This book’s purpose is to address contemporary issues in supporting people with severe disabilities to live rich, full, and high-quality lives in their communities. It will be difficult to achieve the vision established in this book until there is a fundamental change in the way in which disability itself is understood. A new and different way to understand disability in the 21st century does exist. This chapter describes that new paradigm and discusses the implications of its adoption for a future of equity and full participation.

HISTORICAL UNDERSTANDINGS OF DISABILITY

I coedited a book titled Mental Retardation in the 21st Century (Wehmeyer & Patton, 2000). Use of the stigmatizing term mental retardation has been discontinued for reasons subsequently discussed. I coauthored a chapter in that text with Hank Bersani, Jr., and Raymond Gagne, two leaders of the self-advocacy movement, that characterized the current era as representing the third wave of the disability movement. Our formulations were guided by issues pertaining to civil rights and social justice emerging through the field’s growing acceptance of the self-advocacy movement and focus on self-determination. Significant progress in elaborating better ways of understanding disability has provided a theoretical and scientific foundation to bolster the philosophical and moral issues that propelled our proposal of a new wave of the disability movement. The oft-cited adage that “what is past is prologue” is apropos in considering how to ensure a future of equity and full participation.
The First Wave of the Disability Movement: The Professional Era

Professionals dominated the first wave of the disability movement, which spanned through the latter half of the 19th and first half of the 20th centuries. At the height of this first wave, professionals defined the issues and created the then new discipline of disability as a subdiscipline within the fields of medicine, psychology, and education (Dybwad & Bersani, 1996). These professionals made decisions on their own or in consultation with one another. Parents and the public assumed that these professionals knew what was best because of their education and social status. Emphasis was on diagnosing and determining who would benefit from treatment. The images associated with disability were often universally negative. People with disabilities were stereotyped as menaces to society or responsible for many societal problems (see Figure 1.1) (Trent, 1994; Wehmeyer, 2013).

How disability itself was understood during this era was an extension of the medical model adopted by these early professionals. Disability historically was understood as an extension of a medical model that conceived health as an interiorized state of functioning and health problems as an individual pathology; that is, as a problem within the person. Disability within such a context was understood to be medical in nature and a characteristic of a person, as residing with that person. The person was viewed as broken in some way. The language of the professions that emerged to support people with disabilities reflects that conceptualization; people with disabilities were described as diseased, pathological, atypical, or aberrant, depending on the profession (Wehmeyer et al., 2008).

**Figure 1.1.** The menace of the feebleminded from undated report from the New Jersey Institution for Feebleminded Women (author’s collection).
The way in which disability is understood drives how people with disabilities are treated in both the sense of the nature and structure of services and supports provided to them and in the sense of how others, including the public, respond to them. The earliest efforts on behalf of people with disabilities were habilitative in nature and driven by tenets of social justice and social welfare. Thus, schools were established beginning in the 1830s and into the 1870s to educate children who were deaf or blind or who had an intellectual disability. People with severe disabilities were not included in these early efforts, however. For example, early schools for children with intellectual disability included only people who had limited support needs. Such efforts, however, transmogrified over time from habilitative in nature and intended to benefit the person to serving to isolate and segregate people with disabilities from society, eventually for the purposes of protecting society (Smith & Wehmeyer, 2012).

The professionals that built this system were not interested in the rights of people whom they called “retardates” or “mentally deficient.” People with severe disabilities were seen as menaces to society; threats to “racial hygiene”; and links to crime, poverty, promiscuity, and the decline of civilization by the first decades of the 20th century. They were seen as subhuman (“a vegetable”) or as objects to be feared and dreaded by these professionals and society at large. The U.S. Supreme Court ruled in 1927 that involuntary sterilization of people who were deemed to be feebleminded was constitutional, resulting in the forced sterilization of an estimated 50,000 people with intellectual and developmental disabilities by the 1970s (Smith & Wehmeyer, 2012).

More than 275,000 Americans, including most people with severe disabilities, lived in institutions that had become massive warehouses by the late 1960s. The Willowbrook State School on Staten Island, built to house 4,000 people, had an institution census of more than 6,000 inmates by the mid-1960s. After a tour of Willowbrook in 1965, a visibly distraught Senator Robert Kennedy told reporters,

I think—particularly at Willowbrook—that we have a situation that borders on a snake pit; the children live in filth; many of our fellow citizens are suffering tremendously because of lack of attention, lack of imagination, lack of adequate manpower. (Smith & Wehmeyer, 2012, p. 176)

Disability scholar Burton Blatt was propelled by Kennedy’s pronouncements and arranged to tour four institutions in the northeast, none of which were named but one of which was almost certainly Willowbrook, and brought with him photographer Fred Kaplan, who surreptitiously snapped photographs of the horrific conditions in the facilities. The resulting photo essay showed the stark black-and-white photographs of naked and apparently starving “inmates” with severe disabilities and rows of iron beds with children confined to them, juxtaposed with poetry verses and essays selected by Blatt. “There is hell on earth,” began Christmas in Purgatory, “and in America there is a special inferno. We were visitors there during Christmas, 1965” (Blatt & Kaplan, 1969, p. 1).

