desired life experiences and goals as closely as possible. Moreover, an effective ISP should improve coordination and management of supports and should maximize available resources, while minimizing the chances of a person receiving supports that are ineffective, unwanted, fragmented, redundant, or otherwise unnecessary.

A planning team needs to take information from the person-centered planning and supports intensity determination components to prioritize preferences in regard to life experiences and goals. During the process of developing an ISP, the planning team may need to make compromises between what is ideal and what is realistically achievable. Although it is true that many persons with mental retardation and closely related developmental disabilities have had opportunities denied because someone in power decided a certain goal was unrealistic, it can be irresponsible to suggest that persons with disabilities should receive whatever supports they want to obtain whatever life experiences and goals they desire. None of us can do everything we want to do, and it is up to the planning team to specify priorities (perhaps even nonnegotiable priorities) and make the most out of what resources are available to support the individual. This is where a skilled facilitator can help guide the consumer and his or her team to develop a plan that addresses the consumer’s true goals. When this effort is appropriately undertaken, processes will be initiated that lead to an “optimistically realistic” plan.

An ISP is ready for implementation when the planning team has specified (a) the settings where the person is most likely to be as well as the activities in which the individual will participate during a typical week and (b) the types of supports that will be provided and who (or what technology) will be providing the support. A plan should identify the type and intensity of support that will be provided throughout each day of a typical week. In addition, a good support plan will be designed to accommodate occasions when an individual has an atypical schedule, such as when he or she has an illness or is on vacation.

Component 4: Monitor Progress
Component 4 is focused on the differences between the outcomes of the support planning process that were expected and the actual outcomes, including those that were unanticipated. The process will prompt planning teams to identify obstacles and barriers to achieving desired outcomes and select strategies that can address these in the future. As is shown by the arrow in Figure 1, support assessment and planning is cyclical, in that monitoring may lead to a return to Component 1 (reexamining desired life experiences and goals) and/or Component 2 (assessing intensity of support needs).

Supports Intensity Scale
The Supports Intensity Scale—SIS (Thompson et al., 2002) was developed through a multiphase process that included a thorough review of the relevant literature, the use of Q-sort methodology to determine the appropriate categorization of support indicators in support areas, and a pilot test of an initial version of the scale.

Phase 1: Literature Review
Twelve initial support areas (i.e., home living, community living, schooling and education, employment, health and safety, behavioral, social, financial, personal care, self-advocacy, technological, and family) were derived from a review of the professional literature regarding support functions and quality of life. Candidate indicators of support were identified from the relevant literature by searching (a) major electronic databases (e.g., ERIC, Psychlit); (b) published assessments of adaptive behavior (e.g., Inventory for Client and Agency Planning—ICAP, Adaptive Behavior Scale—ABS), (c) relevant texts and recent review articles, and (d) unpublished government reports related to service provision. A total of 33 descriptors (e.g., supported employment, social supports, supported living) were used alone or in combination. These search efforts resulted in the identification of 130 potential indicators of support needs (e.g., shopping and purchasing goods, participating in educational decisions, socializing within and outside the family) drawn from approximately 1,500 sources.

Phase 2: Q-sort
We sought expert opinion to establish the content validity and eventual grouping of the 130 candidate support indicators using Q-sort methodology (McKeown & Thomas, 1988). In this second component, 74 professionals currently working in the field of developmental disabilities were asked to categorize the indicators according to the 12 support
Integrating supports

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areas that had emerged from the literature review. The following instructions were given to each respondent:

This Q-sort asks you to aggregate each support indicator into one of twelve support areas where the support indicator will logically have its maximum impact. For example, “housekeeping supports” would most logically impact “home living” the most.

Please complete your rating based on the following directions:

1. For each support indicator, please place a “1” in the support area column for which the respective support indicator will have its maximum and/or most logical impact. 2. If you feel that the respective support indicator would also have a secondary effect on a specific support area (that is, less than a maximum effect, but still an effect), place a “2” in that support area column.

