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## Educating Students with Severe Disabilities *Foundational Concepts and Practices*

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*“Learn from yesterday, live for today, hope for tomorrow. The important thing is not to stop questioning.”  
—ALBERT EINSTEIN*

### **1.01 Who are students with severe disabilities?**

#### **Learning Outcome**

*Identify definitions of severe disabilities, the role of the supports model in understanding students with severe disabilities, and the influence of societal perceptions and social interactions.*

### **1.02 Reasons for optimism and concern**

#### **Learning Outcome**

*Identify areas where progress has been made in providing individualized supports for people with severe disabilities in inclusive communities, and areas where work is still needed.*

### **1.03 Access to quality education**

#### **Learning Outcome**

*Discuss the foundational principles of providing supports to students with severe disabilities that promote access to (a) inclusive environments, (b) individualized curriculum, (c) purposeful instruction, and (d) necessary supports.*

**P**roviding relevant education for students with severe disabilities requires that we learn from our past practices, both the mistakes and the successes, by drawing on the historical bank of foundational concepts and practices available to us. Our contemporary challenge is to apply what we have learned within today’s context and to do so with a sense of urgency, because as we ponder, debate, and research the merits of our practices, the children who enter our schools are quickly growing up—they and their families do not have the luxury of waiting. Providing individuals with severe disabilities quality education requires that we adopt conceptually sound, evidence-based practices in our schools and confront assumptions about ability that continually threaten current and future opportunities.

People identified as having severe disabilities are the epitome of why Einstein’s challenge “not to stop questioning” is so important. Only 40 years ago, students with severe disabilities had no legal right to attend public schools and many did not—expectations for their educational progress were minimal. Today because of people with disabilities, their family members, and professionals who never stopped questioning, people with severe disabilities are doing things that many would have thought to be unimaginable just a few short decades ago: They are (a) attending general education classes with their peers who do not have disabilities, (b) learning general education curricular content, (c) participating in general education co-curricular activities, (d) engaging in supported employment, (e) transitioning to community-based supported living options, and (f) accessing inclusive post-high school educational opportunities—but, only some.

## WHO ARE STUDENTS WITH SEVERE DISABILITIES?

### Definitions

Although the term *severe disabilities* is used extensively in the professional literature, no single authoritative definition exists. The amendments to the Individuals with Disabilities Education Act (IDEA) (2004), a common source of special education terminology, do not define *severe disabilities*. IDEA and its corresponding Code of Federal Regulations (CFR) (2006) do define 13 distinct disability classifications (34 CFR 300.8), several of which reasonably include students considered to have severe disabilities (e.g., autism, deaf-blindness, intellectual disability, multiple disabilities, traumatic brain injury), although not all students within these categories have severe disabilities. Sometimes people with severe disabilities are described as having *low-incidence* disabilities. Within the school context, the Code of Federal Regulations (2003) allows for up to 1% of the total student population, those with most severe cognitive disabilities, to be assessed based on alternate performance standards (34 CFR 200.13).



Watch the video “Classification and Intellectual Disability” at [www.youtube.com/watch?v=80rc4ZAtQ0I](http://www.youtube.com/watch?v=80rc4ZAtQ0I).

Historically, and all too often contemporarily, attempts to describe or define the characteristics of students with severe disabilities have focused primarily on identifying deficits in domains that influence human functioning, including intellectual, academic, orthopedic, sensory, behavioral, and social. Unfortunately, such definitions tell us very little about people with severe disabilities (McDonnell, Hardman, & McDonnell, 2003) and may, in fact, contribute to the failures to question the capabilities of people with disabilities that have occurred throughout history and led to limited educational opportunities (Schalock et al., 2007).

Newer conceptualizations of disability are emerging, however, that shift the focus from simply identifying deficits in functioning and instead to emphasizing the reciprocal interaction between the personal capacities of people with severe disabilities, such as differences in intellectual, academic, orthopedic, sensory, behavioral, and social functioning, and environmental demands, such as the need to participate and learn in inclusive schools, communities, and classrooms (Schalock et al., 2010; World Health Organization, 2001; 2007). By identifying discrepancies between a person’s current level of functioning and environmental demands, supports needed for participation and learning in those environments can be identified; this is known as the *supports model* (Schalock et al., 2012; Thompson et al., 2009). Supports for participation might include assistive technologies for students as well as environmental changes like the adoption of a co-teaching model or the implementation of a peer support program. Supports for learning might include individualized curricular adaptations as well as the adoption of universal design for learning in the classroom. The supports model shifts the focus from identifying deficits within a person to understanding needed supports and building systems of supports that facilitate success in inclusive environments.

The supports model prompts professionals to never stop questioning the capabilities of individuals with severe disabilities, particularly when needed supports are provided for participation and learning in inclusive environments. It also recognizes that

students with severe disabilities are a widely heterogeneous group in terms of their disability characteristics, capabilities, and educational needs as well as in their characteristics not related to disability (e.g., interests, preferences, personalities, socioeconomic levels, cultural heritage). By focusing on individualized supports identified through a systematic analysis of discrepancies between personal capacities and environmental demands, this collective diversity and need for individualized, lifelong supports can be addressed in inclusive contexts.

A foundational assumption of the supports model is that people with severe disabilities share a fundamental human trait with all other people—the capacity to learn, and that appropriate supports for learning will allow individuals with severe disabilities to demonstrate their capabilities. Although this may seem too obvious to mention, as recently as the early 1980s, there were heated debates in the professional literature about whether individuals with the most severe disabilities were capable of learning and how such judgments affected their right to be educated. The words of Baer (1981) remain relevant today:

*To the extent that we sometimes finally succeed in teaching a child whom we have consistently failed to teach in many previous efforts, we may learn something about teaching technique . . . Too often, in my opinion, we teach children who are not only capable of teaching themselves, but eager to do so; in their wisdom, they cheat us of learning completely how the trick is done because they do some of it for us and do it privately. It is when they cannot do much if any of it for us that we get to find out how to do all of it ourselves, as teachers. (p. 94)*

Approaching *all* students as capable of learning provides us with the opportunity to never stop questioning our own understanding of teaching and learning. The notion of *all* students as capable of learning and entitled to appropriate education is consistent with the federal *zero-reject* principle embedded in IDEA since its passage in 1975. The zero-reject principle established that *all* school-aged children, regardless of the severity of their disability, are entitled to a free, appropriate public education (Turnbull, Stowe, & Huerta, 2007). This principle was tested in the case of *Timothy W. v. Rochester School District* (1989) when a student with severe, multiple disabilities was denied admission to his local public school because school officials deemed him unable to benefit from education due to the severity of his disability. Although the trial court sided with Rochester School District, the U.S. Court of Appeals for the First Circuit overturned this ruling, and strongly reaffirmed the zero-reject principle as a core component of IDEA, stating that

*. . . educational methodologies in these areas are not static, but are constantly evolving and improving. It is the school district's responsibility to avail itself of these new approaches in providing an educational program geared toward each child's individual needs. The only question for the school district to determine, in conjunction with the child's parents, is what constitutes an appropriate individualized education program (IEP). (p. 973)*

This decision, and all subsequent reauthorizations of IDEA, have emphasized that *all* students are entitled to a free, appropriate public education. Schools must continuously question their assumptions about supports for learning and participation, and ensure that teachers have access to state-of-the-art practices for meeting *all* students' individualized needs.

### Societal Perceptions and Expectations

TASH (n.d.), an international advocacy and professional organization focused on promoting the full inclusion and participation of people with severe disabilities, states that people with severe disabilities are

*. . . most at risk for being excluded from society; perceived by traditional services systems as most challenging; most likely to have their rights abridged; most likely to be at*

*risk for living, working, playing, and learning in segregated environments; [and] least likely to have the tools necessary to advocate on their behalf.*

Because people with severe disabilities require ongoing supports to mitigate the risks described above, the ways in which they are perceived and subsequently treated by others can have a major impact on the quality of their lives. When coupled with the historical emphasis on deficits in functioning experienced by people with disabilities, social perceptions and expectations have tended to be low. This can lead to *disability spread*, defined as the tendency to make broad inferences, assumptions, and generalizations about a person on the basis of disability stereotypes within the society (Dembo, Leviton, & Wright, 1975; Liesener & Mills, 1999). Some common stereotypes portray persons with disabilities as sick, subhuman, a menace, an object of pity, an object of charity, or a holy innocent (Smith & Wehmeyer, 2012; Wolfensberger, 1975).

### Opportunities for Interaction and Reciprocal Benefit

As noted by TASH, stereotypes and disability spread have a significant, negative impact on the quality of life of people with severe disabilities. However, it is not just people with severe disabilities that are negatively impacted. If you accept the notion that personal relationships are among a small set of the most defining characteristics that influence the quality of a person's life, then disability spread is a problematic issue for those with and without disabilities alike as it limits relationships between people with and without disabilities (Bogdan & Taylor, 1989).

As you continue to read this chapter and the rest of this book about people who have the label of *severe disabilities*, you are encouraged to think about how these individuals are *like all other people*, *like some other people*, and *uniquely like no other people*. Keep in mind that first and foremost we *all* are human beings—someone's child, someone's sibling, someone's classmate, someone's neighbor, or someone's friend. It is true that some people are born with or acquire disability characteristics that require lifelong systems of supports. Remember, though, that we all need supports, we just differ in the level of those support needs. Our collective attitudes and responses to differences in support needs can influence how much of a barrier those support needs are (or are not) to living a full, engaged, and self-determined life.