The Second Wave of the Disability Movement: The Parent Era

The parent era was the second wave of the disability movement and occurred during the middle of the 20th century. Advances in science and medicine greatly increased the life expectancy of people with disabilities. A growing worldwide
emphasis on rehabilitation and training emerged, catapulted forward by the large number of veterans disabled in World War II. Successes in developing vaccines for diseases such as polio and tuberculosis gave hope to greater cures for disabling conditions. The earlier stereotypes of disability were replaced with more humane ones, though this change was still problematic. People with disabilities were viewed as objects to be fixed, cured, rehabilitated, and, at the same time, pitied. They were viewed as victims of their disabling condition, worthy of charity. Shapiro described this when discussing the emergence of the poster child as a fundraising tool:

> The poster child is a surefire tug at our hearts. The children picked to represent charity fund-raising drives are brave, determined, and inspirations, the most innocent victims of the cruelest whims of life and health. Yet they smile through their unlucky fates. No other symbol of disability is more beloved by Americans than the cute and courageous poster child. (1993, p. 12)

People with severe disabilities were viewed as holy innocents within this stereotype (e.g., special messengers, children of God) and, thus, incapable of sin and not responsible for their own actions. People with severe disabilities came also to be perceived as eternal children, partially based on the prevalent use of mental age calculated from intelligence scores. Although no longer feared and blamed for all social ills, people with intellectual and developmental disabilities were perceived as children that needed protection, pity, and care.

The advances in science and changes in societal perceptions emboldened parents to demand to participate in decisions that affected their children and to reject the pessimistic forecasts of professionals as well as the treatment regimens associated with those forecasts, most notably institutionalization. Parents and family members began to advocate for services that would enable their children to remain at home, attend school, and live and work in their communities. Professionals slowly joined in the parent rebellion and recognized the importance of parents in the decision-making process. The movement eventually gained political clout and radically and unalterably changed the face of disability services during the 1950s, 1960s, and 1970s (Abeson & Davis, 2000).

The parent era ushered in the community era. Inclusion in communities and schools became the focus. Deinstitutionalization, spearheaded by pioneers such as Burton Blatt and nurtured by the wide adoption of the Normalization Principle (Nirje, 1969) and the emergence of the independent living movement, resulted in the shift from large congregate settings to community-based, although still congregate, living and educational settings. Nevertheless, this second wave did not alter the understanding of disability. Disability was still seen as aberrant, atypical, or pathological; as residing outside the normative experience and as a characteristic, quality, or condition of the person. People with disabilities were seen as broken or diseased. Terms such as *invalid*, *cripple*, and *handicapped*, which were prevalent during this era, spoke to this understanding. People with disabilities were treated as victims to be pitied and helped (see Figure 1.2). Beyond the hope for a cure engendered by scientific advances, not much else changed about the way disability was understood.

### The Third Wave of the Disability Movement: The Self-Advocacy Era

The self-advocacy or self-determination movement emerged in the 1970s and 1980s (Wehmeyer, Bersani, & Gagne, 2000). Parents and family members told profession-
als during the second wave of the disability movement that they were the consumers of services and they were the ones who speak for their children. This emphasis changed as their children aged and the movement matured. Parents, family members, and professionals began to recognize that people with intellectual and developmental disabilities could speak for themselves (Abeson & Davies, 2000). The self-advocacy or self-determination movement emerged as people with disabilities, increasingly referred to as self-advocates, began to claim their own voices. This movement emphasized empowerment, self-determination, and community inclusion.

Several factors contributed to the emergence of the third wave. The progress achieved by parents in establishing community-based programs (e.g., education, community living, employment settings) created a climate that led to further protections and higher expectations. Several other movements also contributed to the emergence of the third wave.

The first movement was adopting the Normalization Principle as an organizing basis for service delivery in the 1970s. Bengt Nirje explained that the Normalization Principle had its basis in “Scandanavian experiences from the field” (1969, p. 180) and emerged, in essence, from a Swedish law on mental retardation passed in 1968. In its original conceptualization, the Normalization Principle provided guidance for creating services that “let the mentally retarded obtain an existence as close to the normal as possible” (p. 181). Nirje stated, “As I see it, the normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society” (p. 181). Nirje identified eight facets and implications of the Normalization Principle.