3. If a support indicator has no relation to any of the support areas, please leave the row blank.

4. Based on your experiences, please feel free to add additional support indicators to our list and indicate (with a “1” or “2”) which support area the suggested support indicator would impact.

Fifty responses were returned from individuals employed by universities, state governments, or provider agencies (68% response rate). We arbitrarily established two criteria for retention: 80% of the raters had to rate the item and the item had to have a mean rating of 1.1 or less. A sufficient number of items were retained to justify maintaining 8 of the 12 initial support areas (personal care, technological, family, and financial were dropped as distinct areas of support). In addition, 2 support areas were renamed (self-advocacy was renamed protection and advocacy; schooling and education was renamed education and training). The eight support areas and corresponding support indicators that were retained were incorporated into a pilot version of a supports needs assessment scale. The resulting SIS was developed to measure support needs within each area. Further, the instrument includes sections concerning critical medical and behavioral support needs. These sections were added because certain medical conditions and challenging behaviors dictate that an individual will require maximum levels of support, regardless of his or her relative intensity of support needs in other life areas. For example, consumers who have significant support needs in terms of respiratory care can need maximum support in their daily life, regardless of their needs in the areas of home living, community living, and so forth.

Phase 3: Pilot Field Test

Participants. Forty-six raters from nine sites (New York, NY, n = 10; Morganton, NC, n = 13; Sioux Falls, SD, n = 38; Brookings, SD, n = 5; Bryan, TX, n = 5; Dallas, TX, n = 5; Temple, TX, n = 2; Casper, WY, n = 8; and Thermopolis, WY, n = 7) participated. Each rater completed the SIS on at least one individual with whom he or she worked. A total of 93 individuals with mental retardation or related developmental disabilities comprised the convenience sample for the pilot field test. The demographic characteristics of the raters and those who were rated are found in Table 2. As can be seen, the raters were predominately female European Americans with bachelor’s degrees and several years of experience. Those rated were a diverse group, with good representation across such characteristics as ethnic groups, intelligence levels, and employment status.

Method. The authors sent letters to colleagues who work with adults who have mental retardation and asked them to identify professionals in their area who might be willing to help field test the instrument. Based on the referrals, 46 professionals agreed to complete the SIS on people with mental retardation with whom they worked. Each rater was sent a letter of introduction, an examiner’s manual, multiple copies of the scale, and a postage-paid return envelope. Raters were asked to select adults from their caseload who represented a diverse range of skills. They were also asked to provide anecdotal comments on each item’s wording, intent, and value with regards to support needs assessment.

When the completed protocols were received, data were entered and item analyses were conducted by generating internal consistency coefficients (alpha) and item-total coefficients for each of the SIS subscales. Pearson product-moment coefficients of correlation were calculated to explore the concurrent and construct validity of the scale. All data were analyzed using SPSS.

Before running the data analyses, we computed Pearson product-moment coefficients of correlation to determine whether each SIS subscale score was related to the age and gender of the people who were rated. In all instances, coefficients were less than .2, demonstrating negligible association with both variables. Therefore, neither age nor gender were included as variables in subsequent analyses.

Results. Results of the item analysis are depicted in Table 3. Internal consistency coefficients were extremely high and exceeded .90 in all instances. Several authorities have cited .90 as the acceptable level for demonstrating adequate reliability for assessment scales (e.g., Aiken, 2000; Anastasi & Urbina, 1997; Nunnally & Bernstein, 1994; Salvia & Ysseldyke, 1998), so the SIS subscales far exceed
Table 2  Demographic Characteristics of Raters and Individuals Being Rated

