CHAPTER 1

Introduction to the Education of Students with Severe Disabilities

with IRENE MEIER

Jane is a 12-year-old student who is a member of Denise Bloom's sixth-grade class. Jane has cerebral palsy and ambulates with maximum assistance throughout the school environment. She has a diagnosis of cortical vision impairment (CVI) and an intellectual disability, and she does not use spoken language for communication. Jane has multiple medical disabilities causing an inability to swallow food by mouth and is tube fed. Jane is very social; she communicates by smiling and will also look at a person or object to invite others to talk with her. She is learning to recognize pictures to communicate her needs and wishes and to "show what she knows" during reading and other instruction by using a series of pictures and signs. Jane uses an object schedule against a black background to assist when transitioning from one activity to the next. When an activity is completed, Jane knows to take the object from the object calendar and place it in a "finished" bin. School staff and private therapists communicate regularly so that all staff are using the same consistent pictures and signs. Ms. Bloom has a log that she sends home to Jane's mother daily to show what she has accomplished that day in school. The paraprofessional for the class, Mr. Stack, is helping Jane learn to prepare the report by selecting pictures of her daily activities. Jane participates in many of the sixth-grade classes utilizing supplementary aids and services, including assistive technology and paraprofessional support. Because Ms. Bloom uses individualized assistance, learning centers, experience with books, and hands-on activities, there is usually a way for Jane to be engaged in learning in both special and general education classes. Ms. Bloom works closely with a collaborative team in planning for Jane, and numerous collaborative-learning team meetings are held weekly to support Jane's instructional needs. The general education teacher, Ms. Wilkerson, the assistive technology specialist, Mr. Clayton, and the vision itinerant teacher, Ms. Forrest, work collaboratively to adapt materials, provide systematic instruction, and support Jane with the use of the assistive technology required for her to access her educational environment. Many related services personnel are assigned to work with Jane to ensure that she has the appropriate skills and technology and to support her access

> and progress in the general education curriculum. A school health assistant checks in daily with Jane because of her complex medical needs. Jane's speech–language pathologist works collaboratively with the general education and special education teachers on generalization of her communication skills. Occupational and physical therapists collaborate closely with the team and provide individualized services to Jane to assist her with independent living skills and safe ambulation throughout the school environment. Jane's parents are actively involved in her education and quite knowledgeable about her disability. The school team collaborates with her parents through a daily journal, face-to-face meetings, and school team meetings. They also collaborate with Jane's private therapists and specialized vision consultants to ensure that there is a consistent team approach so that Jane's individualized education program goals are being implemented and so that she is able to access and make progress in her educational environment. Thus Jane can receive a free and appropriate public education required by the Individuals with Disabilities Education Act (2004) regardless of the severity of her disabilities.

The field of special education is much younger than some other areas of education, with the first law guaranteeing a free and appropriate education for all children with disabilities having been passed just over 40 years ago (Public Law 94-142). Although services for students with disabilities were emerging in the schools and community prior to the mid-1970s, students with moderate and severe disabilities often were omitted from these options. In this past 40 years, more attention has been focused on developing educational programs for students with more severe disabilities largely due to an increased research focus in the field on this population of students, as well as accountability measures that include these students in statewide accountability measures. This chapter provides information on who the students are, what the law requires that students receive, and what experts recommend as the qualities that form the foundation of a strong educational program.

WHO ARE STUDENTS WITH MODERATE AND SEVERE DISABILITIES?

Problems with Terminology

The problem that arises in describing any subgroup of a population is that such descriptions overlook the unique qualities of the individual and the many other subgroups to which the student belongs. In describing Jane at the beginning of this chapter, the reader gains a brief perspective on her educational day. A name for the disability (e.g., intellectual disability, cerebral palsy, cortical vision impairment) and some characteristics about Jane's disability are also provided (e.g., ambulates with assistance, medical problems, communicates nonverbally). The reader gets a small glimpse of her personality (e.g., engages others in conversation by looking at them or objects), but each of these descriptors is only part of the picture of Jane. For example, this paragraph could have been written from many other perspectives. If Jane could write it herself, she might want the reader to know about her interests (e.g., popular music, swimming, family pets) or her family or friends. Her school nurse might write about Jane's specific medical diagnoses and health care needs. Jane's older sister would want you to know about the television shows and games they share together and how proud she is of her younger sister. Her father might describe how Jane has taught him to see life with deeper appreciation. Jane's mother might want you to know how much she has had to learn about CVI so that she could educate Jane's therapists and teachers and help her daughter achieve her full potential. To get to know Jane requires learning much more than the label of her disability, as the label might actually bring to mind stereotypes that are not true for Jane.