1. Normalization means a normal rhythm of day;
2. Normalization implies a normal routine of life;
3. Normalization means to experience the normal rhythm of the year;

Figure 1.2. Retarded children can be helped campaign from the National Association for Retarded Children (author’s collection).
4. Normalization means the opportunity to undergo normal developmental experiences of the life cycle;
5. Normalization means that the choices, wishes and desires [of the mentally retarded themselves] have to be taken into consideration as nearly as possible, and respected;
6. Normalization also means living in a bisexual world;
7. Normalization means normal economic standards [for the mentally retarded];
8. Normalization means that the standards of the physical facility should be the same as those regularly applied in society to the same kind of facilities for ordinary citizens. (1969, pp. 181–182)

Scheerenberger noted that “at this stage in its development, the normalization principle basically reflected a lifestyle, one diametrically opposed to many prevailing institutional practices” (1987, p. 117) and suggested that “no single categorical principle has ever had a greater impact on services [for people with mental retardation] than that of normalization” (p. 117).

Second, the independent living and disability rights movements were critical to the emergence of the new wave of the disability movement. The independent living movement began in the 1960s and was strongly influenced by the social and political consciousness of other civil rights movements occurring in the United States at that time (Ward, 1996). This civil rights perspective and the recognition of the lack of power held by and value held for people with disabilities at that time led many people with disabilities to equate their experiences and marginality with members of racial and ethnic minority groups and to begin to respond to societal barriers to social, economic, and political inclusion within an empowerment framework. Empowerment is a term usually associated with social movements and typically is used in reference to actions that enhance the possibilities for people to govern their own lives (Rappaport, 1981). The concepts of right to integration and meaningful equality of opportunity stressed by other civil rights groups, as well as the methods and tactics utilized by these groups, was adopted by the disability rights movement.

Ed Roberts, a leader in the independent living and disability rights movement, emphasized the connection between the struggle of other minorities for equality and the marginal status of people with disabilities. Roberts defined independence in terms of the control people with disabilities had over their lives and argued that it should be measured not by the tasks one can perform without assistance, but by the quality of one’s life with adequate support.

A third factor of note was the emergence of the self-advocacy or people-first movement. The origins of the self-advocacy movement in the United States are usually attributed to a small group of people with intellectual disability in Salem, Oregon, who were credited with formulating the phrase, “We are people first” (Edwards, 1982). The roots of that movement lie in Sweden in the late 1960s and 1970s. Beginning in 1965 in Sweden, Bengt Nirje described the use of social clubs called flamslattsklubben to promote training in Sweden for adolescents with intellectual disabilities. This training was embedded within Nirje’s (1969) development of the Normalization Principle. Within just a few years, training for the social groups included instruction in parliamentary procedures.

The self-advocacy movement rapidly gained ground both in the United States and internationally. There were 1,000 members in Oregon alone, with sister groups in 3 states and requests from 42 states for assistance in starting similar organizations, within 5 years of forming the Oregon self-advocacy group (Edwards, 1982). The
first self-advocacy conference took place in October of 1974 in Otter Crest, Oregon. Edwards described one moment from that historic meeting: “The earth moved just a bit when Valerie Schaaf, first president of People First, stepped onto the podium and spoke clearly into the microphone: ‘This, the first People First convention, is officially called to order’” (p. 4).

It was increasingly evident by the 1990s that there was a need for new ways of conceptualizing disability. Historic models that focused on impairment, pathology, and incapacity were inconsistent with the empowerment focus of the independent living and disability rights movements. People with disabilities became unwilling to accept conceptualizations of disability that focused on personal incapacity and incompetence.

**A 21st-CENTURY UNDERSTANDING OF DISABILITY**

Traditional conceptualizations began to be replaced toward the end of the 20th century by ways of thinking about disability that focused more on the interaction between personal capacity and the context in which people with disabilities lived, learned, worked, and played. The most notable of these were the World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF) and the American Association on Mental Retardation’s (AAMR) 1992/2002 classification system. The ICF and AAMR (now American Association on Intellectual and Developmental Disabilities [AAIDD]) frameworks are functional classification systems because disability is seen as an outcome of the interaction between a person’s limitations and the environmental context in which that person must function.

The WHO’s ICF is forwarded as a biopsychosocial model in which disability and functioning are viewed as outcomes of interactions between health conditions (diseases, disorders, and injuries) and contextual factors, which include environmental and personal factors. The ICF proposes three levels of human functioning on which these health conditions and contextual factors act.

1. *Body functions and structures:* The physiological functions of body systems and the anatomical parts of bodies, including organs and limbs
2. *Activities:* The execution of tasks or actions by the person
3. *Participation:* Pertaining to involvement in life situations

The effect of health conditions and contextual factors on body functions and structures might result in impairments, defined as problems in body function or structure, whereas the impact on activity and participation factors may result in activity limitations or participation restrictions. The notion that disability is a function of the relationship between the person, his or her health condition, and the social context is the key element of the ICF.