<table>
<thead>
<tr>
<th>Variable</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Raters (n = 46)</strong></td>
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<tr>
<td>Gender</td>
<td></td>
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<tr>
<td>Male</td>
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</tr>
<tr>
<td>Female</td>
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<tr>
<td>Education</td>
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<td>Doctorate</td>
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<td>Ethnicity</td>
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<td>European American</td>
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</tr>
<tr>
<td>Hispanic American</td>
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<tr>
<td>Years experience</td>
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<tr>
<td>&lt;1</td>
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</tr>
<tr>
<td>1–2</td>
<td>4</td>
</tr>
<tr>
<td>3–5</td>
<td>14</td>
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<tr>
<td>6–10</td>
<td>27</td>
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<tr>
<td>&gt;10</td>
<td>48</td>
</tr>
<tr>
<td><strong>Individuals being rated (n = 93)</strong></td>
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<tr>
<td>Gender</td>
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<tr>
<td>Male</td>
<td>62</td>
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<td>Female</td>
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<tr>
<td>Age</td>
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<td>&lt;21</td>
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<td>21–30</td>
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<td>31–40</td>
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<td>41–50</td>
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<td>&gt;50</td>
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<tr>
<td>Intelligence levels (in quotients)</td>
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<td>20–35</td>
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<tr>
<td>51–69</td>
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<tr>
<td>Ethnicity</td>
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<tr>
<td>African American</td>
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</tr>
<tr>
<td>American/Indian/Eskimo/Aleut</td>
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Table 2  Continued.

<table>
<thead>
<tr>
<th>Variable</th>
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<tr>
<td>Hispanic American</td>
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</tr>
<tr>
<td>Other</td>
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</tr>
<tr>
<td>Residence</td>
<td></td>
</tr>
<tr>
<td>At own home without supports</td>
<td>9</td>
</tr>
<tr>
<td>At own home with supports</td>
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<tr>
<td>At home with parents</td>
<td>14</td>
</tr>
<tr>
<td>Staffed apartment building</td>
<td>15</td>
</tr>
<tr>
<td>Foster care/live-in staff</td>
<td>15</td>
</tr>
<tr>
<td>Midsize group home</td>
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</tr>
<tr>
<td>(7–15 residents)</td>
<td>20</td>
</tr>
<tr>
<td>Nursing facility</td>
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</tr>
<tr>
<td>Institution*</td>
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</tr>
<tr>
<td>Presence of disabilities other than MR</td>
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</tr>
<tr>
<td>Legal blindness</td>
<td>14</td>
</tr>
<tr>
<td>Deafness/hearing impairment</td>
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</tr>
<tr>
<td>Psychiatric disability</td>
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<tr>
<td>Developmental disability</td>
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<tr>
<td>Physical disability: arm/hand limitations</td>
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</tr>
<tr>
<td>Physical disability: mobility limitations</td>
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<tr>
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<td>Brain/neurological damage</td>
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<tr>
<td>Speech/language impairment</td>
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</tr>
<tr>
<td>Learning disability</td>
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<td>Other</td>
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<tr>
<td>Employment</td>
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<td>Student</td>
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<tr>
<td>Competitive employment</td>
<td>7</td>
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<td>Supported employment</td>
<td>14</td>
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<td>Sheltered employment</td>
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<tr>
<td>Nonpaid employment/volunteer work</td>
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<tr>
<td>Unemployed</td>
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<td>Other</td>
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<tr>
<td>Primary language understood</td>
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<td>English</td>
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<td>Spanish</td>
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<tr>
<td>Other</td>
<td>2</td>
</tr>
</tbody>
</table>

*State school/state hospital with over 15 residents.
Table 3  Item Analysis Data by Support Intensity Scale Subscale

<table>
<thead>
<tr>
<th>Item</th>
<th>Subscale</th>
<th>HL</th>
<th>CL</th>
<th>E/T</th>
<th>EMP</th>
<th>H&amp;S</th>
<th>BEH</th>
<th>SOC</th>
<th>P&amp;A</th>
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<tbody>
<tr>
<td>Internal consistency reliability</td>
<td></td>
<td>.97</td>
<td>.98</td>
<td>.99</td>
<td>.98</td>
<td>.98</td>
<td>.98</td>
<td>.98</td>
<td>.98</td>
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<tr>
<td>Median rating</td>
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<td>2.05</td>
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<td>1.61</td>
<td>1.94</td>
<td>1.71</td>
<td>1.67</td>
<td>1.82</td>
<td>1.77</td>
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<tr>
<td>Median discriminating power</td>
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<td>.52</td>
<td>.54</td>
<td>.76</td>
<td>.69</td>
<td>.74</td>
<td>.74</td>
<td>.68</td>
<td>.63</td>
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</tbody>
</table>

Note. All coefficients significant, \( p < .01 \).