In contrast, there are several situations in which Jane's label will be relevant and required to be used. First, in many school districts, Jane will need a formal classification to receive required special education and related services due to state and federal regulations. Second, Jane's teachers and her parents will use the label to locate information related to her needs (e.g., information on CVI and intellectual disabilities). Third, Jane's family may need to use her label to access any county and state adult health and disability services (e.g., Medicaid waiver, vocational rehabilitation, supported employment).

Given that labels are sometimes needed, some guidelines should be followed in using them ethically. First, educators should use what is called "person-first" terminology. These terms avoid reference to the disability alone (e.g., "the disabled," "autistic," "Down syndrome") and emphasize the individuality of those who share this one characteristic of disability (e.g., "individuals with disabilities"). The best way to emphasize a person-first perspective in referring to a specific child is to use the child's name ("Jane"), rather than the disability ("the child who is disabled"). A second guideline is to respect individuals' and their families' choices of how to refer to their own disability. Some individuals may find the term *severe* uninformative or pessimistic or the term *intellectual* confusing. They may prefer the term *developmental disability* or simply *disability*. A third guideline is to use the most current terminology for the disability. Because disability labels have become stigmatizing, the terminology for disability groups has evolved over time, and now some of the terms now considered pejorative (*retarded, moron*) were at one time considered professional classifications.

Professional associations and legislation have also changed terminology to avoid terms such as *handicap* and *mental retardation*. The American Association on Mental Retardation became the American Association on Intellectual and Developmental Disabilities (AAIDD). In 1876 the organization was called the Association of Medical Officers of American Institutions for Idiotic and Feeble Minded Persons, and in 1906 it was called the Association for the Study of the Feeble Minded (Collins, 2007). The advocacy organization TASH began in 1974 as the American Association for the Education of the Severely/Profoundly Handicapped (AAESPH). Presently, it simply uses the acronym *TASH*. Similarly, the former Association for Retarded Citizens is now simply the *ARC*. The term *handicap* refers to a limitation created by the lack of accommodations in an environment and not to the disability per se (Vergason & Anderegg, 1997). *Neurodiversity* has become a more acceptable term, relating to the variance in abilities within the population rather than focusing on the weaknesses. The educator focusing on neurodiversity creates an environment in which students can thrive while using a strengths-based model to educate their students (Armstrong, 2017).

Current Terminology

Throughout this book, we use the term *moderate and severe disabilities* to refer to this umbrella group of individuals. According to Westling, Fox, and Carter (2015), "individuals with severe disabilities have weaknesses in general learning abilities, personal and social skills, and/or sensory and physical development" (p. 3). Independent living skills are often affected, and the individual with severe disabilities relies on others without disabilities for support. Students with moderate and severe disabilities may have intellectual, sensory, physical, multiple disabilities and autism spectrum disorders (Westling et al., 2015). Throughout the United States, the term *intellectual disabilities* has replaced the term *mental retardation*. Individuals with intellectual disabilities have limitations in both intellectual functioning and adaptive behavior. The disability originates before age 18 (AAIDD Ad Hoc Committee on Terminology and Classification, 2010). The term *intellectual disability* continues to be used in state and federal regulations for educating students with disabilities (Individuals with Disabilities Education Act [IDEA], 2004) and may be the classification educators will see on students' psychological assessments. According to the previous *Diagnostic and Statistical Manual of Mental Disorders* (fourth edition, text revision [DSM-IV-TR]; American Psychiatric Association, 2000), IQ ranges include *moderate* (35–50), *severe* (20–35), and *profound* (below 20–25). All three of these ranges of intellectual functioning incorporate students referred to as having severe disabilities. According to the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association, 2013), there is not an emphasis on IQ score ranges. The current focus of assessment is in three domains: (1) conceptual (academic skills, reasoning, knowledge, and memory, (2) social (empathy, social judgment, interpersonal skills), and (3) practical (self-management skills). Individuals with intellectual disabilities may or may not have a recognizable syndrome such as Down, Angelman, or fragile X syndromes, for example. Intellectual disabilities can vary in severity, as does the level of support students require based on cognitive level of functioning, adapted skills, and concomitant disabilities.