The AAMR’s 1992 definition and classification system followed the lead of the WHO ICF by proposing a functional definition of “mental retardation.” Disability within this definitional framework is not something that a person has or something that is a characteristic of the person but is instead a state of functioning in which limitations in functional capacity and adaptive skills must be considered within the context of environments and supports. The manual’s authors proposed that “mental retardation is a state in which functioning is impaired in certain specific ways”
A functional limitation is defined as the “effect of specific impairments on the performance or performance capability of the person,” whereas disability is described as the “expression of such a limitation in a social context” (p. 10). Luckasson and colleagues noted that “mental retardation is a disability only as a result of this interaction” (p. 10); that is, only as a result of the interaction between the functional limitation and the social context, in this case the environments and communities in which people with intellectual disability live, learn, work, and play. This functional model suggests that intellectual disability is not something a person has, such as a disease, nor is it something someone is, but is instead a state of functioning that exists based on the interaction between the person’s functional limitations and the social or environmental context in which that person functions.

By defining the disability as a function of the reciprocal interaction between the environment and the person’s functional limitations, the focus of the problem shifts from being a deficit within the person to being the relationship between the person’s functioning and the environment and, subsequently, to identifying and designing supports to address the person’s functioning within that context. Historic models of disability services created programs that provide services that were largely designed to meet the needs of people within largely homogeneous groupings based on indicators of personal incompetence.

From Programs and Services to Personalized Supports

It is important to understand what is intended by the use of the term supports because the idea of supports, the process of providing supports, and the categorization of levels of supports are at the heart of the new paradigm. The 1992 AAMR manual defined supports as

- Resources and strategies that promote the interests and causes of individuals with or without disabilities; that enable them to access resources, information and relationships inherent within integrated work and living environments; and that result in their enhanced interdependence, productivity, community integration, and satisfaction. (Luckasson et al., 1992, p. 101)

What characteristics of providing supports differentiate this intervention approach from traditional models of service delivery? First, three key aspects of supports are identified in the AAMR manual: 1) they pertain to resources and strategies; 2) they enable individuals to gain access to other resources, information, and relationships within integrated environments; and 3) their use results in increased integration and enhanced personal growth and development. In other words, supports have the unambiguous intent to enhance community integration and inclusion by enabling people to gain access to a wide array of resources, information, and relationships. Second, supports are individually designed and determined with the active involvement of key stakeholders in the process, particularly the person benefiting from that support. Traditional service delivery models have too often been designed primarily in a top-down process; that is, beginning with purported homogenous characteristics of a given population and designing one-size-fits-all programs. Finally, Luckasson and Spitalnik suggested that “supports refer to an array, not a continuum, of services, individuals, and settings that match the person’s needs” (1994, p. 88). Luckasson and Spitalnik referred to a constellation of supports needed by people.
with intellectual disabilities in which the person is in the center and the types of supports range from self-directed and self-mediated supports (e.g., the person, his or her family and friends, nonpaid co-workers or neighbors), to generic supports (those that everyone uses) and specialized supports (e.g., those provided in a disability service system).

In summary, the new paradigm in disability supports abandons old notions of disability as residing within or being a characteristic of a person. It instead focuses on the interaction between the individual; his or her personal characteristics, including competencies; and the environment or context in which that person must function. This emphasis on functioning requires that interventions focus less on fixing or curing the individual and more on designing and implementing supports that address the fit between the person and the context in which he or she must function. Second, the array of supports needed must be provided in the community, which culminated with the independent living, deinstitutionalization, and normalization movements. Third, the independent living and civil rights movements have resulted in a focus on legislative and civil protections and assurances of equal opportunity and access and the emergence of a new disability movement (i.e., self-advocacy or self-determination movement). This movement focuses on natural supports, consumer controlled and directed services, and empowerment.

This shift in understanding disability has implications for supporting people with severe disabilities across the life span. The following sections examine the effect of this shift on education and life span practices and supports.

**BEYOND DISABILITY IN EDUCATION: THIRD-GENERATION INCLUSIVE PRACTICES**

Numerous educational practices show evidence of the effect of functional models of disability and focus on a supports model. These practices emphasize enhancing personal capacity and modifying the context in which the student learns, including modifications to the curriculum itself, which reduces the gap between the student’s capabilities and the demands of the environment. These practices include applying universal design for learning (UDL), using educational and assistive technology, applying positive behavior interventions and supports (PBIS), and promoting access to the general education curriculum, the latter of which is a central theme in the third generation of inclusive practices. These are briefly described by illustrating how the educational process may differ as a function of the changing ways of thinking about disability.

Turnbull, Turnbull, Wehmeyer, and Shogren (2013) suggested that this new paradigm of disability and the design of supports to enable people with disabilities to be successful, along with school reform efforts, led the field of education into a third generation of inclusive practices. The first generation of inclusive practices focused on changing prevailing educational settings for students with disabilities from separate, self-contained settings to the regular education classroom. First-generation inclusion was additive in nature; that is, resources and students were added to the general education classroom. The second generation of inclusive practices was more generative in nature because they focused on improving practice in the general education classroom and moving students from separate settings to regular classroom settings. Research and practice during this phase emphasized
aspects of instructional practices that promoted inclusion, such as collaborative teaming and team teaching; differentiated instruction; developing family, school, and community partnerships; and so forth.