\( ^{a} \text{HL} = \text{Home Living}, \text{CL} = \text{Community Living}, \text{E/T} = \text{Education/Training}, \text{EMP} = \text{Employment}, \text{H&S} = \text{Health & Safety}, \text{BEH} = \text{Behavior}, \text{SOC} = \text{Social}, \text{P&A} = \text{Protection & Advocacy} \).

this criterion. Also shown in Table 3 are indices of item, and therefore content, validity (Guilford & Fruchter, 1978), depicted as median discriminating powers for the items composing each subscale. Ebel (1972) and Pyrczak (1973) suggested that discrimination indexes of .35 or higher are acceptable, whereas Anastasi and Urbina (1997) and Garrett (1965) suggested that indexes as low as .20 are acceptable under some circumstances. We selected the more conservative value of .35 as our criterion for acceptability. Table 3 reveals that all median coefficients exceeded this value, demonstrating the content validity of the items that compose each SIS subscale.

The median ratings for each subscale are also shown in Table 3. Anastasi and Urbina (1997) reported that average scores should be in the mid-range of possible responses, with a fairly wide dispersion, to demonstrate item variance. Given that the values range from 1 to 4 for most items, the ratings in the 2-point range that appear in Table 3 would seem to somewhat satisfy the criterion.

Criterion-related validity was explored next. This type of validity is examined by correlating results from a new scale with results measuring performance from an existing measure or individuals’ estimates of abilities on the construct of interest (Hamill, Brown, & Bryant, 1992; Salvia & Ysseldyke, 1998), in this case support needs. To explore the criterion-related validity of the SIS subscales, we asked each rater to estimate on a 5-point Likert scale the overall support needs of the person being rated in each of the eight support areas defining the SIS subscales. This estimate was made prior to the scale items being completed. The estimates were correlated with the total score of each subscale (i.e., Home Living, with estimated support needs in Home Living; Social, with estimated support needs in Social, and so on); the results are reported in Table 4. As can be seen, all but one of the resulting coefficients exceeded .35, the minimum value suggested by Hamill et al. as demonstrating acceptable criterion-related and construct validity. Thus, evidence for the criterion-related validity of all SIS scores except Protection and Advocacy was secured.

Finally, construct validity of the SIS scores was examined in two ways. First, each subscale was intercorrelated with the other subscales to determine the extent to which the subscales measure the same construct, support needs. If the subscales do indeed measure the same overall construct, one would expect the coefficients to be in the moderate to very high range, or about .4 to .9 (MacEachron, 1982). Perusal of Table 5 shows the coefficients to range from .45 to .87, with a median coefficient of .715. Reexamining Table 4 provides further exploration of the construct validity of the SIS subscales. Here, several coefficients depict the relationship between the subscales and the raters’ estimates of support needs in the other areas. The results indicate that six of seven coefficients met or exceeded .35 for Home Living. The remaining subscales have the following acceptable rates: Community Living, seven of seven; Education and Training, seven of seven; Employment, four of seven; Health and Safety, six of seven; Behavioral, five of seven; Social, seven of seven; and Protection and Advocacy, six of seven. According to Hamill et al. (1992), if half of the coefficients reach .35 in magnitude, evidence of construct validity is demonstrated. This criterion was achieved for the SIS subscales.

The second examination of construct validity was conducted by comparing SIS subscale scores with scores from the ICAP (Bruininks, Hill, Weatherman, & Woodcock, 1986), a popular adaptive behavior scale. Fifty-seven people who were rated on the SIS had also been rated using the ICAP. Because the ICAP is an adaptive behavior scale and
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Table 4  Intercorrelations of Supports Intensity Scale Subscales With Rater Estimates of Abilities

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Rater estimates&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HL</td>
</tr>
<tr>
<td>HL</td>
<td>.59&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>CL</td>
<td>.53&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>E/T</td>
<td>.57&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>EMP</td>
<td>.38&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>H&amp;S</td>
<td>.59&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>BEH</td>
<td>.32&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>SOC</td>
<td>.45&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>P&amp;A</td>
<td>.60&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

Note. All coefficients significant, <i>p</i> < .01.