## REASONS FOR OPTIMISM AND CONCERN

From an historical perspective, our current times are among the best for individuals with severe disabilities, at least thus far. We write this with the full recognition that our current *best* is relative and is quite a long way from *good* for far too many people labeled as having severe disabilities. This section highlights a set of key reasons for optimism about the education of students with disabilities followed by a set of continuing concerns.

### Reasons for Optimism

Table 1–1 lists five areas for optimism about our present and future. Such optimism about our collective potential to make a positive difference in the lives of students with and without disabilities is an essential ingredient of the creative problem solving necessary to tackle these important challenges.

First, nowhere is progress more evident or reason for optimism more warranted than with regard to *inclusive educational opportunities* (see Table 1–2 for key elements of inclusive education). Across the country, students with severe disabilities are increasingly accessing general education classrooms and other inclusive settings with their same-age peers without disabilities (Downing,



Karrie Shogren discusses self-determination at [www.youtube.com/watch?v=ZdArcPCH8FQ&src\\_vid=S0dHpLvpVH4&feature=iv&annotation\\_id=annotation\\_2241971059](https://www.youtube.com/watch?v=ZdArcPCH8FQ&src_vid=S0dHpLvpVH4&feature=iv&annotation_id=annotation_2241971059)

**TABLE 1–1**  
Areas for Optimism

1. Inclusive education and schoolwide reform
2. Access to the general education curriculum
3. Positive behavior interventions and supports
4. Peer supports
5. Self-determination and transition to adult life

2008); such options were rare or non-existent just two or three decades ago. Inclusive schools promote equity, opportunity, and social justice for all their students (Jorgensen, McSheehan, & Sonnenmeier, 2009; Sapon-Shevin, 2011; Theoharis, 2009). These outcomes are relevant for any student across a range of diverse characteristics (e.g., race, culture, primary language, socioeconomic level), as well as any student who simply is having difficulty becoming part of a classroom's learning community. The tenets of inclusive schooling are increasingly being linked with broader *school reform and restructuring* efforts designed to improve educational opportunities for *all* students. The Schoolwide Applications Model (SAM) (Sailor, 2002; Sailor & Roger, 2005), Whole Schooling (Peterson, 2004; Peterson & Hittie, 2010), Schools of Promise (Causton-Theoharis, Theoharis, Bull, Cosier, & Dempf-Aldrich, 2011), and Schoolwide Integrated Framework for Transformation (SWIFT, [www.swiftschools.org/](http://www.swiftschools.org/)) offer examples of successful efforts to bridge general and special education, and transform schools into inclusive communities that meet the needs of the diverse array of students in our schools.

Second, curricular options for students with severe disabilities have extended beyond functional life skills to include greater alignment and *access to the general education curriculum*. Promising approaches have emerged that demonstrate positive learning outcomes for students with severe disabilities in literacy, math, and science (Hudson, Browder, & Wood, 2013; Riggs, Collins, Kleinert, & Knight, 2013; Spooner, Knight, Browder, & Smith, 2012). In inclusive settings, the principle of universal design for learning (i.e., designing the curriculum with the needs of *all* learners in mind right from the start) has enabled teachers to create learning environments that accommodate the range of learners in their classrooms (Coyne, Pisha, Dalton, Zeph, & Smith, 2012; Dymond

**TABLE 1–2**  
Elements of Inclusive Education

*Inclusive education exists when each of the following six characteristics occurs on an ongoing, daily basis.*

1. *All* students are welcomed in general education. The first placement options considered are the general education classes in the school that the students would attend if they did not have a disability.
2. Disability is recognized as a form of human diversity. Hence, students with disabilities are accepted as individuals and are not denied access because of their disabilities.
3. Appropriate supports are available, regardless of disability label or the level and/or type of supports needed. Given their portability, supports are provided in typical environments instead of sending students to specialized settings to receive supports.
4. The composition of the classrooms in which students are educated reflects the naturally occurring proportion of students with and without disabilities or other identified needs (referred to as *natural proportions*). Therefore, the percentage of students without disabilities in each class is substantially higher than the percentage of students with disabilities or other special needs.
5. Students, irrespective of their performance levels and/or support needs, are educated with peers in the same age groupings available to those without disability labels instead of with younger students. Students with disabilities need not function at or near the same academic level as their classmates (although some do) to benefit from a chronologically age-appropriate, inclusive placement.
6. Students with and without disabilities participate in shared educational experiences while pursuing individually appropriate learning outcomes with the necessary supports. Educational experiences are designed to enhance valued life outcomes that seek an individualized balance between both the academic-functional and the social-personal aspects of schooling.

(From *Choosing Outcomes and Accommodations for Children (COACH): A Guide to Educational Planning for Students with Disabilities, Third Edition* (2011) by M.F. Giangreco, C.J. Cloninger, & V.S. Iverson. (Baltimore, Paul H. Brookes Publishing Co, Inc.). Adapted with permission.)

et al., 2006). Furthermore, students with severe disabilities are now included in statewide accountability systems through alternate assessments that are aligned with state academic standards (Individuals with Disabilities Education Act, IDEA, 2004; No Child Left Behind Act, NCLB, 2001). This increased emphasis on academic instruction has presented new opportunities for students with severe disabilities to access challenging curriculum and for school personnel to be held accountable for their learning.

Third, the rapidly developing technology of *positive behavior interventions and supports (PBIS)* has resulted in effective, non-aversive interventions for students with severe disabilities who exhibit problem behavior (Brown & Michaels, 2006; Dunlap et al., 2010; Freeman et al., 2006; Goh & Bambara, 2012; Sailor, Dunlap, Sugai, & Horner, 2008) (see Chapter 7). PBIS is based on the premise that all behavior serves a function (or purpose) and interventions must be designed to teach alternative behaviors that serve the same functions. Since the reauthorization of IDEA in 1997, schools have been required to consider the use of PBIS for students with problem behavior. Schools are increasingly implementing PBIS strategies schoolwide, which has resulted in the creation of more positive learning environments for all students, including students with severe disabilities.

Fourth, drawing upon *peers* to lend support to students with severe disabilities has emerged as a prominent area of research because it is central to social and academic classroom success (Carter, Cushing, & Kennedy, 2009; Janney & Snell, 2006). Peers without disabilities can effectively provide an array of supports to their classmates with disabilities in ways that enhance educational experiences. Increasingly, school personnel are recognizing the benefits of peer supports instead of the common response of relying too heavily or unnecessarily on extra adult supports (e.g., one-to-one teacher assistants) (Giangreco, Doyle & Suter, 2012) (see Chapter 11).

Finally, the focus on family involvement has expanded to include student involvement and *self-determination*. Self-determined young people have skills and attitudes that allow them to act as causal agents, to make things happen in their own lives. Self-determination emerges as students learn the skills needed to make choices and decisions about their own lives, have opportunities to make decisions, and then have those decisions honored (Wehmeyer, 2005). As succinctly summarized in self-advocacy circles, “Nothing about me without me!” Self-determination is critically important as it pertains to *transition to adult life* (Shogren, 2013; Thoma, Bartholomew, & Scott, 2009). Self-determination skills facilitate successful transitions into supported employment (Wehman, Inge, Revell, & Brooke, 2007), supported community living (Jameson & McDonnell, 2010; Taylor, 2006), and postsecondary education (Feldman, Fialka, & Rossen, 2006; Grigal & Hart, 2009).

## Reasons for Concern

Although the five areas for optimism presented in the previous section are encouraging trends, the field of special education is not at a stage of development where the curricular, instructional, and support needs of students with severe disabilities are consistently and sufficiently addressed. Table 1–3 lists six continuing areas of concern.

First, inclusive educational opportunities have remained relatively static, and *inconsistent access to inclusive classrooms* continues to plague public school systems, especially for students with severe disabilities. Primary placement in general education

**TABLE 1–3**

Areas for Continuing Concern

1. Inconsistent access to inclusive classrooms
2. Questionable quality of curriculum and instruction
3. Too many families are frustrated by the lack of professional responsiveness
4. Continued use of aversive procedures
5. Challenging working conditions for special educators
6. Limited postschool options

means that a student with a disability receives 80% or more of his or her instruction in a general education classroom with appropriate supports. The U.S. Department of Education (2012b) indicates that for all students with disabilities (ages 6–21) in U.S. states, including the Bureau of Indian Education (BIE) and outlying areas, 61% have their primary placement in general education classrooms. A closer look at categories most likely to include students with severe disabilities (e.g., autism, deaf-blindness, intellectual disability, multiple disabilities, and traumatic brain injury) depicts a more stark reality. For example, only 17% of students with intellectual disability nationally are included in general education classrooms for 80% or more of their school day. Currently, 15 states (i.e., AZ, CA, HI, IL, ME, MN, MO, NV, NJ, NY, SC, TX, UT, WA, WY) include less than 10% of their students with intellectual disability for 80% or more of the school day. In contrast, only five states (i.e., AL, CT, IA, KY, VT) along with two American Territories (i.e., Puerto Rico, Northern Mariana Islands) include over 35% of their students with intellectual disability in general education classes for 80% or more of their school day (U.S. Department of Education, 2012a). Unfortunately, placement in general education classrooms depends, in large part, on where a student lives and what disability category has been assigned to him or her. Although placement does not equal inclusion, it is a telling indicator of access to general education environments and a first step toward inclusive opportunities.