The most salient characteristic of the third generation of inclusion is that the focal point for such efforts switched from advocacy and supports with regard primarily to where a student receives his or her educational program, which Turnbull et al. (2013) suggested was the focus of the first two generations of inclusive practices, to a focus on what the student is taught. The third generation of inclusion presumes a student’s presence in the general education classroom and emphasizes the quality of the educational program in that setting instead of focusing on integrating into the classroom. Nothing about the first or second generations of inclusion is either obsolete or unimportant. In fact, both remain critical to ensure high-quality educational programs for students with disabilities. The need to consider issues pertaining to third-generation inclusive practices is an outcome of the success of efforts during these first two generations. The expectations for students have become higher as more students with disabilities are educated and successfully supported in the general education classroom. At this point in the evolution of inclusive practices, educators need to consider how to maximize participation in the general education classroom and progress in the general education curriculum. Fortunately, most educators believe that ensuring access to the general education curriculum for students with disabilities is important, as is raising expectations held for students (Agran, Alper, & Wehmeyer, 2002).

The shift toward promoting access to the general education curriculum for students with disabilities has been the most visible change in educational practice since the mid-2000s. The Individuals with Disabilities Education Improvement Act (IDEA) of 2004 (PL 108-446) required schools to ensure that students are involved with and make progress in the general education classroom by providing modifications to the curriculum and supplementary aids and services to ensure that students are educated with their typically developing peers to the maximum extent. Emerging practices related to new ways of thinking about disability enable us to meet the challenge presented by third-generation inclusive education demands and promote access to the general education curriculum.

**Universal Design for Learning**

Content information, particularly in core academic areas, historically has been presented through print-based formats (e.g., textbooks, worksheets) and lectures. Students who cannot read well or who have difficulty with memory or attention do not have access to the content exclusively presented through these mediums and, thus, will not have the opportunity to learn that content. Applying principles of UDL to curriculum development by providing multiple means for presenting information and for students to respond to that information is an example of these functional models’ emphasis on modifying the context to ensure a better fit between the student’s capacities and that context. Orkwis and McLane defined UDL as “the design of instructional materials and activities that allows learning goals to be achievable by individuals with wide differences in their abilities to see, hear, speak, move, read, write, understand English, attend, organize, engage, and remember” (1998, p. 9).

UDL promotes flexibility in representing content (how instructional materials present the content), presenting content (how educators and materials deliver
content), and demonstrating content mastery (how students provide evidence of their learning). Flexibility in the presentation and representation of content information can be achieved by providing information in a variety of formats, including text, graphics or pictures, digital and other media formats (audio or video, movies), or performance formats (plays, skits). Developing curricular materials in digital (electronic text) formats allows computers to provide multiple output formats. For example, electronic text can be converted to multiple output formats using specially designed media players, including electronic braille, digital talking book format, and sign language avatars, as well as allowing for output in multiple languages and letting the user modify features of the presentation, including font size and color and background color. Students can provide evidence of their learning in multiple ways, including written reports, exams, portfolios, drawings, performances, oral reports, videotaped reports, and other alternative means (Wehmeyer, 2011).

Pedagogical or instructional modifications can provide greater access to content information. For example, using graphic or advance organizers improves the comprehension of students with and without disabilities. Both graphic and advance organizers are flexible ways of presenting content information to students.

Using UDL to drive curriculum design is a perfect example of the effect of functional models of disability on education. These modifications alter the context to enable learners with a wide array of abilities and experiences to have access to content information. They improve the fit between the student with a disability and the curriculum through which content information is presented.

**Educational and Assistive Technology**

Providing supports to promote a better fit between a student’s capacities and the educational context places a greater emphasis on using educational and assistive technologies. The role of technology in special education traditionally has been narrowly prescribed as benefiting only students with more severe impairments who need some assistive technology device, such as an augmentative and alternative communication (AAC) device, to accommodate for their impairments. This was consistent with an understanding of disability that focused on fixing the person. The role of technology, including information, electronic, and assistive technologies, within a functional model and supports system, however, becomes critical to addressing not only the student’s capacities but also the educational context. Computer-assisted instruction (CAI), for example, involves using computer-based technologies to perform a variety of instructional roles, from initial delivery of content information to drill-and-practice activities. Research supports the efficacy of CAI with students with and without disabilities, including students with more severe disabilities (Wehmeyer, Smith, Palmer, Davies, & Stock, 2004).