<sup>a</sup>HL = Home Living, CL = Community Living, E/T = Education/Training, EMP = Employment, H&S = Health & Safety, BEH = Behavior, SOC = Social, P&A = Protection & Advocacy. <sup>b</sup>Coefficients evident of criterion-prediction validity. <sup>c</sup>Coefficients evident of construct-prediction validity.

the SIS is not, results from the latter should correlate less with the ICAP than another measure of support needs (i.e., rater estimates of support needs). Thus, in some instances, we would expect the ICAP adaptive behavior scores and the SIS scores to intercorrelate in the moderate range (about .4 to .6). In regard to the Maladaptive Indexes of the ICAP, we would expect negligible coefficients (i.e., < .2) or coefficients that are not significant at the .05 level. This is consistent with the relationship between adaptive behavior and maladaptive behavior as indicated in various test manuals (e.g., AAMR Adaptive Behavior Scales, Residential and Community Edition, 2nd edition, Nihira, Leland, & Lambert, 1993).

Table 6 summarizes the relationships among the SIS and ICAP subscales. The results are equivocal, possibly because the nature of the relationship between adaptive behavior and support needs requires further examination before concrete hypotheses can be generated. For Home Living, all six coefficients with adaptive behavior exceed .35, and all four coefficients with maladaptive behavior are not significant at the .05 level of confidence. Community Living and Health and Safety have similar findings, with five of six and four of four coefficients appearing as hypothesized for adaptive and maladaptive behaviors, respectively. However, for Education and Training, Employment, and Protection and Advocacy, the relationship to the ICAP adaptive behavior scores are either one of six or two of six meeting criterion for acceptability, indicating a

Table 5  Intercorrelations of Supports Intensity Scale Subscales With One Another

<table>
<thead>
<tr>
<th>Subscale&lt;sup&gt;a&lt;/sup&gt;</th>
<th>HL</th>
<th>CL</th>
<th>E/T</th>
<th>EMP</th>
<th>H&amp;S</th>
<th>BEH</th>
<th>SOC</th>
<th>P&amp;A</th>
</tr>
</thead>
<tbody>
<tr>
<td>HL</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CL</td>
<td>.66</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E/T</td>
<td>.55</td>
<td>.70</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EMP</td>
<td>.49</td>
<td>.74</td>
<td>.84</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>H&amp;S</td>
<td>.75</td>
<td>.84</td>
<td>.80</td>
<td>.81</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BEH</td>
<td>.45</td>
<td>.73</td>
<td>.70</td>
<td>.78</td>
<td>.79</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SOC</td>
<td>.68</td>
<td>.82</td>
<td>.73</td>
<td>.79</td>
<td>.88</td>
<td>.85</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>P&amp;A</td>
<td>.47</td>
<td>.81</td>
<td>.75</td>
<td>.80</td>
<td>.85</td>
<td>.87</td>
<td>.84</td>
<td>1.00</td>
</tr>
</tbody>
</table>

Note. All coefficients significant, <i>p</i> < .01.

Table 6  Intercorrelations of Supports Intensity Scale (SIS) Subscales With Inventory for Client and Agency Planning (ICAP) Subscales

