

Five Trends that Created the Need for the Supports Intensity Scale

Trend 1: Changes in Expectations for Persons with Disabilities

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

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

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

Trend 2: Functional Descriptions of Disabilities

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

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

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

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

Trend 3: Chronologically Age Appropriate Activities

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

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

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

Trend 4: Consumer-Driven Services and Supports

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

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

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

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

Trend 5: Support Networks that Provide Individualized Supports

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

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

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

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

The Spirit of the Age: The Supports Paradigm

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

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

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

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

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