

## **The *Supports Intensity Scale*: How was it developed?**

In December 2003, the American Association on Mental Retardation (AAMR) published the *Supports Intensity Scale (SIS)*, a unique planning tool designed to help professionals determine the true support needs of persons with intellectual disabilities. The *SIS* was developed by a team of 10 disability, psychology, and assessment experts over a period of five years, a portion of which was spent on norming the Scale, a pivotal step in the development of a test instrument. In assessment, the term norming or standardization refers to the collection of data from the broadest and best representation of a randomly selected population so that the Scale truly reflects the needs of the population it is geared to serve. This article describes the norming process of the *Supports Intensity Scale*. From an interview with *SIS* co-author Dr. Marc J. Tassé, we see the many efforts taken by the *Supports Intensity Scale* authors and hundreds of professionals across the country—all on a volunteer basis—to make the Scale a reliable and workable tool for persons with intellectual disabilities.

The standardization of the *Supports Intensity Scale* was a major process. Dr. Tassé co-managed the field-testing of the Scale with Dr. James R. Thompson, Chair of the *SIS* author team. From seeking participation from agencies and individuals to writing letters of requests and collecting data from hundreds of people across the country, the magnitude of the project was formidable. However, it was a job well worth the effort, points out Dr. Tassé, given the significance of the Scale for the disability community worldwide. The *Supports Intensity Scale* is the first instrument of its kind that has a unique, positive approach to evaluating the needs of a person with an intellectual disability. The Scale considers the support *needs* of a person with an intellectual disability rather than *deficits* or what he or she *lacks*, as the basis for determining supports required to live a successful, independent life in society.

The *SIS* standardization process began in 1999 when the authors sent out personalized letters to several hundred agencies and professionals across the country requesting their participation in the field-testing of the *Supports Intensity Scale*. After not receiving much response, the authors decided to focus instead on the AAMR membership, specifically those professionals who worked with adults 18 years or older with mental retardation. This was easier said than done since it meant culling through a database of more than 7,000 contacts to select those that were most

appropriate for the *SIS* field-testing process. Over the next few months, the *SIS* author team carefully reviewed each member listing and created a shorter list of around 2,000 individuals. The authors took care to recruit, in particular, a group that reflected the U.S. Census data as closely as possible, including the actual demographic split of the population—22% from the West, 23% from the Midwest, 36% from the South, and 19% from the North East—as per the 2000 U.S. Census data. This goes back to the principle behind standardization of a Scale—that the sample should be a true reflection of the population it is meant to serve. Not only did the authors consider geography, but they also accounted for other factors, such as the male to female ratio, the cognitive and adaptive functioning level, the percentage of elderly population, and the ethnic origin of the population.

The authors then sent each AAMR member selected a personalized letter enquiring about their willingness to use the *Supports Intensity Scale* to interview people they knew or worked with between the ages 16-72. The letter specifically requested each participant to administer the *SIS* on a minimum of 5 people and a maximum of 100 persons. Each *SIS* interview form required the administrator to spend at least 45 minutes, and conducting 10 *SIS* interviews boiled down to spending 450 minutes or a good portion of a work day on this effort!

The effort paid off, with some individuals volunteering to administer *SIS* to as many as 100 persons within their agency. Says Dr. Tassé, “When AAMR members were contacted, there was an explosion of participation.” Phone calls, emails, and letters expressing enthusiasm at the task poured in. Dr. Tassé points out that kinship to the Association was a major factor that contributed to the overwhelming response from AAMR members. “They knew this was an important task for the field at large and they wanted to make sure they participated.”

In 2002, the authors and an active group of volunteers began the long process of mailing *Supports Intensity Scale* protocols to the 2,000-odd agencies and individuals who agreed to participate in the final standardization phase of the instrument. The center for this new mailing effort was Dr. Jim Thompson’s office at the Illinois State University. Each *SIS* field test participant was sent a package containing a copy of the *SIS* interview form, instructions on how to use the *SIS*, and a prepaid envelope with a return address. Each agency was sent the number of forms requested, anywhere from 1- 100 in number. The completed forms were received by Dr. Thompson’s office

and data was entered electronically by volunteers between spring 2002 and fall 2002. From the 2,000 protocols mailed, around 1,300 interview forms were returned and a solid dataset that would serve as a foundation for creating what was to become the *Supports Intensity Scale* two years later.

The path to creating *SIS* was a long and arduous one and we asked Dr. Tassé what was the biggest challenge of all. “Time,” he responded. “Finding time from our varied schedules, one that was convenient to all 10 authors was the most challenging aspect of creating *SIS*, but we did it!” Needless to say, the *SIS* could not have happened without the time and efforts of volunteers at each step of the field-testing process—from mailing and data entry to the professionals who administered the instrument and the persons with mental retardation who participated in the testing process. Thanks to their commitment, the *SIS* was finally normed on 1,306 people between the ages of 16 and 70+ from 33 states and 2 Canadian provinces.

Behind every successful invention, there are people, and this article is an acknowledgement of the hard work and commitment of the people who made *Supports Intensity Scale* happen. And for self-advocates, the *SIS* is the dawn of something new, a journey down a progressive path that understands them as capable human beings who have needs like all of us and just need a little extra help achieve their life goals and aspirations.

If you’d like to read more about *SIS*, visit [www.aamr.org](http://www.aamr.org)

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