<table>
<thead>
<tr>
<th>ICAP subscale</th>
<th>SIS subscale</th>
<th>HL</th>
<th>CL</th>
<th>E/T</th>
<th>EMP</th>
<th>H&amp;S</th>
<th>BEH</th>
<th>SOC</th>
<th>P&amp;A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor Skills</td>
<td></td>
<td>.67</td>
<td>.41</td>
<td>NS</td>
<td>NS</td>
<td>.40</td>
<td>NS</td>
<td>.11</td>
<td>NS</td>
</tr>
<tr>
<td>Social and Community Skills</td>
<td></td>
<td>.63</td>
<td>.57</td>
<td>.31</td>
<td>.34</td>
<td>.52</td>
<td>NS</td>
<td>.49</td>
<td>.33</td>
</tr>
<tr>
<td>Personal Living Skills</td>
<td></td>
<td>.76</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>.13</td>
<td>NS</td>
</tr>
<tr>
<td>Community Living Skills</td>
<td></td>
<td>.68</td>
<td>.58</td>
<td>.32</td>
<td>.38</td>
<td>.58</td>
<td>NS</td>
<td>.51</td>
<td>.32</td>
</tr>
<tr>
<td>Broad Independence Index</td>
<td></td>
<td>.51</td>
<td>.35</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>.15</td>
<td>NS</td>
</tr>
<tr>
<td>Internalized Maladaptive Index</td>
<td></td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>.32</td>
<td>.39</td>
<td>NS</td>
</tr>
<tr>
<td>Asocial Maladaptive Index</td>
<td></td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>.24</td>
<td>NS</td>
</tr>
<tr>
<td>Externalized Maladaptive Index</td>
<td></td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>.30</td>
<td>.29</td>
</tr>
<tr>
<td>General Maladaptive Index</td>
<td></td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>.37</td>
<td>.39</td>
</tr>
<tr>
<td>ICAP Service Score</td>
<td></td>
<td>.79</td>
<td>.66</td>
<td>.39</td>
<td>.42</td>
<td>.66</td>
<td>.45</td>
<td>.61</td>
<td>.50</td>
</tr>
</tbody>
</table>

Note. Coefficients indicated as absolute values.

*HL = Home Living, CL = Community Living, E/T = Education/Training, EMP = Employment, H&S = Health & Safety, BEH = Behavior, SOC = Social, P&A = Protection & Advocacy. *Not significant at the .05 level; all other coefficients were significant at .05 or better. Because SIS and ICAP items are inversely worded, all correlations were negative.

weak relationship to adaptive behavior (although the maladaptive coefficients were as hypothesized). The Behavioral and Social SIS subscales also do not meet criterion, with one of six and two of six coefficients below .35, respectively. Also, the Behavioral and Social SIS subscales, respectively, have one and two of four coefficients depicting relationships above .35 with the maladaptive scales, which provide somewhat equivocal findings.

Discussion. When one considers all of the data exploring the construct validity of the subscales (i.e., subscale intercorrelations, correlations with rater estimates of support needs in other content areas, and the relationship with SIS scores), the results seem to provide considerable evidence of the construct validity of the SIS. Clearly, however, more research is needed.

To summarize, the item analyses support the reliability and content validity of the SIS subscales, verifying the appropriateness of the process of selecting items based on comprehensive literature review followed by a Q-Sort by experts in the field of mental retardation. Criterion-related validity was examined by comparing SIS scores to ratings by professionals of their clients’ support needs in the eight areas assessed by the SIS subscales. The findings provide support for the criterion-related validity of seven of the eight subscales. Finally, SIS scores were examined by looking at the subscales’ intercorrelations, the intercorrelation of the subscales with estimates of support needs in different content areas, and comparisons of SIS scores with the ICAP. Converging evidence for the construct validity of the SIS was evident, providing strong justification for the continued development of the instrument.

Proposed Uses of a Systematic Approach to Support Needs Assessment and Planning

Information generated from the four-component assessment and planning process can be used for a number of purposes. In this section we suggest that three primary uses will involve (a) determining ISFs, (b) identifying persons based on their intensity of needed supports, and (c) developing objective and equitable approaches to funding supports for persons with disabilities.

Individualized Support Plans

As indicated earlier, a planning team will consider an individual’s personal goals and preferences as well as the nature and intensity of support needs in developing the ISP. In addition, the team must consider all of the sources of support that are available to the individual and the settings in which supports will be provided. Once an ISP is devel-
veloped, the planning team must ensure that it is implemented with fidelity and as intended throughout an individual's day and throughout the year. A detailed and comprehensive ISP will specify who will be responsible for providing what type of support, and where and when the support will be provided (e.g., an ISP may identify a coworker to help an individual with limited vision choose lunch items in the cafeteria at work during lunch breaks).