Finally, technology can play a meaningful role in promoting the inclusion of students with disabilities in general education classrooms. Assistive technologies, such as AAC devices, provide alternative means for students with disabilities to interact with their peers without disabilities as well as participate in classroom learning activities. Many devices can promote peer interactions by providing a topic of conversation between the student with a disability and a peer. Technology devices such as tablet PCs and smartphones are socially desirable and can facilitate social interactions as well as provide needed supports.
Positive Behavior Interventions and Supports

Implementing schoolwide PBIS is a final example of applying functional models and support paradigms to education. Managing the classroom to ensure a nondisruptive learning environment for all students and dealing with challenging behavior problems exhibited by a few students is an ongoing concern for many teachers working with students with disabilities. PBIS is an area of intervention and treatment that has moved from emphasizing the person with a disability as the problem to be fixed to recognizing that treatment and intervention must focus on the social and environmental context and the interaction between that context and the individual’s limitations. PBIS changes the environment to make the exhibition of problem behaviors irrelevant or counterproductive for the person. PBIS focuses on two primary modes of intervention—altering the environment before a problem behavior occurs and teaching appropriate behaviors as a strategy for eliminating the need for problem behaviors to be exhibited (Carr et al., 1999).

PBIS has focused attention on addressing problem behaviors in school settings and school violence by providing interventions at an individual, classroom, or whole-school level (Carr et al., 1999). PBIS has reduced office referrals in schools, created classroom environments more conducive to learning, and assisted students with chronic behavior problems to improve their behavior. PBIS applies behaviorally based approaches to enhance the capacity of schools, families, and communities to design effective environments that improve the fit or link between the students and the environments in which teaching and learning occurs. Attention is focused on creating and sustaining school environments that improve lifestyle results (e.g., personal, health, social, family, work, recreation) for all children and youth by making problem behavior less effective, efficient, and relevant and desired behavior more functional.

Turnbull, Turnbull, Erwin, and Soodak (2006) discussed the effect of PBIS at several levels of activity. First, the approach recognizes that “a student’s behavior is affected by the philosophies, policies, procedures, practices, personnel, organization and funding of education agencies and other human service agencies involved in the student’s education” (p. 185). The first level of intervention will necessarily focus on systems change, that being the process of changing features of the agency or agencies that may contribute to problem behavior. Included in such systemic efforts are service integration efforts that bring together a wide array of supports in a unified and easily accessible manner.

Second, PBIS emphasizes altering the environment. Turnbull et al. noted that such environments are altered by

- Making different life arrangements by building on student strengths and preferences, identifying student and family priorities, building social and friendship networks and promoting health and wellness;
- Improving the quality of the student’s physical environment, including increasing the predictability and stability of events in school building, minimizing noise and other irritants;
- Making personal accommodations for students;
- Making instructional accommodations for students (2006, p. 185)

Focusing on skill instruction to enhance the possibility that students will act appropriately is a third level of action for PBIS. Such activities can extend from teaching specific behavior patterns or routines (e.g., how to behave in school hallways between classes) to promoting general problem-solving and self-management skills.
Once again, PBIS attempts to modify the context in which students learn, in this case school and classroom settings, to ensure a better fit for the student. Capacity building and context modification activities are involved.

Self-Determination

Promoting self-determination and student-directed learning is the main aspect of third-generation inclusive practices (Turnbull et al., 2013). Functional models of disability are strength based and focus on promoting students to become their own support to the greatest degree possible.

The international literature in special needs education documents that an effective education for students with disabilities must include instruction to promote student self-determination. Research has linked higher levels of self-determination to positive adult outcomes, including employment and independent living, for youth with special educational needs (Shogren, Palmer, Wehmeyer, Williams-Diehm, & Little, 2012; Wehmeyer & Palmer 2003; Wehmeyer & Schwartz, 1997), as well as to a higher quality of life (Lachapelle et al., 2005; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Wehmeyer & Schwartz, 1998). Furthermore, most school standards for all students include a focus on skills leading to enhanced self-determination (e.g., goal setting, problem solving, decision making, self-advocacy, self-management), and all students benefit when instruction is available schoolwide to address these component elements (Wehmeyer, Field, Doren, Jones, & Mason, 2004). Finally, there is evidence that students with special educational needs can acquire the knowledge and skills to become more self-determined if provided such instruction (Algozzine, Browder, Karvonen, Test, & Wood, 2001; Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, 2013; Wehmeyer et al., 2012).

What Is Self-Determination? Numerous frameworks serve as a basis for instructional design to promote self-determination (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003) as well as specially designed instructional methods, materials, strategies, and assessments to promote and measure self-determination (Wehmeyer et al., 2007; Wehmeyer & Field, 2007). Wehmeyer proposed a functional model of self-determination in which self-determined behavior refers to “volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life” (2005, p. 117). An act or event is self-determined if the individual’s action reflects four essential characteristics: 1) the individual acted autonomously, 2) the behaviors were self-regulated, 3) the person initiated and responded to event(s) in a psychologically empowered manner, and 4) the person acted in a self-realizing manner. Self-determination refers to self-caused (versus other) action; that is, to people acting volitionally, based on their own wills. The word volitional is defined as the act or instance of making a conscious choice or decision. Conscious means intentionally conceived or done; that is, deliberate. Volitional behavior, then, implies that one acts consciously and with intent. Self-determined behavior is volitional and intentional, not simply random and nonpurposeful.