Second, even in situations where access to inclusive environments is better, the *questionable quality of the curriculum and instruction* for students with severe disabilities in general education classrooms continues to be a serious and ongoing issue (Halle & Dymond, 2008/2009; Hunt, McDonnell, & Crockett, 2012). Being physically present in settings with same-age peers who do not have disabilities is necessary, but not sufficient, to be included. Too many students with severe disabilities who are placed in general education classes are subjected to undesirable conditions, such as being (a) separated within the classroom (e.g., taught primarily by a paraprofessional apart from classmates), (b) taken through the motions of a lesson or activity without having appropriately targeted learning outcomes (i.e., not learning much of value or importance to them), or (c) presented with lesson content that is inconsistent with their abilities or learning and communication characteristics. The very concept of inclusive education has become distorted because fragmented, partial, or low-quality implementation efforts have been mislabeled as “inclusive” (Davern et al., 1997). While public debates continue to be waged regarding the *least restrictive environment* provision of the IDEA and the curriculum focus for students with severe disabilities, years pass and the lives of real children and their families are adversely affected.

Third, *too many families are frustrated by the lack of professional responsiveness* to their children’s educational needs (Jegatheesan, 2009; Soodak & Erwin, 2000). While some educators interact with parents and students as consumers and embrace them as partners in the educational process, others still resist, preferring to retain the role of professional as *expert* (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2010). Families from culturally diverse backgrounds experience further frustration when school personnel fail to understand or respect the values inherent in their culture (Jegatheesan, 2009; Shogren, 2013). Family members, friends, and persons with disabilities themselves also have expertise and knowledge concerning issues such as an individual’s likes and dislikes, understanding of behavioral challenges, rest/sleep patterns, idiosyncratic communication, personal history, and other important information that may contribute to educational and support planning. It is when the respective expertise of professionals and families are combined that teams have the opportunity to experience the synergy that comes from true collaboration (Harry, 2008) (see Chapter 2).

Fourth, concern exists about the *continued use of aversive procedures* to manage problem behaviors (Brown & Traniello, 2010; Westling, Trader, Smith, & Marshall, 2010). Sadly and unnecessarily, some students with severe disabilities continue to be subjected to an arsenal of aversive procedures and punishments (e.g., contingent electric shock, restraints, seclusion, noxious smells, white noise, physical assaults) in the

name of “treatment,” resulting in lost learning opportunities, degradation, psychological trauma, physical injury, and, in a small number of cases, even death (Gonnerman, 2007; National Disability Rights Network, 2009; U.S. Government Accountability Office, 2009). This problem persists despite the availability of effective, positive alternatives (Goh & Bambara, 2012; Sailor, Dunlap, Sugai, & Horner, 2008) and a national campaign to end the use of restraint and seclusion ([www.stophurtingkids.com](http://www.stophurtingkids.com)).

Fifth, *challenging working conditions for special educators* contribute to the concerns about the education of students with severe disabilities. Of particular alarm is the national shortage of qualified special educators, as well as the need to train and retain more of them (Boe & Cook, 2006; McLeskey, Tyler, & Flippin, 2004). Boe, Cook, and Sunderland (2008) report that annual turnover in special education has increased to one in four teachers in recent years. Some of the key factors contributing to special educators leaving the field include excessive paperwork, large caseloads, and lack of administrative support (Kozleski, Mainzer, & Deshler, 2000). Teacher shortages and high turnover rates interfere with students receiving an appropriate, high quality education. This is particularly true for students with severe disabilities, who constitute a small proportion of the overall population of students with disabilities and require teachers with specialized expertise and skills.

Finally, *limited postschool options* adversely affect young adults with severe disabilities. While some students with severe disabilities are accessing meaningful post-school opportunities, many are not (Certo, Luecking, Murphy, Brown, Courey, & Belanger, 2008). All too often youth with severe disabilities exit school unemployed, without basic skills, lonely, and unnecessarily isolated. At a time when the lives of their same-age peers are growing more interesting with expanding opportunities, the lives of young adults with severe disabilities is becoming smaller and more restricted.

If you are interested in improving the lives of people with severe disabilities through education, there is plenty to motivate you to act, regardless of whether you see this point in time as the glass half full or half empty. For those of you motivated by positive news, there is a continually growing set of examples and body of literature documenting steady progress to encourage your continuing contributions to these efforts. Regardless of what “fuels your fire”—the slow pace of progress or ongoing injustices facing people with severe disabilities—there is plenty of motivation to act and work to do!

## ACCESS TO QUALITY EDUCATION

The remainder of this chapter offers foundational information and ideas about access to quality education for students with severe disabilities in four main areas including access to (a) inclusive environments, (b) individualized curriculum, (c) purposeful instruction, and (d) necessary supports. All of these components of quality education and others are given in depth attention in the subsequent chapters and embedded throughout the book.



Watch “IDEA and Special Education Best Practices” at [www.youtube.com/watch?v=IQE4zEGXOGE](http://www.youtube.com/watch?v=IQE4zEGXOGE).

### Access to Inclusive Environments

Since its passage in 1975, IDEA has mandated that students with disabilities be educated in the least restrictive environment (LRE) (Rebhorn & Smith, 2008; Turnbull et al., 2007). The LRE provisions state that “to the maximum extent appropriate, children with disabilities . . . are educated with children who are non-disabled. . . . special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplemental aids and services cannot be achieved satisfactorily” (34 CFR 300.114).

Ironically, it has been this second part of the LRE mandate that, at times, has been used to justify the continued segregation of students with the most severe disabilities.

Across the country, far too many students who have severe disabilities are automatically placed in self-contained special education classes or schools, and thus are denied opportunities to build relationships with their peers without disabilities as well as access to general education classrooms and curricula.

The federal government, however, expresses a strong preference for placement in general education classes for students with disabilities, including those with severe disabilities (Rebhorn & Smith, 2008). As the U.S. Department of Education wrote in the regulation's "Analysis of Comments and Changes," the IDEA

*. . . presumes that the first placement option considered for each child with a disability is the regular classroom in the school that the child would attend if not disabled, with appropriate supplementary aids and services to facilitate such placement. Thus, before a child with a disability can be placed outside of the regular educational environment, the full range of supplementary aids and services that could be provided to facilitate the child's placement in the regular classroom setting must be considered.* (CFR, 2006, p. 46588)

The IDEA goes on to state

*In all cases, placement decisions must be individually determined on the basis of each child's abilities and needs and each child's IEP, and not solely on factors such as category of disability, severity of disability, availability of special education and related services, configuration of the service delivery system, availability of space, or administrative convenience.* (CFR, 2006, p. 46588)

Further evidence of federal support for educating students with severe disabilities in the LRE is found in a jointly submitted *amicus curiae* (friend of the court) brief that the U.S. Department of Justice (Office of Civil Rights) and the U.S. Department of Education wrote in support of a student with severe disabilities (named Spike who attended Valley Grove School District) to be educated in the general education classroom with supplemental supports and aids.

*. . . The IDEA does not require that Spike be able to perform at or near the grade level of non-disabled students before placement in the regular class can be considered the LRE for him. Congress expressed a strong preference in favor of educating children with disabilities in an inclusive manner and an integrated environment and requires States accepting IDEA funds to educate children with disabilities in the least restrictive environment (i.e., with their non-disabled peers in the regular classroom) to the maximum extent appropriate. States and school districts are not asked to determine whether LRE is an appropriate policy but rather to determine how a child can be educated in the LRE. Thus, school districts must determine how a child can be educated in the regular class with the use of supplementary aids and services. Valley Grove did not even attempt to make the necessary determination of how Spike could be educated in the LRE. Indeed, Valley Grove argues instead that, directly contrary to IDEA regulations, Spike must be removed from his age-appropriate regular classroom solely because his educational level is below that of the class.* (U.S. Department of Justice, 2002, pp. 13–14)

IDEA is clear that the default placement—in other words, the starting point—for *all* students with disabilities is the general education classroom with appropriate supports. IDEA *does not* say that students with disabilities should be denied access to general education classes

- if they have a particular label (e.g., autism, intellectual disability, multiple disabilities)
- if they require supports or accommodations (even if potentially extensive)
- if they function at a substantially different level than their classmates
- if they are pursuing different learning outcomes than their classmates
- just because it hasn't been done that way before in the school
- if it is administratively inconvenient or if needed services are not currently in place
- if the adults in the school are unaccustomed to the characteristics presented by the students and/or their support needs

Despite trends toward greater access to general education classrooms, students with severe disabilities remain most at risk for segregated placements. Yet, for every student with a severe disability who remains educationally segregated there are other students with similar attributes, abilities, and needs who are successfully included and learning relevant skills. This suggests that whether a student with a severe disability is meaningfully included may have less to do with his or her characteristics and more to do with the attitudes, skills, structure, and practices of the adults responsible for providing education (Giangreco, Carter, Doyle, & Suter, 2010). Placement teams must ask themselves the question, “How can we change our practices so that more students with disabilities can be successfully included and educated?”

### Access to Individualized Curriculum

IDEA provides a potent framework to enhance the lives of students with disabilities through *special education* and the development of an *individualized education program (IEP)*. Special education is defined as “specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability” (20 U.S.C. § 1400 (2004); IDEA, sec. 602(29)). Specially designed instruction means, “adapting . . . content, methodology, or delivery of instruction to meet the unique needs of the child that result from the child’s disability; and to ensure access of the child to the general education curriculum” (34 CFR 300.39 [3]).