According to DSM-IV-TR, diagnoses included autistic disorder, Asperger syndrome, and pervasive developmental disorder not otherwise specified (PDD-NOS). In DSM-5 (American Psychiatric Association, 2013), these separate conditions were combined into one diagnosis, termed *autism spectrum disorder* (ASD). According to DSM-5 (American Psychiatric Association, 2013), persons with autism have difficulty with communication and social interaction and display repetitive behaviors and restrictive interests. These symptoms interfere with the person's ability to function in school, work, and other areas of life. Autism is classified as a developmental disorder because symptoms appear typically within the first 2 years of life. The most recent prevalence data for individuals with ASD is 1:59 in the general population (Baio et al., 2018). Although ASD presents with a wide range of intellectual abilities, from gifted to intellectually disabled, our focus is on students with ASD who also have a moderate to severe intellectual disability. *Developmental disabilities* also is an umbrella term to refer to students with intellectual disabilities, ASD, and multiple disabilities. Table 1.1 provides a summary of terms for students with moderate and severe disabilities with recommendations on when to use each term.

CHARACTERISTICS OF A HIGH-QUALITY EDUCATIONAL PROGRAM

In planning services for students with severe disabilities, educators will want to plan those that will provide a full educational opportunity and promote independent functioning, leading to appropriate postsecondary outcomes. In the literature of the late 1970s, the term *criterion of ultimate functioning* was introduced to refer to "the ever changing,

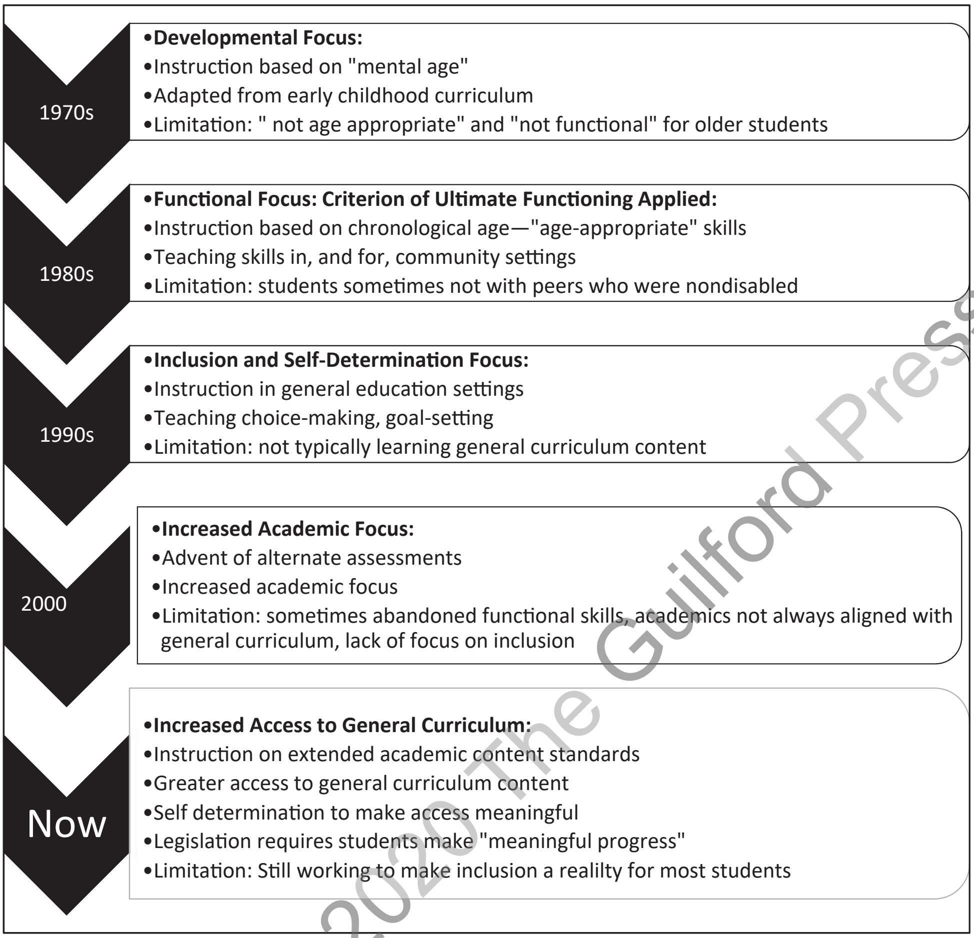
TABLE 1.1. Recommended Terminology for Use in Describing Students with Severe Disabilities

