

A Breakthrough Approach to the Provision of Services is Creating a Brighter Outlook for People with Developmental Disabilities

The AAMR Supports Intensity Scale Shifts the Focus from Deficits to Needs

By Dan Sperling

The prospects of leading a quality life have never looked brighter for people with developmental disabilities, thanks to a new approach to providing services that focuses on the individual rather than on statistical norms – and on the supports a person needs to find fulfillment in life, rather than on the ways in which he or she falls short of the general population.

The cornerstone of the new approach is a groundbreaking planning tool developed by the American Association on Mental Retardation (AAMR). Called the Supports Intensity Scale (SIS), it enables professionals to assess the practical support needs of people with intellectual disabilities and, in the process, shift the focus from a person's deficits to his or her specific needs, goals and aspirations. Through a comprehensive interview process that includes friends and family members as well as the client, SIS helps case managers and other professionals identify what supports are needed in medical, behavioral, and life activity areas to help developmentally disabled adults participate in their communities, assume valued social roles and experience greater satisfaction and fulfillment.

This should come as good news for the country's 4 to 7 million people with developmental disabilities, as well as to their families and caregivers. Already, three states – Georgia, Utah, and Louisiana – have officially adopted SIS, with dozens of other states in the preliminary stages of that process. And many private service providers across the country have also become SIS users.

“The Supports Intensity Scale is the first assessment that recognizes that disability is much more of a social construct than a biological one,” says Steven Hall, director of the Georgia Office of Developmental Disabilities. “Rather than determining what is wrong or deficient within the person, as conventional assessments do, SIS helps us determine what kind, amount and intensity of supports are needed for someone to succeed in the important areas of his or her individual life.”

Georgia began using SIS in November 2005, opting for a web-based version of the tool (SIS is also available in CD-ROM and hardcopy versions), which includes electronic scoring options to help states gather data and develop a better understanding about people with developmental disabilities. Hall anticipates that by June of 2006, every one of the 12,000 Georgians with developmental disabilities who are receiving services will have benefited from SIS.

“SIS ensures that the very real support needs of the individual are addressed, instead of the imagined support needs based on a disability level,” he says. “Never again in Georgia will a person with a disability have to fit into a preconceived set of services or programs.”

The philosophy behind SIS can be traced back to 1992, when AAMR published the first supports-based definition and classification system of mental retardation. This was at one and the same time a radical step away from the deficits-based view of mental retardation that had prevailed for so long, and a reflection of the direction in which thinking in the field had been evolving. “Expectations have heightened dramatically over the past half-century for people with disabilities,” says AAMR executive director M. Doreen Croser. “As a society, we’ve moved away from viewing them as ‘deficient’ and now see them as individuals who have their own abilities and need support to maximize them.”

However, it wasn’t until AAMR published SIS in 2004 that professionals had a practical tool to help them put the supports-based definition of mental retardation into practice by enabling them to gauge the needs of clients in a more comprehensive manner than ever before. Five years of work by a team of assessment and disability experts led to the publication of SIS, which consists of an eight-page interview form that ranks a person’s needs in 85 different areas, as well as a manual that explains how to administer it.

“For years I begged for a tool that wasn’t deficit-driven, and now we have one,” says Greg Kirk, director of professional counseling services for Americus, Inc., a support coordination/case management agency serving 4,000 people with developmental disabilities in Georgia.

“Finally we’re identifying strengths, and we’re looking at supports that people who happen to have developmental disabilities need in order to be successful in life. SIS causes providers of services to look at people with developmental disabilities as being genuine parts of the general population, rather than less than the general population.”

One immediate effect of SIS has been to quickly, and sometimes dramatically, expand the horizons of many professionals who serve people with developmental disabilities – and even those of family members. “SIS includes things such as employment and lifetime learning that a lot of providers, and even family members, would never imagine the client doing,” says Colleen McLaughlin, an evaluation coordinator at the Institute on Disabilities at Temple University in Philadelphia and an AAMR SIS trainer. “In so doing, it forces them to ask questions that open up a whole new range of possibilities.”

Developed over a five-year period by a team of AAMR disability and assessment experts who applied rigorous standards combined with state-of-the-art research, SIS measures the level of practical supports required by people with intellectual disabilities to lead normal, independent, quality lives in society. It covers 85 general, medical and behavioral areas, including home living, community living, lifelong learning, employment, health and safety, social activities, protection and advocacy, as well as medical and behavioral support needs. All of these supports are rated for frequency (how often support is needed), daily support time (how many hours of support is needed) and type of support (verbal, gesturing, physical assistance, etc.).

Intended as the cornerstone of a systematic process of identifying goals and needed supports and creating an individualized plan, SIS is being enthusiastically adopted by psychologists,

case managers, transition coordinators, nurses, occupational therapists, social workers, supports brokers, teachers, trainers, special educators and doctors. In addition to benefiting clients, it also boosts efficiency, both on a program and state level.

“We’ve found SIS to be a very useful tool to help us allocate resources to people with developmental disabilities,” says John Stern, assessment project program director of the Aging and Disability Services Administration in Washington state, which plans to begin using SIS in March 2007. “Just as importantly, it covers such a breadth of topics that it helps providers and family members stay focused on the easily overlooked fact that clients can still grow, change and learn.”

“SIS is a tremendous tool for identifying how to support an individual in very practical ways,” adds Dave Wyher, president of Delta Community Supports Inc. in Lower Gwynedd, Pennsylvania, which provides services for developmentally disabled adults throughout that state. “It enables us to improve the quality of our individual support plans, leading to better allocation of resources and, ultimately, better results for the people we serve.”

For more information on SIS, including how to order, visit www.siswebsite.org. For queries on SIS, email books@aamr.org

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