As described in the IDEA, special education is a service, not a place (Taylor, 1988). At its heart, special education refers to the *individualized* ways in which we provide instruction to students in an effort to respond to their unique learning characteristics resulting from their disability. Sometimes individualization means (a) *changes in curriculum* to account for a student’s present level of performance or support needs, (b) *adaptations to the delivery of instruction* (e.g., sensory, physical, behavioral, environmental) that allow a student to have access to learning opportunities, or (c) use of *different instructional methods* applied to the general education curriculum or to individually determined learning outcomes that extend beyond the general education curriculum.

### Individualized Participation Options Within General Education

The participation of students with severe disabilities within general education classes and activities can be broadly characterized along two dimensions: (a) their *educational program content* (i.e., individualized curriculum, IEP annual goals with corresponding benchmarks or short-term objectives, and designated learning outcomes from the general education curriculum) and (b) their *supports*, namely, what is provided to assist the student in accessing and pursuing achievement of his or her educational goals (e.g., assistive technology, materials, adaptations, learning strategies, related services). As shown in Figure 1–1, this can be conceptualized as four basic options for including students with severe disabilities (or any student for that matter) within typical class activities; each is described in the sections that follow. During the course of a school day, even sometimes within a single activity, an individual student will move among these different options, depending on the nature of the activity and his or her individual needs. This approach requires deliberate collaboration among teachers, special educators, and related services providers (see Chapter 6).

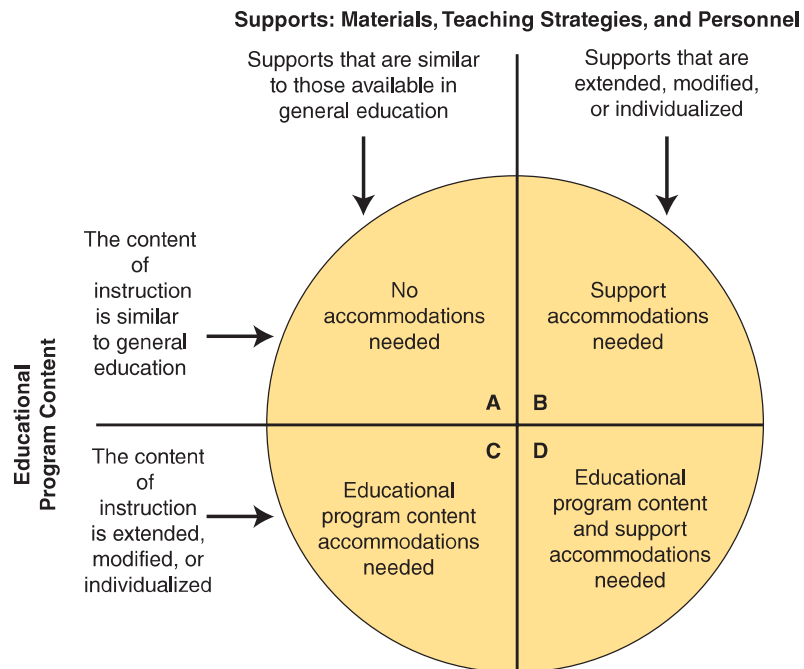
#### Option A: No Accommodations Required

Option A exists when a student is participating in the same activity with students without disabilities in the same way, and is pursuing the same content at the same level of difficulty. However, supports (e.g., teacher, classmates, classroom equipment) that are typically available can and do vary widely from class to class or school to school.

The participation of students with severe disabilities may be characterized as Option A during certain parts of the day. If Option A existed all of the time, the student would not be in need of special education nor would he or she be characterized as having severe disabilities. For example, in a primary classroom, when the teacher is reading a

**FIGURE 1-1**

Inclusion Options Within General Education Environments and Activities



(From Giangreco, M.F., & Putnam, J. [1991]. Supporting the education of students with severe disabilities in regular education environments. In L.H. Meyer, C. Peck, & L. Brown [Eds.], *Critical issues in the lives of people with severe disabilities* [p. 247]. Baltimore: Paul H. Brookes Publishing Co.; adapted by permission. As it appears in *Choosing Outcomes and Accommodations for Children (COACH): A Guide to Educational Planning for Students with Disabilities, Third Edition* (2011) by M.F. Giangreco, C.J. Cloninger, & V.S. Iverson.)

story to the class, the student with severe disabilities may not require specialized instruction or specialized supports. The teacher may position the child close by so that the teacher can show each page and respond if the student's attention wanders, or the teacher may have a peer sit nearby in case the student starts to lose his or her balance while seated on the floor with the rest of the class. However, these types of simple supports are not so specialized that they are considered "special education."

It is important to recognize times when a student with a severe disability can participate within Option A because (a) it provides opportunities for the teacher to interact with a student who has disabilities in typical (non-specialized) ways, (b) it allows classmates to see that the student doesn't always need extraordinary help, and (c) it allows the student to avoid unnecessary supports that may inadvertently interfere with peer interaction or teacher engagement. Many students with severe disabilities have one-to-one paraprofessional support while they are in general education class activities (Suter & Giangreco, 2009). There can be a tendency to provide such support, even at times when it is not needed. Using the previous example, having the student with a severe disability sit beside or on the lap of the paraprofessional not only may be unnecessary, but also may have unintended negative consequences such as stigmatization, unnecessary dependency, interference with peer interactions, and interference with teacher engagement (Giangreco, 2010). Therefore, teams should continually look for Option A opportunities by considering how naturally available supports can be utilized (Carter, Cushing, & Kennedy, 2009; Downing, 2010; Giangreco, Broer, & Suter, 2011).

### Option B: Support Accommodations Required

Option B exists when a student with a disability requires extended, modified, or otherwise individualized supports while pursuing substantively the same general education program. For example, in order for a student with deafness or blindness to access

the general education program, he or she may require signing from an interpreter or the use of tactile materials as necessary supports. Similarly, a student with severe orthopedic or multiple disabilities might require a digital recorder and adapted switch to “take notes” during a high school class.

### Option C: Educational Program Content Accommodations Required

Option C exists when a student requires extension, modification, or individualization of the content of the general education program but *does not* require specialized supports. For example, the teacher might adjust the content with regards to (a) the amount (e.g., 4 new vocabulary words instead of 10), (b) the level (e.g., posing less complex questions), or (c) the type of content (e.g., 1:1 correspondence instead of fractions). Across each of these possibilities, once the content adjustment is made, the student does not require other specialized supports—although, like Option A, natural supports might be provided.

### Option D: Educational Program Content and Support Accommodations Required

Option D exists at times when a student needs extension, modification, or individualization of both the general education curriculum content *and specialized supports* to participate. In addition to adjusting the content of the curriculum with regards to the amount, level, and/or type, individualized supports are provided to assist the student with learning and participation. Some examples of individualized supports that a student with severe disabilities might receive include a visual picture schedule that identifies the steps for completing an activity, individualized prompting from a peer or adult, or an adapted keyboard for use with the computer. These supports allow students to actively engage in educational activities by removing barriers that interfere with learning.

Within both options C and D, teams may employ the *principle of partial participation* (Baumgart et al., 1982; Ferguson & Baumgart, 1991). This principle is based on the premise that students with severe disabilities “can acquire many skills that will allow them to function, at least in part, in a wide variety of least restrictive school and nonschool environments and activities” (Baumgart et al., 1982, p. 19). For example, a student with severe disabilities might have a job in the school library that involves taking returned books from the book drop and placing them on a cart. A peer may then assist the student with severe disabilities to find the correct shelf and position for the book. In this manner, the student performs some, but not all, of the skills that are typically performed by students at school who serve as library assistants.

Partial participation is designed to foster socially valued roles for people with disabilities that have a positive influence on their image and personal competencies. Rather than excluding students from activities because they may never be able to perform independently or in the same way as most students, partial participation focuses on engaging students to the maximum extent possible. Consider Kendra, a middle school student with multiple disabilities who has extensive support needs related to oral-motor skills (e.g., chewing, swallowing).

*Many foods that Kendra is supported to eat fall out of her mouth. When in the bustling cafeteria, she seems particularly distracted. Her parents identified eating in busy environments as a priority because the family often eats in busy restaurants.*

*School personnel, however, were concerned that eating in the cafeteria was socially problematic for Kendra and would detract from how she was perceived by others. So she has been eating lunch in a private area while working on goals to improve her eating and drinking skills with a paraprofessional. Unfortunately, this practice, while intended to be respectful of her, took an all-or-nothing approach. A subgroup of Kendra’s educational team, including her mother, special education teacher, and occupational therapist, came up with a plan designed to respect her dignity while also providing her with access to the cafeteria with classmates.*

*The principle of partial participation was key to various aspects of their plan that systematically shifted from eating alone to eating with peers in the cafeteria. First, recognizing that Kendra quickly fatigued and her eating skills deteriorated as time went on, they decided that instead of having Kendra eat her entire lunch in one 20-minute sitting, she ate two 10-minute mini-meals spread out over 40 minutes. During the regularly scheduled lunch period for her class, she spent only 5 minutes in a private area working on her eating and drinking goals. The remaining 15 minutes was spent in the cafeteria with her peers, eating only foods that she could better manage and hanging out just like everyone else in the middle school cafeteria. After a couple of weeks the amount of time that she spent in the cafeteria was gradually increased. Kendra's parents and occupational therapist identified a specific set of foods that she was able to chew and swallow most effectively without spilling. She would still lose food occasionally; this would allow her peers to learn that some people eat differently and for the adults to model that it's not a big deal. Kendra continued to work on eating more challenging foods in private. The team recorded data on both her eating goals and social interactions—they met regularly to discuss Kendra's progress. Gradually her eating shifted to the cafeteria completely, although she still didn't eat her entire meal during the scheduled lunchtime. The team used partial participation by offering her only certain foods in the cafeteria and using only part of the time for eating; these modifications in the usual lunch routine allowed Kendra to be more fully part of the life of the school.*

It is often the case that Option D will be necessary, at least part of the time, for students with severe disabilities because of their extensive or pervasive support needs. Teams are encouraged to consider when options A, B, or C are possibilities and to be conscious of not overusing Option D if less intrusive options are appropriate. When Options C and D are warranted, care must be taken to structure the learning environment in a manner that promotes access to individualized curricular content as well as access to learning with peers. Unfortunately, Options C and D are frequently operationalized by assigning a paraprofessional to teach individualized curricular content (i.e., a parallel educational program) in the back or side of the classroom. Such an approach minimizes the potential benefits of participation in a general education class and has been linked to a host of unintended detrimental effects (Giangreco, 2010). Delegating primary instructional responsibilities to a paraprofessional also relegates students with the most significant learning challenges to receiving their instruction from the least qualified personnel, who tend to be undertrained and inadequately supervised (Giangreco, Doyle, & Suter, 2014). Two alternatives include *multilevel curriculum/instruction* and *curriculum overlapping* (Giangreco, 2007). See Table 1–4 and Figure 1–2 for shared and distinct components of these two related approaches.