Term (students with . . .)	Reference group	When to use
Significant cognitive disabilities	Students who participate in alternate assessment based on alternate achievement standards; many, but not all, of these students have moderate to severe developmental disabilities.	When referring to students who take alternate assessments based on alternate achievement standards; sometimes also used as a general term for students with severe disabilities.
Developmental disabilities	An umbrella term for students with intellectual disabilities, autism spectrum disorders, and multiple disabilities, including intellectual disabilities.	When referring generally to students with autism, intellectual disabilities, and multiple disabilities that may be mild to severe.
Severe disabilities	An umbrella term for students with moderate and severe developmental disabilities.	As shorthand for moderate and severe development disabilities.
Intellectual disabilities	Students who have limitations in intellectual functioning and adaptive behavior; onset before age 18.	Instead of older term *mental retardation*; may specify level as mild, moderate, severe (*severe* replaces older term, *severe/profound*).
Autism spectrum disorders	Includes students who have symptoms of significant difficulties with social interaction, delayed verbal and nonverbal communication, and unusual patterns of behavior; usually apparent before 3 years of age.	To refer to students who may have any one of these cluster of disabilities; the term *autism* is sometimes also used generally.
Physical disabilities	Students who have disabilities that affect mobility and motor functioning (e.g., cerebral palsy, muscular dystrophy).	When a broad term is needed for physical disabilities; when possible, use the more precise disability (e.g., type of cerebral palsy).
Sensory disabilities	Students who have disabilities that affect vision, hearing, or both (e.g., deaf, hearing impaired, blind, visually impaired, deaf/blind).	When a broad term is needed for both hearing and visual impairments; when possible, use the more precise disability (e.g., type of hearing impairment).

expanding, localized, and personalized cluster of factors that each person must possess in order to function as productively and independently as possible in socially, vocationally, and domestically integrated adult community environments" (Brown, Nietupski, & Hamre-Nietupski, 1976, p. 8). Educators began to refer to skills and activities such as making purchases while shopping or learning to dress as "functional" because they related to this criterion of adult functioning. As research on effective interventions was just emerging in the 1980s, Donnellan (1984) suggested applying the *criterion of the least dangerous assumption* by choosing practices that would have the least dangerous effect on students' independent adult functioning. For example, it is less dangerous to assume that a student can use money skills in real community environments if he or she has opportunities to practice these skills in these contexts than to assume that generalization will occur. Donnellan and Neel (1986) proposed that the combination of the criterion of ultimate functioning and least dangerous assumption, although two separate concepts, could be used in evaluating program decisions.

In 1987, Meyer, Eichinger, and Park-Lee outlined a social validation study of program quality indicators in educational services for school-age students with severe disabilities. The survey respondents included four expert groups in the following areas: (1) behavior therapy, (2) services for students who were deaf–blind, (3) researchers in the area of mental retardation, and (4) severe disabilities experts identified by TASH. In addition, stakeholders, such as state special education directors and parents of students with disabilities, were included in the sample. Respondents identified five criteria for best practice in providing services for students with severe disabilities: (1) integration, (2) individualized professional practices and home–school instructional strategies, (3) staff development, (4) data-based instruction, and (5) criterion of ultimate functioning. Since this survey in the late 1980s, many experts in the field have built on these concepts to describe best practices for the field (Browder & Spooner, 2006, 2011; Brown, McDonnell, & Snell, 2016; Spooner, Knight, Browder, & Smith, 2012; Westling et al., 2015).