Collaboration and communication among support providers and the planning team is critical to ensure that all supports are, to the greatest extent possible, provided as specified in the ISP without duplication or interruption. For example, if a family member typically drives an individual to school or work, but the family member is for any reason unavailable, the planning team must identify an effective alternative. Ongoing monitoring is critical to evaluate the extent to which the ISP is being implemented effectively as well as to determine (a) the individual's satisfaction with support received and (b) areas of support requiring modification and accommodation.

Identifying an Individual's Support Needs Level

The AAMR's 1992 definition of mental retardation and its proposed supports intensity-based classification system (Luckasson et al., 1992) highlighted the issue of measuring support needs within the field of mental retardation and closely related development disabilities. MacMillan, Gresham, and Siperstein (1993) expressed concern that the absence of instruments to measure the intensity of support needs made such a classification system “less precise and less reliable” than traditional alternatives that focused on the extent of a person’s limitations/deficits. Vig and Jedysek (1996) questioned how a support needs classification system could be relevant to young children. They pointed out that all young children “need maximum adult support in all aspects of their lives because of their young age. Attempting to specify support functions or kinds and intensities of supports for this age group is apt to be subjective or artificial” (p. 246). Luckasson, Schalock, Snell, and Spitalnik (1996) responded to Vig and Jedysek by asserting that assessment for young children with mental retardation should center on identifying the types and intensity of supports that families of the children need. They concluded that a support need orientation was especially relevant and useful for this age group.

Although the discourse on the merits of implementing a classification system based on support needs has been enlightening, there is a danger that a false dichotomy may emerge, pitting the measurement of personal support needs against the measurement of personal competence (i.e., an individual’s relative strengths and weaknesses in areas traditionally associated with intelligence and adaptive behavior). Support needs and personal competence are related but distinct constructs, and both need to be adequately assessed.

It is important to note that efforts to measure support needs are in their infancy and that there is currently no process that has gained wide acceptance. However, despite a much longer history, procedures to measure personal competence are certainly less than perfect. In terms of identifying and classifying individuals in regard to personal competence, there are considerable differences in diagnostic and classification practices across states and over time (Butterworth, Gilmore, Kiernan, & Schalock, 1999; Denning, Chamberlain, & Pollock, 2000; Frankenberger & Fronzaglio, 1991; MacMillan, Gresham, Siperstein, & Bocian, 1996). Moreover, for over 20 years, Greenspan and others have argued convincingly that components of personal competence associated with social intelligence have been overlooked during the assessment process (Greenspan, 1979; Greenspan & Driscoll, 1997; Greenspan & Granfield, 1992).

Whether people should be identified and/or classified by level of support needs or by level of personal competence should not mask the need to assess both areas, nor should it divert attention from the importance of developing reliable and valid assessment instruments to measure both areas. The SIS appears to have the potential to identify people's support needs within specific areas as well as on the basis of a summative score.

Data-Based Approach to Funding Supports

There are many factors that influence how much funding is provided to an individual for the purpose of purchasing supports (e.g., disability profile and actual needs, strength of advocacy network, service program models, geographic location, diagnostic label and classification, residential setting). One use of the four-component approach for assessing support needs that has been described in this article is to provide objective information regarding individual support needs and strengthen the weight given to this information in the process of allocat-
ing public funds. With everything else being equal, people with more significant support needs will require more resources (including funding) in order to participate in home and community life. Although decisions regarding funding formulas must always be made thoughtfully and will always be influenced by a multitude of considerations, a system for objectively identifying and measuring support needs should be among the major priorities of those who strive to achieve an equitable system for distributing public funds.

Although a support needs scale such as the SIS has the potential to provide helpful information in regard to broad decisions about the composition of funding formulas, data from an assessment scale is not going to be sufficient for resolving all budget dilemmas. As stated previously, the individual with the disability, his or her family, and other members of the support team must be prepared to make choices regarding support priorities in a world of finite resources. Information from a person-centered planning process (i.e., Component 1) should be helpful in deciding how funds are spent in individual cases.