### **Multilevel Curriculum/Instruction**

There are two requirements of multilevel curriculum/instruction. First, it occurs when a student with disabilities and peers without disabilities participate together in a shared activity such as a science lab experiment. Second, each student has individually appropriate learning outcomes that may be at multiple levels (i.e., below, at, or above grade level), all within the same curricular area. While one student may be learning at a basic knowledge or comprehension level, another student simultaneously may be working at a more advanced level.

*Imagine second-grade students playing a teacher-designed, small-group, social studies board game to learn about their neighborhood, town, and state. A set of 10 game cards has been prepared for each student that targets individual learning outcomes. For three students (at grade level), the game cards require applying knowledge about the roles of community helpers (e.g., police, firefighters, store clerks, postal workers) by moving game pieces to respond to scenarios on the cards (e.g., “Move your player to the place*

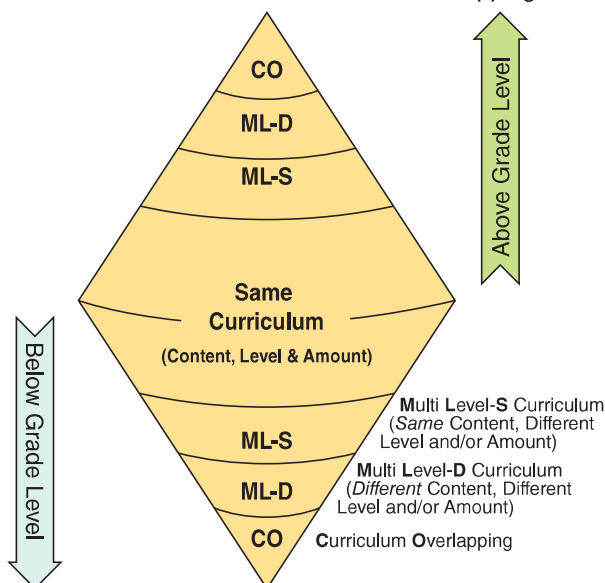
**TABLE 1-4**  
Components of Multilevel Curriculum/Instruction and Curriculum Overlapping

Shared Components	
1. Lessons include a diverse group of same-age learners (e.g., advanced, those with disabilities, at grade level, at risk). 2. Learning occurs within a shared activity or experience within a regular class activity. 3. Each learner has individually appropriate learning outcomes at an appropriate level of difficulty.	
Distinct Components	
Multilevel Curriculum/Instruction	Curriculum Overlapping
4. Targeted learning outcomes are within the same curricular area (e.g., science or math or social studies) and students are responsible for more or less of them in terms of amount and complexity.	4. Targeted learning outcomes for the student with a disability come from a different curricular area (e.g., communication, socialization, or personal management) than those targeted for other classmates (e.g., science, math, history).
Variations: (a) Same topical subject matter in same curricular area (b) Different topical subject matter in same curricular area	

(From *Extending inclusive opportunities. Educational Leadership*, 64(5), 34–37. Reprinted by permission of the author.)

*where you might go if you wanted to send a card to your grandmother for her birthday.”). For another student who has autism and has occasionally gotten lost or separated from his family, game cards have the student answer questions about himself and where he lives (e.g., last name, street address, phone number, where his parents work). A third student (who is performing above grade level) is using map skills such as north, south, east, and west to respond to questions (e.g., “If you started at the bookstore, went two blocks north and one block east, where would you be?”). In this example, all of the students have individualized social studies learning outcomes, pertaining to different content/subject matter, within a shared activity.*

**FIGURE 1-2**  
Multilevel Curriculum and Curriculum Overlapping



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By definition, multilevel curriculum/instruction involves individually appropriate learning outcomes that may be provided at any level (i.e., below, at, or above grade level) and can include variations across subject content.

*In one seventh-grade social studies class focusing on history from the American Revolution through the Civil War, the topic is the same for Joseph—a student with disabilities—and his classmates without disabilities. But his level of learning outcomes is adapted to suit him (e.g., historical people, places, events). In Joseph’s algebra class, however, the subject content for Joseph is different from that for many of his classmates, focusing on counting and basic computation (e.g., adding is a variation within the subject content). In this case, the level and quantity of the learning outcomes would be adapted as well. In both classes, Joseph is working on individualized learning outcomes within the same curricular content area as his classmates, just at a different level.*

### Curriculum Overlapping

Curriculum overlapping starts in the same way as multilevel curriculum/instruction; a student with disabilities and peers without disabilities participate together in a shared activity where each student has individually appropriate learning outcomes. Curriculum overlapping differs in that the learning outcomes being pursued within a shared activity come from two or more different curricular areas; this is unlike the multilevel curriculum/instruction examples, where they were all within the same curricular area.

*In a middle school biology class, students are grouped in teams of three for lab activities. They are assembling a model of a human heart. Two students have goals related to the identification, anatomy, and physiology of the human heart. The third student, who has an intellectual disability and extensive support needs, participates in helping to assemble the model heart but is working on communication and social skills (e.g., taking turns, following instructions, responding to yes/no questions, maintaining socially acceptable behavior for longer periods of time).*

Curriculum overlapping is appropriate to use when there are large differences between the level of learning outcomes being pursued by most of the students in a class and the student with a severe disability. Before employing curriculum overlapping, the team should consider whether the student could pursue the same learning outcomes as the rest of the class or whether either of the two multilevel curriculum/instruction variations are viable options; this helps to ensure that we do not underestimate students with severe disabilities.

*In a middle school math class, six students are arranged in a circle for a game that involves throwing and catching a beach ball covered with numbers to practice multiplication. The game starts by having one student call a classmate by name and then toss the ball: “Terry, I’m throwing the ball to you.” After catching the ball, the student is asked to multiply the two numbers that are touched by his or her thumbs. All of the students have math learning outcomes except for Jesse, a student with an intellectual disability and extensive support needs. Jesse participates in the same activity but has a series of non-math goals. He is learning to orient himself toward a person who calls his name, react to the tossed ball by moving his arms to attempt a catch, match to a sample by pointing to a photograph of a classmate in the group, and then orient himself toward that person before being assisted to toss the ball.*

At times, both multilevel curriculum/instruction and curriculum overlapping can be used within the same activity. By pursuing more than one learning outcome within class activities, students with severe disabilities are provided with numerous opportunities to learn and practice skills. Research has demonstrated the effectiveness of embedding individually determined learning outcomes within general class activities (Hudson, Browder, & Wood, 2013; McDonnell, Johnson, Polychronis, & Risen, 2002).

Such approaches have become increasingly relevant with the advent of the Common Core State Standards Initiative ([www.corestandards.org](http://www.corestandards.org)). Occasionally, it may be necessary to plan an alternate activity if a student needs to work on a high-priority goal that does not lend itself to being incorporated into the multilevel curriculum/instruction or curriculum overlapping options. For example, a high school student with severe disabilities may need specific, alternative instruction on a skill that does not readily lend itself to available high school curriculum, such as how to safely cross various types of intersections to travel to a community-based work or recreation site. At other times, students' privacy requirements dictate the need for alternatives, such as when a student is learning to use the toilet or dressing skills.

### The Curricular Balancing Act

Ensuring access to a relevant, individualized curriculum for a student with severe disabilities also requires a balancing act *between focus and breadth* (Hunt, McDonnell, & Crockett, 2012). Providing access to a breadth of learning outcomes that includes, but is not limited to, general education curriculum ensures that students with disabilities will have opportunities that may have been denied them in the past. A sound curriculum establishes a clear focus, based on a reasonably small set of the highest educational priorities agreed to by the team; these are documented as IEP goals (Giangreco, Cloninger, & Iverson, 2011).

Historically, curricula for students with severe disabilities have emphasized the identification of *chronologically age-appropriate functional skills* needed to participate in current and future environments (Brown, Nietupski, & Hamre-Nietupski, 1976; Brown et al., 1979). Chronologically age-appropriate skills are ones that are performed by same-age peers without disabilities. For example, when thinking about the use of a coat at school, a 7 year old may learn to hang his or her coat on a hook in the classroom whereas a 15 year old would learn to use a locker in the hallway. Selection of age-appropriate skills is particularly important when addressing functional skills. Functional skills are skills that are used across one's lifetime and would need to be performed by someone else if an individual was unable to perform the skills for him- or herself. Typical skills identified as functional include self-care (e.g., dressing, bathing, toileting), home living (e.g., cooking, cleaning), leisure (e.g., hobbies, fitness), community (e.g., using the grocery store, traveling in the community), and vocational (e.g., job and job-related skills) (Dymond, 2011).