One way the quality indicators have evolved is that educators have had new expectations for what students will learn. Browder and colleagues (2003; Browder et al., 2004) described the evolution of curricular expectations for students with severe disabilities. As shown in Figure 1.1, when the first public programs for students with severe disabilities were formed in the 1970s, educators adapted early childhood or infant curricula with the idea that education could be planned based on a student's "mental age." The limitation of this approach is that skills were not age appropriate nor useful for functioning in real-life settings (i.e., functional). This developmental model was rejected in the 1980s with the emergence of the concept of the criterion of ultimate functioning. Applying this criterion, educators planned for functional life-skills instruction, including teaching both in and for community settings. Although it was a huge improvement in providing meaningful instruction, this functional approach often took students away from their same-age peers in school, for example, by teaching them in community environments and self-contained classrooms set up to simulate apartments. Social inclusion and self-determination were integrated with this functional curriculum in the 1990s. Educators planned for ways for students to be full members of their schools, including learning with typical peers. They also promoted students' choice making, goal setting, and self-directed learning. Unfortunately, educators did not yet realize that students with moderate and severe disabilities could learn the same content as their peers. Students often spent time in inclusive contexts doing separate functional tasks, or they remained in self-contained settings, as in the 1980s. Inclusion, self-determination, and teaching academic and functional skills all continue to be components of a quality program. At the beginning of the new millennium, the requirement for students to participate in alternate assessments in reading and mathematics created a surge of new interest in academic instruction. Although students were gaining new benefits from learning these skills, the content was still often far from what peers in general education were learning and often taught in self-contained settings. In the excitement to teach new academic skills, the importance of students' functional skill needs was sometimes overlooked. IDEA (2004) promoted access and progress in general curriculum for all students with disabilities, including those with moderate to severe disabilities. In the current era, most students receive academic instruction with links to the general curriculum, often in the form of state-defined extended standards. Best practice is to also incorporate some functional skill instruction for transition to adult living, to



1970s

- **Developmental Focus:**
- Instruction based on "mental age"
- Adapted from early childhood curriculum
- Limitation: " not age appropriate" and "not functional" for older students

1980s

- **Functional Focus: Criterion of Ultimate Functioning Applied:**
- Instruction based on chronological age—"age-appropriate" skills
- Teaching skills in, and for, community settings
- Limitation: students sometimes not with peers who were nondisabled

1990s

- **Inclusion and Self-Determination Focus:**
- Instruction in general education settings
- Teaching choice-making, goal-setting
- Limitation: not typically learning general curriculum content

2000

- **Increased Academic Focus:**
- Advent of alternate assessments
- Increased academic focus
- Limitation: sometimes abandoned functional skills, academics not always aligned with general curriculum, lack of focus on inclusion

Now

- **Increased Access to General Curriculum:**
- Instruction on extended academic content standards
- Greater access to general curriculum content
- Self determination to make access meaningful
- Legislation requires students make "meaningful progress"
- Limitation: Still working to make inclusion a realilty for most students

FIGURE 1.1. Changing expectations for students with severe disabilities.

promote self-determination, and to make sure students show progress. The challenge of the current era is that inclusion has still not been realized for many students.