The concept of causal agency is central to this perspective. Broadly defined, causal agency implies that it is the person who makes or causes things to happen in his or her life. “Doing it yourself” is one frequent misinterpretation of self-determination. An obvious problem exists for most students with special educational needs when self-determination is interpreted this way because they...
frequently have limits to the number and types of activities they can independently perform. The capacity to perform specific behaviors, however, is secondary in importance to whether one is the causal agent (e.g., caused in some way to happen) over outcomes those specific behaviors are implemented to achieve. Students who may not be able to independently make a complex decision or solve a difficult problem may be able to participate in the decision-making process with support and, thus, have the opportunity to be the causal agent in the decision-making process and consequently act in a self-determined manner.

Wehmeyer et al. (2003) argued that self-determination emerges across the life span as children and adolescents learn skills and develop attitudes and beliefs that enable them to be causal agents in their lives. These skills and attitudes are referred to in this model as component elements of self-determined behavior and include choice-making, problem-solving, decision-making, goal-setting and attainment, self-advocacy, and self-management skills.

**Self-Determination and Access to the General Education Curriculum**

There are two ways that promoting self-determination provides access to and promotes progress in the general education curriculum. First, educational standards frequently include goals and objectives that pertain to component elements of self-determined behavior, including educational emphasis on teaching goal-setting, problem-solving, and decision-making skills. Students are expected to learn and apply effective problem-solving, decision-making, and goal-setting processes in virtually every set of school standards. Teachers can promote self-determination and promote progress in the general education curriculum by identifying where in the general education curriculum all students are expected to learn skills and knowledge related to the component elements of self-determined behavior.

Second, teaching young people with and without disabilities self-regulation, self-management, problem-solving, goal-setting, and decision-making skills provides an effective means to enable students to more effectively engage with and progress through activities in the general education curriculum.

**Raising Expectations for Students with Severe Disabilities**

Changing expectations of people with disabilities is at the heart of the shifting understanding of disability and of third-generation inclusive practices. This is very important for people with severe disabilities. Functional models of disability begin with the student’s strengths and focus on enhancing capacity or modifying the learning context so that students can be successful. It is important to point out that in this regard the IDEA 2004 regulations do not require that the educational programs of students with severe disabilities be exclusively determined by the general education curriculum. Indeed, these regulations stipulate that the educational programs of students with disabilities should include a focus on the general education curriculum to the maximum degree appropriate. IDEA 2004 continues to require that the educational programs of students with disabilities address other educational needs that are not part of the general education curriculum. IDEA 2004 also clearly expects students to receive instruction to promote both academic achievement and enhanced functional performance. The individualized education program team determines what proportion of the student’s educational program reflects instruction derived from the general education curriculum versus functional content, and factors such as age, grade level, and severity of disability will all factor into that
decision (Turnbull et al., 2013). Still, the social, functional, and nonacademic content that students with severe disabilities need is equally affected by practices such as PBIS or UDL. The proliferation of tablet PC-based programs and cloud computing programs focused on social issues illustrates the relevance.

BEYOND DISABILITY IN ADULTHOOD: COMMUNITY INCLUSION AND QUALITY LIVES

Functional models of disability present as much of a challenge to traditional ways of supporting adults with severe disabilities as they do to the education system. First, these models emphasize the role of assessing support needs to ensure that people with disabilities are best enabled to succeed in typical environments. Thompson and colleagues (2009) differentiated between supports and support needs as such:

- Supports are resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and enhance individual functioning (Luckasson et al., 1992).
- Support needs is a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning.
- Support needs do not intend to reflect a disturbance of human capacity; rather, the person's support needs reflect a limitation in human functioning as a result of either personal capacity or the context in which the person is functioning.

Addressing the person–environment mismatch is a major implication of conceptualizing disability as a state of functioning instead of an inherent trait. The focus is not solely on fixing the person, as historically has been the case. Figure 1.3

Figure 1.3. Supports model. (From Thompson, J.R., Bradley, V., Buntinx, W., Schalock, R.L., Shogren, K.A., Snell, M.E.,…Yeager, M.H. [2009]. Conceptualizing supports and the support needs of people with intellectual disability. Intellectual and Developmental Disabilities, 47[2], 135–146; reprinted by permission. Copyright 2009 by the American Association on Intellectual and Developmental Disabilities.)

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Wehmeyer shows a mismatch between personal competency and environmental demands that results in support needs that necessitate particular types and intensities of individualized supports. Second, it is more likely that individualized supports based on thoughtful planning and application will lead to improved human functioning and personally valued outcomes (Thompson et al., 2009).