While the foundational concepts of chronological age appropriateness and functional curriculum remain contemporary, variations on the themes have been expanded. Today, the basis for selecting IEP goals and objectives for students with severe disabilities has shifted to place a greater emphasis on determining which goals and objectives are most likely to result in positive lifestyle improvements (Giangreco, Cloninger, & Iverson, 2011; Halle & Dymond, 2008/2009; Hunt, McDonnell, & Crockett, 2012). By asking parents who have children with disabilities and people with disabilities themselves what does or would contribute to living a "good life," we can better identify and select goals and objectives that will contribute to the development of *valued life outcomes* (Giangreco, Cloninger, & Iverson, 2011).

*Juanita Perez is in first grade and has severe disabilities. Her special education teacher worked collaboratively with the team, including Juanita's parents, to identify the highest priorities for Juanita from the family's perspective that would be translated into IEP goals and objectives. These priorities included (a) expressing "more," (b) making a selection when given options, (c) responding to yes/no questions using eye gaze, (d) calling others to her using a switch and recorded message, and (e) using a switch to activate leisure devices (e.g., digital music player, battery-operated toys). The team cross-referenced each of these priorities to one or more valued life outcomes. For example, being able to activate toys was designed to give Juanita more choices and control and was hoped to be a point of connection that might serve to extend her*

*relationships with other children her age. The team also considered a set of additional learning outcomes to establish the breadth of Juanita's educational program. They did this by systematically looking at the general education curriculum in each subject area, as well as functional skill categories, to decide which learning outcomes would make the most sense for Juanita. As a result, they selected a series of additional functional skills (in addition to the family's highest priorities), such as imitating skills used in daily life, eating finger foods, drinking through a straw, and increasing the amount of time that she could sustain attention to a task. From the general education curriculum, they started with skills such as recognizing symbols, distinguishing between shapes, writing her name using an adapted stamp, and using a variety of art media, among others.*

A sound curriculum also *balances the assessed level of appropriateness with a measure of challenge*. An age-old tenet of instruction is that a student's learning outcomes should be selected at an *appropriate level of difficulty* on the basis of assessment data. Targeted learning outcomes should be reasonably attainable yet challenging, although not so challenging as to be unattainable or frustrating. Although it is logical to select instructional targets on the basis of the student's current level of performance and known learning characteristics, quality instruction should *provide ample opportunities for students to surprise us with their capabilities*.

Therefore, we should never presume to know the upper limits of a student's abilities, especially if the student has not been sufficiently exposed to a concept or skill or has not received ongoing, competent instruction using research-based interventions. This is consistent with Donnellan's (1984) *criterion of the least dangerous assumption*, which asserts, "in the absence of conclusive educational data, educational decisions should be based on assumptions which, if incorrect, will have the least dangerous effect on the student" (p. 142). For example, if an individual with a severe disability is non-verbal and does not have a fluent alternative or augmentative method of communication, it would be most dangerous to assume that he or she does not understand much, if any, of what is said to or near him or her. It would be less dangerous to assume that he or she understands everything being said to or near him or her. Similarly, it would be most dangerous to prevent the student's exposure to a general education curriculum and least dangerous to provide not only exposure but also instruction.

*Juanita's team did not select any science learning outcomes for her because they felt that the concepts were too advanced for her and because they were not able to adequately assess her science learning given her challenges with expressive communication. Recognizing that this could be a dangerous assumption given the challenge of knowing how much Juanita understands, they decided to include her in science class and start with curriculum overlapping so that the learning outcomes that she focused on during science class were primarily communication and social skills. By including her in the science activities and exposing her to instruction in this area along with her classmates, they are providing her with opportunities that would not deny the possibility that she understands more than they were currently able to discern. At least at the outset, accountability for learning during science class will focus on the non-science communication and social skills. Over time, on the basis of the teacher's observations during science class activities, Juanita's additional learning outcomes may be expanded to include science class outcomes.*

### Access to Purposeful Instruction

Over the past several decades, the field of educating students with severe disabilities has relied extensively on the use of systematic instructional methods to pursue meaningful curricular outcomes because of their strong theoretical foundation and documented effectiveness (Alberto & Troutman, 2013). This set of instructional methods,

such as chaining, shaping, prompting, time delay, and error correction (see Chapter 5), offered a bright spot in a special education system that was all too often characterized by unnecessarily low expectations, too much instructional downtime, limited access to peers without disabilities, and questionable curricula. Use of systematic instructional methods played a major role in documenting the wide range of skills and functional routines that people with severe disabilities could learn if offered consistent, quality instruction. In fact, the use of these methods was instrumental in helping to establish, once and for all, the belief in the “educability” of students perceived as having the most profound disabilities.

Ironically, as students with severe disabilities have gained greater access to general education classes, peers without disabilities, and a broader curriculum, new questions have been raised about the integrity of their instruction. The field is wrestling with the challenge of how to utilize evidence-based, systematic instructional approaches in new and contextually viable ways (Koppenhaver & Erickson, 2008; Schnorr, 2011). In part, this has included a shift from individual instruction and small homogeneous groups to mixed-ability groupings where there is only one student with a disability with classmates who do not have disabilities.

As teams pursue quality instruction, it is important to remember that the principles of teaching and learning remain the same regardless of a student’s ability or where that student receives his or her education (see Box 1–1). Many doors have been opened for people with severe disabilities using foundational principles of instruction, and these remain critical for learning in inclusive settings. As with all strategies, however, the specific and changing learning environments and individual learning needs of each student will shape how strategies are used and adjusted to fit the evolving context. (For more on this topic, see Chapter 6.)

### Know Each Student’s Characteristics

Quality instruction always starts by making sure you know your students. This means more than being familiar with their disability label, although that is important to understand. It means understanding their cognitive, physical, and sensory characteristics that affect instruction. It also means being cognizant of their social/emotional traits (e.g., temperament, behaviors), motivations, preferences and dislikes, interaction patterns, and creative attributes. Understanding such aspects of your students’ support needs allows for *individualization*, a hallmark of special education, and encourages the development of instructional approaches that build on each student’s strengths and preferences.

### Select Meaningful Learning Outcomes

Quality instruction really matters only if it is applied to meaningful learning outcomes (Halle & Dymond, 2008/2009; Hunt, McDonnell, & Crockett, 2012). Highly effective instruction applied to irrelevant, non-functional, or chronologically age-inappropriate learning outcomes is a waste of the student’s time as well as your own. Effective teams establish and maintain a positive sense of urgency about their work without simultaneously creating undue stress on the student or team. They know that,

#### Box 1–1

#### Principles of Quality Instruction

1. Know each student’s characteristics.
2. Select meaningful learning outcomes.
3. Establish shared expectations among team members.
4. Create a motivating and welcoming learning environment.
5. Select effective teaching methods.
6. Provide sufficient and consistent learning opportunities.
7. Use data to make instructional decisions and evaluate outcomes.

relatively, they have precious little time to teach, so their curricular selections and instructional intensity matter.

In addition to considering curricular aspects related to instruction mentioned earlier in this chapter (e.g., functionality, age appropriateness, balance of breadth and focus), teams should also consider (a) the frequency with which a learned skill will be used both now and in the future and (b) the extent to which a learned skill will increase independence. Clearly, skills that are used frequently and have current and future utility generally are more important than those that are used infrequently or will not be useful in the future. Selecting meaningful learning outcomes is always a judgment. Sometimes, skills with a lower frequency of use can be extremely important for being safe (e.g., street crossing, evacuating a building in response to an alarm) or for personal preferences (e.g., the leisure skills that one enjoys, predictable environments, unstructured time). For individuals with the most severe or multiple disabilities, another major consideration is the extent to which a learned skill will allow a person to control his or her environment. For example, learning to use an adapted microswitch may allow a person with severe or multiple disabilities to activate a wide variety of electrical or electronic devices across a range of locations and activities (e.g., communication, cooking, leisure, work).

### Establish Shared Expectations Among Team Members

Having the perspectives of a variety of team members can be an asset to planning good instruction (Giangreco, Cloninger, & Iverson, 2011; Hunt, McDonnell, & Crockett, 2012). In order for teams to plan effectively, they must share common expectations and be willing to come to consensus about the direction of instruction for each student. Establishing shared expectations means that all members should (a) know the student's learning-related characteristics and support needs, (b) be aware of the student's priority learning outcomes (e.g., IEP goals), (c) be aware of the breadth of learning outcomes that are targeted for instruction (e.g., general education curriculum), (d) know when learning outcomes will be addressed throughout the school day, (e) know what general supports or accommodations need to be made for the student, (f) know the student-specific instructional procedures and adaptations, and (g) know what information should be collected on the student's progress.

### Create a Motivating and Welcoming Learning Environment

Although it may seem obvious, the importance of *creating a motivating and welcoming learning environment* for all students cannot be underestimated. Establishing a sense of belonging is considered a key building block for effective learning (Schnorr, 1990, 1997; Swedeen, Carter, & Molfenter, 2010). In order for students with disabilities to develop meaningful relationships with peers who do not have disabilities and to have access to a broad range of meaningful learning outcomes, they must share learning experiences with peers on an ongoing basis. This includes experiences not only in the academic classroom but also in typical school routines (e.g., changing classes in the hallways, eating in the cafeteria, hanging out before school), special events (e.g., field trips, job fairs, talent night), school jobs (e.g., office helper, library assistant), and extracurricular activities (e.g., drama club, student council, intramurals).