Inclusive Practices

According to Alper (2003), full inclusion has been defined as "the practice of educating students with moderate and severe disabilities alongside their chronological age peers with disabilities in general classrooms within their home neighborhood schools" (p. 15). Full inclusion encompasses social and physical integration into activities that occur in school that are educational, recreational, and social. Inclusion, as opposed to full inclusion, refers to the "placement of special education students in general education settings" (Sailor & Roger, 2005, p. 503). Some students may be included for some portion of their school day. How much time students spend in general education settings is an individualized education program (IEP) team placement decision, as described in Chapter 4. The reality is that only a small percentage of students with moderate and severe disabilities have inclusive school programs (Smith, 2007). This discrepancy may be caused by a variety of factors, including resource allocation, professional development, administrative support, and technical assistance for planning inclusion. According to Sailor and McCart (2014), truly inclusive schools need a common vision shared by all, including administrators, staff, families, and community. For Jane to be successfully included throughout the school day requires a great deal of planning, collaboration with family, and a common shared vision to create an inclusive school environment. Inclusion is more than planning for the student to be present in general educational settings (temporal inclusion). It also is more than encouraging social membership in the class and school for students with moderate and severe disabilities (social inclusion). To meet their educational needs, students also must have the opportunity to learn from the curriculum and to address their unique instructional needs. Sometimes the adapted curricular priorities of students with more severe disabilities and the fast-paced academic priorities of general education can seem to create a "mismatch" for instructional inclusion. Careful team planning is needed to determine how to meet the individual needs of students with more moderate to severe disabilities in general educational settings.

Schools that want to promote the belonging of all students should begin by outlining what the outcomes will be once all students are included. Based on earlier work, Giangreco, Dymond, and Shogren (2016) outlined characteristics of inclusive education. First, students with disabilities attend the district school that they would attend if they were not disabled, appropriate supports are available, and all students are welcome in the general education program. Second, students with disabilities are educated with age-appropriate peers in classes in which the proportion of students with disabilities is related to the proportion in the community. Third, shared educational experiences take place in general education classes and integrated community settings. Fourth, students receive educational services that are individually designed to balance academic–functional and social–personal domains of learning.

Morningstar and colleagues (2016) suggest that, as students with severe disabilities are placed in more inclusive settings (general education), improvements in academic achievement, social engagement, and behavior occur. Teachers develop higher expectations as students learn more age-appropriate curricular content. Finally, students may increase their chances for increased participation in lifelong integrated activities. One of the challenges of providing inclusive programs for students with moderate and severe disabilities is identifying how students' needs for intensive instructional and personal support will be met. Ryndak and Ward (2003) suggest meeting instructional needs by using cooperative learning strategies, small-group instruction, and peer partnering with peer tutoring and study buddies. Carter and Brock (2016) suggest the use of peer supports as a viable strategy to support students in inclusive settings. For example, Carter, Cushing, Clark, and Kennedy (2005) conducted a study with three middle school students with severe disabilities and six general education students. Peers were taught strategies including how to adapt materials, how to provide instruction on IEP goals, how to implement behavior plans, how to give feedback to the student, and how to promote communication between the students with disabilities and their peers in the classroom. Results indicated that students with disabilities increased social interaction when two peers were provided versus one peer, but this did not affect their interactions with other students in the class. Peer supports also encouraged the student's activities being aligned with the general curriculum. A checklist of indicators for program quality can be found in Figure 1.2.

Quality Indicator	Strengths	Weaknesses	Goals
Promotion of Inclusive Practices			
Home–School Collaboration			
Collaborative Teaming			
Positive Behavior Support			
Evidence-Based Instruction			
Access to General Curriculum			
Teaching Functional Life Skills			
Teaching Academic Skills			
Promotion of Self-Determination			

FIGURE 1.2. Checklist of indicators of program quality for students with severe disabilities.

Home–School Collaboration

In order for a student like Jane to be successful in her school program, there must be a strong collaborative relationship with her family. Because Jane is nonverbal, frequent communication between the school and home is required in order for her family to remain involved in their child's education. Chen and Miles (2004) note that "teachers not only must have instructional skills for teaching children but also must have the competency to work effectively with families" (p. 31). Although schools today appear to be child focused, there is a need to focus more on families and to utilize a family-centered approach when working with students with severe disabilities (Childre, 2004). Family and educator collaborative practices are more likely to be positive when using a family-centered approach. According to Powell, Batsche, Ferro, Fox, and Dunlap (1997), major principles for establishing a family-centered approach are: (1) building trust, (2) maintaining open communication, (3) enabling and empowering family and student, and (4) using a collaborative problem-solving approach. For Jane, this communication can take the form of phone calls, face-to-face meetings, emails, journal entries, messages on an augmentative communication device, and use of online messaging tools.