**Issues and Challenges Associated With Support Needs Assessment and Planning**

Any new approach to measuring support needs and planning personalized support programs will raise significant issues and encounter challenges. These should be anticipated and addressed whenever possible to increase the likelihood of broad acceptance, adoption, and utilization. Several of these major concerns have been considered in developing the approach described in this article.

The first concern has to do with the breadth of acceptance. As of yet, no specific procedures for systematically identifying the support needs of individuals with disabilities have gained widespread acceptance. The lack of a clearly defined procedure to measure support needs may be a major reason why the AAMR’s 1992 definition and classification system has not been implemented universally (Followay, Chamberlain, Denning, Smith, & Smith, 1999). The adoption of recommendations by existing organizations and authorities is essentially discretionary. Therefore, it is important that proposals are structured to be appealing, both practically and intuitively, to as broad a community of potential users as possible. Otherwise, the proposed approach will have a narrow constituency and minimal impact on practice.

A proposed approach to assessing individual support needs must be manageable in scope if it is going to be widely adopted. Support need assessments must be concise enough to be completed in an acceptable amount of time. Moreover, they must be simple enough to permit participation by individual consumers or people with significant firsthand familiarity with the consumer’s priorities. Also, assessments must entail acceptable costs.

Information collected through a support needs assessment process should capture the full range of individual needs within the population of persons with mental retardation and related developmental disabilities. Assessment scales should have adequate reliability and validity and should be sufficiently objective and representative to permit meaningful comparisons among individuals and across time within individuals.

These considerations all require that an assessment process provide sufficient structure and uniformity to permit ISPs to be developed in an objective, even-handed, dynamic, and realistic way. The situation for each consumer will be unique with respect to individual priorities and environmental settings. Further, each provider agency may have established procedures that are not readily compatible with a new approach to evaluation. Therefore, sufficient flexibility must be incorporated into the design of the assessment process to permit each support plan to be tailored to the unique needs of each individual within their particular support network.

On the other hand, a support needs assessment process should acknowledge practical constraints that are currently imposed, either by lack of support availability or the limits of consumer abilities. However, these limitations need not be permanent barriers, and a good approach to measuring needs and planning personalized support programs will encourage both the expansion of services and growth of consumer capabilities. Although a successful approach needs to address current circumstances effectively, it must also stimulate enhancements in supports availability to broaden access to best practices.

Obviously, a fine balance will need to be achieved in order to deal with these concerns successfully, and whether this has been achieved in the current case will be a matter for the future record to decide. Considering these concerns, we have
tried to maximize the chances for broad implementation of the proposed approach for determining individual needs and designing programs of supports that are most likely to be consistent with consumer priorities. Ultimately, our goal is to facilitate the provision of supports that will have the greatest positive impact on each individual’s quality of life, and we believe that the approach described in this article will provide a significant step in that direction.

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Authors:
James R. Thompson, PhD, Chairperson, Department of Special Education, Illinois State University, Mail Code 5910, Normal, IL 61790–5910. Carolyn Hughes, PhD, Professor, Department of Special Education, Vanderbilt University, Box 328, Peabody College, Nashville, TN 37203. Robert L. Schalock, PhD, Professor Emeritus, Hastings College, PO Box 285, Chewelah, WA 99109–0285. Wayne Silverman, PhD, Senior Research Scientist, New York State Institute for Basic Research in Developmental Disabilities, 1050 Forest Hill Rd., Staten Island, NY 10314. Marc J. Tassé, PhD, Clinical Scientist, Center for Development and Learning, University of North Carolina at Chapel Hill, CB# 7255, Chapel Hill, NC 27599. Brian R. Bryant, PhD, President, Psycho-Educational Services, 5114 Balcones Woods Dr., #307–163, Austin, TX 78759. Ellis M. Craig, PhD, Research Specialist, Texas Department of Mental Health and Mental Retardation. Edward M. Campbell, PhD, President, E=MC2 Consulting, Inc., 502 E. Missouri, Pierre, SD 57501.