### Select Effective Teaching Methods

Part of instructional access involves selecting effective teaching methods as a starting point for intervention (Alberto & Troutman, 2013). Students with disabilities often respond favorably to many of the same teaching methods that are common and effective for students who do not have disabilities. Some of these common methods include modeling and demonstration, repeated practice, guided discovery, participatory activities, using educational games or play, using positive and negative examples, giving corrective feedback, or cooperative group learning approaches. Challenges

arise when students do not progress adequately when you have relied on typical instructional methods. In such cases, it is often necessary to be more precise in the application of methods; break the skills down into smaller components; or use different instructional methods, such as task analysis, chaining, shaping, and time delay (see Chapters 4, 5, 6, 10, 12, 13, and 14). Consider how Tom learned a new skill because of the use of a systematic instructional procedure and its impact on his life:

*Tom had a traumatic brain injury that resulted in severe physical, cognitive, and sensory disabilities, including cortical visual impairment, loss of language, and the inability to walk, sit up independently, or use his arms and hands. Tom was fed primarily through a gastrostomy tube, although his parents had worked with him so that he could eat soft foods and drink by mouth. His only consistent, voluntary skill was some head movement from side to side when supported from behind, the ability to open and close his mouth, and some chewing. Tom communicated primarily through vocalizations (e.g., groaning was recognized as discomfort). This usually meant that it was time to get him out of his wheelchair for a while. At a meeting when Tom was 14 years old, his parents were asked for their input into Tom's IEP goals for the year. Tom's father said, "I don't care what he learns; I just want to know that he can learn." Building on Tom's strengths, the team decided to teach Tom to respond to the verbal instruction "Open up" so that he would open his mouth to receive food, drink, and medicine, and have his teeth brushed. The team knew that Tom currently didn't respond to "Open up" or any other instruction, but he did open his mouth wide when his lower lip was touched lightly (e.g., by a spoon with food). Some team members wondered if he was actually responding to the lip touch or something else, such as the air movement of something coming toward him, smell, or cues from some residual vision. Their assessment convinced them that it was the touch cue only that caused him to open his mouth. They decided to use an instructional procedure called "time delay." This was started by simultaneously pairing the cue that they knew Tom responded to (i.e., touching his lip with a spoon) with the cue that they wanted him to respond to (i.e., the verbal instruction "Open up"), followed by giving him a spoonful of fruit yogurt. This simultaneous pairing is known as a zero delay because there is no time delay between the presentations of both cues. This was done numerous times throughout the day when Tom would normally be expected to open his mouth in an effort to help Tom to make the connection between the two cues. After this had been done for a few days, a one-second time delay was inserted between the cues. The teacher would say "Open up," then wait one second before touching his lip. Over the next couple of weeks, the time delay between asking Tom to "Open up" and touching his lip was gradually increased in one-second intervals, always followed by a small bite to eat or a sip to drink. When the time delay was increased to five seconds, Tom opened his mouth to accept the food before his lip was ever touched—he had responded to the instruction! He soon was opening his mouth immediately and consistently following the request. Time delay had been successfully used to transfer control from the one cue to another. Some people might think that this didn't matter much, but it did! For the first time in years, people who worked with Tom were excited and encouraged that he had learned a new skill. People interacted with him differently, more positively, as someone capable of learning. They were anxious to find out what else Tom could learn. Tom will always need substantial support, but this small change had a big impact. Once it was clear that he could respond to the "Open up" cue, the staff was sensitive to considering that Tom might keep his mouth closed as a way to indicate that he no longer wanted more to eat. Increasingly, the team was more aware of subtle behaviors that might have communicative intent.*

### Provide Sufficient and Consistent Learning Opportunities

Once instructional methods have been selected, with the individual student's learning characteristics in mind, the team needs to ensure that sufficient and consistent learning opportunities are provided for the student. A *scheduling matrix* (Giangreco, Cloninger, & Iverson, 2011) provides a way for the team to ensure that the student's IEP goals and additional learning outcomes are incorporated into the daily or weekly

schedule. A scheduling matrix is set up as a simple grid. Listed across the top are regularly occurring class activities (e.g., arrival, language arts, math, science, physical education, lunch, recess). Listed down the left side of the matrix are IEP goals and other targeted learning outcomes (see Chapters 4 and 6 examples). It can be helpful to note the amount of time devoted to each activity. For example, arrival may be only 10 to 15 minutes at the beginning of the day, whereas a full hour might be devoted to language arts. The time frame is important to know because the number of learning outcomes that can reasonably be addressed will vary accordingly. Because daily schedules often change (e.g., on one day math is at 9:00 a.m., and on a different day it is at 10:30 a.m.), when using a scheduling matrix it is not crucial to arrange the general class activities in a specific order according to the schedule. The team examines the matrix, determines which learning outcomes will be addressed in each class, and marks those locations on the matrix. The match between the learning outcomes and the class where they will be taught will be the same regardless of what time the class occurs or on which day of the week. In this way, the scheduling matrix can then be used to clarify which of a student's learning outcomes can be embedded within all classes (e.g., express greetings and farewells, respond to yes/no questions, follow instructions, make choices when presented with options) and which will be targeted to specific classes or activities that make the most sense.

Providing sufficient and consistent learning opportunities requires persistence and creativity on the part of team members to embed opportunities for learning within class activities. Since students with severe disabilities often present a very unique constellation of learning characteristics, team members need a certain level of instructional flexibility. They need room to explore new approaches and combinations of approaches and to capitalize on unscheduled, teachable moments.

### Use Data to Make Instructional Decisions and Evaluate Outcomes

Along with instructional flexibility comes accountability in the form of data collection. Just as we collect data and examples of work completed by students who do not have disabilities in order to monitor and document progress and be accountable for our teaching, teams have a responsibility to do the same for students with severe disabilities (see Chapter 5). Individualized data provide essential information for making reasoned instructional decisions (Alberto & Troutman, 2013; Farlow & Snell, 2005).

As we think about collecting data on student learning, it is important to remember that performance related to specific IEP goals and objectives is only part of what is necessary. Regardless of the extent of student progress, it is important for each priority goal to be evaluated on the basis of its real impact on a person's life. Wolf's (1978) classic article introduced the field of applied behavior analysis to the assessment of *social validity*. Wolf argued that we must augment objective observable measures of behavior with the subjective perspectives of consumers if we are to achieve outcomes of social importance. He suggested that we evaluate (a) the social significance of the goals being sought, (b) the social appropriateness of the procedures being used, and (c) the social importance of the effects. The concept of social validity acknowledges that a student's attainment of an established goal is not necessarily synonymous with its importance or with meaningful changes in the student's life.

*Maria is learning a set of social skills (e.g., responding to the presence of others, greeting, taking turns) with the intent that the attainment of these skills will contribute to establishing or extending friendships with her peers. Merely knowing that she has acquired those skills is a good first step, but it is incomplete until we determine whether her relationships with peers have changed for the better and whether her improved skills contributed to those socially important changes.*

Sometimes, socially important outcomes can occur even when target skills are not achieved. There may be circumstances where a student does not progress much in the development of the targeted skill, but where the nature of the instructional

arrangement (e.g., peer involvement in typical class activities) leads to improvement in valued life outcomes because something in the environment has changed (e.g., access to typical settings, attitudes of classmates). Improvements in valued life outcomes for individuals with severe disabilities can be enhanced by a combination of skill acquisition on their part, as well as changes in the environment, especially the attitudes and actions of the people in those environments.

### Access to the Necessary Related Services and Supports

As described earlier, one of the defining characteristics of people with severe disabilities is their need for supports in multiple domains to meet the demands of inclusive environments. Systems of supports for students with severe disabilities typically include supports for learning and participation (such as those described in the previous sections) as well as related services and supports. Related services and supports, according to IDEA, include

*transportation, and such developmental, corrective, and other supportive services (including speech-language pathology and audiology services; interpreting services; psychological services; physical and occupational therapy; recreation, including therapeutic recreation; social work services; school nurse services designed to enable a child with a disability to receive a free appropriate public education as described in the individualized education program of the child; counseling services, including rehabilitation counseling; orientation and mobility services; and medical services, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a child with a disability to benefit from special education, and includes the early identification and assessment of disabling conditions in children.* (20 U.S.C. § 1400 (2004); IDEA, sec. 602(26)(A))

### Team Decisions About Related Services

The goal of related services is to support students with severe disabilities to receive an appropriate education in the least restrictive environment. For this reason, related services providers, education professionals, and family members must work together as a *team* to identify the best ways to build a system of support that meets the individualized needs of each student.

When considering how to build a system of support for an individual student, different stakeholders may bring different value systems to the decision-making process. Some related services disciplines are rooted outside of education, such as allied health fields (e.g., speech language, physical therapy, occupational therapy) that may have discipline-specific values and perspectives. Coming to an agreement on shared values can enable teams to work together more effectively. In the sections that follow three common value systems that teams might encounter are described. The first two are inconsistent with sound educational practices; the third is suggested as a desirable alternative.