Supports are a universe of resources and strategies that enhance human functioning. No person will need all of the types of supports available. And there must be few people who do not need any supports, regardless of ability or disability. People’s support needs differ both quantitatively (in number) and qualitatively (in nature) (Thompson et al., 2009). Planning to enable adults with severe disabilities to live better quality lives should incorporate a supports plan (see Figure 1.4). The process depicted in this figure is fairly self-explanatory, and although it is not feasible to discuss the process in detail in this chapter, it is important to observe that supports assessment, using instruments such as the Supports Intensity Scale (Thompson et al., 2003), must become more prevalent if educators are to achieve the potential envisioned by the new disability paradigm, and such assessments must contribute information to planning teams for designing personalized supports.

**Self-Determination as a Gateway to a Better Life**

Promoting self-determination becomes central in supporting adults with disabilities to achieve more positive outcomes. Walker and colleagues (2011) proposed a social-ecological model to promote self-determination that 1) adopts the person–environment fit model of disability, emphasizing both capacity enhancement and modifications to environments and contexts; 2) proposes that efforts to achieve meaningful adult outcomes (e.g., employment, community inclusion, independent

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**Figure 1.4.** Incorporating supports planning into person-centered planning. (From Thompson, J.R., Bradley, V., Buntinx, W., Schalock, R.L., Shogren, K.A., Snell, M.E.,...Yeager, M.H. [2009]. Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities, 47*(2), 135–146; reprinted by permission. Copyright 2009 by the American Association on Intellectual and Developmental Disabilities.)
living) for adults with disabilities must recognize principles of adult learning, particularly that adults learn in more self-directed, self-guided fashions; and 3) uses efforts to promote self-determination as a gateway to achieving meaningful adult outcomes. A thorough description of this model is beyond the scope of this chapter, but the model recognizes that learning in adulthood is complex and involves mediating and moderating factors, such as gender or cultural contexts, that must be taken into account when supporting people with severe disabilities to achieve outcomes such as employment or independent living. The social-ecological model emphasizes the importance of social networks and social capital on achieving meaningful outcomes for adults with disabilities.

**Supported Employment and the Promise of Technology**

Practices that abide by the principles proposed in the Walker et al. (2011) model and reflect new ways of thinking about disability are already in place. Supported employment is the most obvious practice. It has been known for decades that people with severe disabilities can competitively work through strategies used in supported employment, such as job carving or job sharing, as well as in innovative employment models, such as customized employment or self-employment. These outcomes are achieved by supports that enable the worker to gain as many skills needed for the job as possible, and modifications to the job description, job tasks, or workplace environment further reduce the gap between the person's capacities and his or her success on the job (Wehman, 2011).

In addition, the potential for technology to reduce the gap between personal capacity and the demands of the environment for adults with severe disabilities and enable them to live, learn, work, and play in their communities is significant. Technology advances are already making better lives available to people with cognitive impairments. Scanning and computer technologies in most stores make it possible for someone who does not know how to calculate totals or count change to work in retail settings; tablet and smartphone technologies can provide audio and video prompting that enable people with cognitive disabilities to successfully complete multistep, complex tasks without another person prompting them (Davies, Stock, & Wehmeyer, 2003). Those same smartphones can use global positioning satellite data to enable a person to navigate a transit system or walk to a destination (Davies, Stock, Holloway, & Wehmeyer, 2010). The potential for technology to support successful functioning across multiple domains is promising, to say the least (Stock, Davies, Wehmeyer, & Lachapelle, 2011).

**CONCLUSION: SEEKING A FUTURE OF EQUITY AND FULL PARTICIPATION**

Society is at a tipping point for achieving a future of equity and full participation for people with severe disabilities. Gladwell (2000) described a *tipping point* as that moment of critical mass at which a phenomenon goes from obscurity to popularity, the threshold right before some idea or practice becomes widely adopted. All of the ingredients are present to achieve a future of equity and full participation. Recognizing and adopting the idea that disability is not a problem within a person but the gap between personal capacity and the demands of the context that can be closed with adequate supports is the final and critical element to achieve society’s goals and the goals and dreams of people with disabilities and their families.

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Questions for Study and Reflection

1. What is self-determination, and why is it important for students and adults with disabilities?

2. Describe how people with more severe disabilities can be supported to become more self-determined.

3. How does a functional/social-ecological model of disability differ from historic understandings of disability?

4. What implications exist for education and adult supports as a result of a new paradigm for disability?

5. What are supports and support needs, and why are they important?

RESOURCES


National Gateway to Self-Determination http://www.ngsd.org


University of Kansas Beach Center on Disability http://www.beachcenter.org/

University of North Carolina–Charlotte Self-Determination/Self-Advocacy Synthesis Project http://www.uncc.edu/SDSP/

University of Oklahoma Zarrow Center for Learning Enrichment http://education.ou.edu/zarrow/


REFERENCES