***More Is Not Necessarily Better.*** Some team members advocate for *more* related services. If one session of a therapy is recommended, they think that two would be better, and three better yet. The *more-is-better* approach is misguided because it confuses quantity with value. Although rooted in benevolent intentions, the more-is-better approach can have unintended, negative consequences for students by interfering with participation in other school activities by

- decreasing the time available for participation in the general education curriculum with peers who do not have disabilities, particularly when a student is removed from the classroom to receive related services
- stigmatizing students if the provision of special services violates contextual norms
- fostering unnecessary or unhealthy dependencies
- unnecessarily complicating communication and coordination among team members
- causing inequities in the distribution of resources, with some students remaining unserved or underserved

***The Fallacy of Return on Investment.*** Another misguided value system, called *return on investment*, places a high value on “fixing” student’s deficits and it gives higher priority for supports and services to those students most likely to be “fixed.” This approach fails to recognize that disability is not something to “fix,” and instead, as IDEA states, is “a natural part of the human experience.” It can lead to devaluing and discrimination based on the intensity of a person’s support needs. Anytime that schools sanction practices that imply that some students are more worthy of staff time and resources than other students, there is a serious problem. And, imagine what it might be like to continually get the message “You are not okay the way you are. In order to be okay, your disability has to be fixed and you need to be more like us (people without disabilities).”

***Only as Specialized as Necessary.*** An alternative value system is referred to as *only as specialized as necessary*—providing enough but not too much support. Remember, the goal of providing individualized supports to people with severe disabilities is to address the mismatch between a person’s capacities and the demands of inclusive environments. This requires an individualized system of support that balances the capacities of the individual with the demands of the environment. The conceptual basis for this value system has a legal foundation in a U.S. Supreme Court precedent (*Board of Education of the Hendrick Hudson Central School District v. Rowley*, 1982).

Systems of supports for students with severe disabilities should include multiple sources of supports, including both natural supports (e.g., peers, family members, community members) as well as specialized supports (e.g., educators, related service professionals). When specialized services and supports are used, ongoing data should be collected to document the impact of the services and supports and to explore ways for the services to be provided in the most natural and sustainable way, which may involve natural supports.

It is important to recognize that the only-as-specialized-as-necessary approach does not automatically mean “less is always best” or “only a little is plenty.” Some advocates have voiced concern that this approach might be misused to justify the denial of needed services; this certainly is not its intended use. When used as intended, the only-as-specialized-as-necessary approach results in students getting the supports they need to receive an appropriate education. Further, it provides a values-orientation for members of a student’s team that can lead to educationally sound decision-making. (See Chapter 6 for further discussion of the only-as-specialized-as-necessary approach.)

### **Educational Relevance and Necessity**

When considering a value orientation such as the only-as-specialized-as-necessary approach within the context of the IDEA definition of related services, teams must ask themselves challenging questions about the educational relevance and necessity of a proposed service. A related service has *educational relevance* when it can be explicitly linked with a component of a student’s educational program (e.g., IEP goals, general education curriculum).

*Ms. Burns, an occupational therapist, based on an individualized evaluation has made recommendations for supports to enable Adam, a student with autism, to develop his handwriting skills. If handwriting skills are a goal or objective on Adam’s IEP or part of the general education curriculum, then the recommended occupational therapy supports are educationally relevant.*

Educational relevance alone, however, is not sufficient to warrant the provision of services; services must also be *educationally necessary*. A service is educationally necessary if, after establishing its educational relevance, the team determines that the service is essential. Many teams may start by asking themselves, “Could the proposed related service help?” and the answer is almost always, “Yes.” But, a way to ask the question that is more consistent with the IDEA and to promote educationally-sound

decision-making, is “If the student does not receive a proposed related service, is there reason to believe that he or she will not (a) have access to an appropriate education or (b) experience educational benefit?”

To understand how this applies to a specific student, think about Jana, a student with multiple disabilities, and her team. Ms. Reeve, Jana’s mother, takes Jana to a private clinic for an evaluation, and a clinic consultant recommends that Jana receive music therapy once a week as a related service at school. Ms. Reeve brings this recommendation to the school team. The clinic consultant, in making this recommendation, was asking the question, “Could Jana benefit from this service?” But, remember, the question the team must start with is, “If the student does not receive music therapy as a related service, is there reason to believe that he or she will not be able to receive an appropriate education?” It can be particularly challenging for external clinics and consultants to make appropriate decisions about necessary related services when they are unfamiliar with the student’s educational program, which is why inviting outside consultants to be a part of the educational team can be helpful.

Some questions the team will have to ask themselves as they determine if music therapy (or any related service) is necessary for an appropriate education include the following (Giangreco, 2001):

- Could the benefit provided by the proposed related service be addressed appropriately by the special educator or classroom teacher or by other core school faculty or staff (e.g., school nurse, guidance counselor, librarian, physical education teacher, bus drivers, cafeteria staff, custodians)?
- Has the student been benefiting from his or her educational program without the service?
- Could the student continue to benefit from his or her educational program without the service?
- Could the service appropriately be provided during non-school hours (as established in the 1984 U.S. Supreme Court decision, *Irving Independent School District v. Tatro*, 1984)?
- Does the proposed service present any undesirable or unnecessary gaps, overlaps, or contradictions with other proposed services?

The answers to these questions will guide the team in making decisions about the educational relevance consistent with the Supreme Court’s decision in *Board of Education of the Hendrick Hudson Central School District v. Rowley* (1982). In that case, the court established that if a student was receiving educational benefit without the service, educational teams could use this as evidence that the service was not needed, even if providing the service might provide some additional benefit to the student.

In the example of Jana, the school might not agree to provide music therapy as related services if (a) Jana was receiving educational benefit without the service, (b) the service wasn’t deemed necessary for Jana to receive educational benefit, or (c) the service could be appropriately provided during non-school hours, in accordance with the reasoning presented in both the Rowley and Tatro cases. Jana’s team might, however, work to provide opportunities to experience music as part of a general education music class with support from peers and the general education teacher. Ultimately, by staying focused on the supports students need to meet the demands of inclusive environments, given their personal capacities, IEP teams can consider the full range of related services, then select and implement those that are educationally relevant and only as specialized as necessary. Well-conceived and well-executed related services can make a substantial contribution to a student’s educational program and system of support, as Jamal’s case illustrates.

*Jamal is a student with multiple disabilities, including deaf-blindness. The related service providers on his team have worked closely with the special educator, his classroom teacher, and his parents to ensure that his related services are both educationally*

*relevant and necessary. The physical and occupational therapists have selected and modified equipment (e.g., specialized seating, arm/hand supports, adapted computer interface) to provide supports for participation and learning. The speech-language pathologist has developed an augmentative communication system and corresponding instructional approaches that create opportunities for Jamal to communicate more effectively with teachers and peers. The vision and hearing specialists have adapted materials and learning environments (e.g., tactile labels, individualized amplification) to allow Jamal to access the general education curriculum.*

These are only a few of the many ways that educationally relevant and necessary related services can be imperative for some students with disabilities. Making team decisions is not always easy, but it is important.

## LEARNING OUTCOME SUMMARIES

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### 1.01 Who are students with severe disabilities?

#### Learning Outcome

*Identify definitions of severe disabilities, the role of the supports model in understanding students with severe disabilities, and the influence of societal perceptions and social interactions.*

There is no authoritative definition of severe disabilities in the field. Historically, professionals attempted to understand students with severe disabilities through their deficits, but newer models of disability focus on the interaction between personal capacities and the demands of inclusive environments. This focus brings attention to support needs and building systems of supports, with the underlying assumption that people with severe disabilities have a fundamental capacity to learn and a right to supports that enhance learning and participation. This assumption has been codified in IDEA in the zero-reject principle, and upheld in multiple court decisions. In society, negative assumptions about people with severe disabilities still exist, and disability spread, which is the tendency to make broad inferences about people with disabilities because of stereotypes, can still create low expectations. But by creating opportunities for social interaction and participation in inclusive communities, disability spread can be limited and people with severe disabilities can lead full, engaged, and self-determined lives.

### 1.02 Reasons for optimism and concern

#### Learning Outcome

*Identify areas where progress has been made in providing individualized supports for people with severe disabilities in inclusive communities, and areas where work is still needed.*

Substantial advancements have been made to improve the education of students with severe disabilities. These advancements include increased opportunities for inclusion in educational settings with same-age peers, access to a broader array of curricular options that includes the general education curriculum, the use of positive behavior supports and peer supports, and emphasis on teaching individuals to be self-determined as they transition into adult life. Despite these areas for optimism, many concerns continue to exist. These concerns include inconsistent access to inclusive classrooms, the questionable quality of curriculum and instruction, family frustrations with professional responsiveness, the continued use of aversives, challenging working conditions for special educators, and limited post-school options for individuals with severe disabilities.

### 1.03 Access to quality education

#### Learning Outcome

*Discuss the foundational principles of providing supports to students with severe disabilities that promote access to (a) inclusive environments, (b) individualized curriculum, (c) purposeful instruction, and (d) necessary supports.*

Broadly conceptualized, quality education for students with severe disabilities must include access to (a) inclusive environments alongside peers without disabilities, (b) individualized curriculum, (c) purposeful instruction, and (d) necessary supports. Options for including students with severe disabilities in general education environments can be conceptualized across individualized combinations of educational program and supports; these can fluctuate over time and even within a school day. When students require educational program accommodations, multilevel curriculum/instruction and curriculum overlapping can be implemented to meet students' support needs within shared educational experiences with their classmates without disabilities. In order to achieve meaningful outcomes, careful decisions must be made by educational teams about the curriculum a student receives and how instruction is provided. The determination of individualized supports should be guided by educational necessity, educational relevance, and an "only-as-specialized-as-necessary" approach. When conceived in this manner, individualized supports enable students with severe disabilities to pursue meaningful learning outcomes and self-determination through participation in inclusive contexts.