One way to build trust and open communication is to strive to understand and respect the family's cultural perspective. One way to build strong relationships with families is to gain more understanding about multicultural perspectives. Hall (1976), as described in Lim and Browder (2001), uses the concept of "high-context" and "low-context" cultures to describe how communication patterns may differ. In a high-context culture, members will share a well-defined pattern of interaction through established hierarchies and situational cues, will prefer nonconfrontational responses, and will place greater value on personal style and relations. Even though high-context cultures place greater emphasis on well-defined roles and formality, their members also value a personal approach to communication and relations, and they may need a longer time to "warm up" to meeting and knowing others. There is a belief in high-context cultures that relationships take time and trust before personal disclosure can happen. Professionals who do not share this cultural perspective may judge parents of high-context cultures as evasive, passive, and "beating around the bush." In contrast, low-context cultures emphasize and encourage direct expressions of messages and feelings. European American cultures are generally low-context cultures. Freedom to say what one thinks is viewed as an individual right. Unlike high-context cultures, in which much significance is placed on the process of interaction before trust and personal rapport can be built, low-context cultures value interactions that focus on achieving desired outcomes through expedience, direction, and "getting the job done" (Hanson, Lynch, & Wayman, 1990). Members of high-context cultures may interpret such interactions as cold and impersonal. Hall's (1976) schema is just one of many options for understanding how culture may influence communication.

Culture not only influences the style of communication, but it can also influence how families view and manage the student's disability (Gartner, Lipsky, & Turnbull, 1991). Mary (1990) found that Hispanic American mothers reported a self-sacrificing attitude and spousal denial of disabilities more than some other ethnic groups. Marion (1980) found that Mexican American and African American parents were more likely to report feelings of protection and acceptance, as opposed to shock and grief about their child's disability. Chan (1986) noted that some Asian families viewed disability as a source of shame. Harry (1992) and Fowler (1998) note that most Native American languages do not have words for disability and tend to be more inclusive of individuals with disabilities. Of course, individual members of an ethnic group may differ in their personal perspectives. For example, whereas some may find a disability to be a source of shame, others may be strong advocates for disability rights. One way to build trust with families and understand their individual perspectives is to invite them to share their stories about how they have come to understand their child's disability. Professionals also need to remember that families have the most extensive history with, and knowledge of, the child. Through careful listening, the professional may gain insights about what motivates the student, what skills need to be developed, and what does not work or is not appropriate for the child's cultural context. Chapter 2 addresses family collaboration and cultural perspectives.

Collaborative Teaming

For students with severe disabilities to experience school success, a certain degree of collaborative teaming among professionals is required. In a collaborative team it is important that members share (1) their expertise so that all students benefit, (2) responsibility in developing educational activities that facilitate learning for all students, (3) delivery of instruction across instructional content areas, and (4) accountability for students' acquisition of knowledge across content areas, activities, and settings (Ryndak & Pullen, 2003). A collaborative team functions differently from a transdisciplinary team in that the members focus on the students' needs and work together to accomplish their goals as a team rather than individually (Thousand & Villa, 2000). In collaborative teaming, professionals brainstorm to meet a student's needs in many environments, including school, home, and the community. The team shares roles and responsibilities and treats the student as a "whole" rather than just focusing on the student's needs in their particular discipline. Collaborative teams plan services in locations that would be considered "natural." For example, collaborative services are delivered in locations where the target skill may naturally occur (e.g., the occupational therapist works with the student while he or she is eating in the cafeteria) rather than working on skills in isolation. In order for Jane to access the general education curriculum and be successfully included, several grade-level and specialty collaborative teams must plan together.

One of the benefits of collaborative teaming for students with severe disabilities is that the students have an increased number of practice trials during the instructional day, which may result in a faster acquisition and generalization of skills. A second benefit is that collaborative teams provide information to parents relative to instructional strategies and application to real-life situations. A third benefit is that collaborative teams will problem-solve and provide technical and moral support to each other, to the classroom teacher, and to families and students (Armbruster & Howe, 1985; Ferguson, Meyer, Jeanchild, Juniper, & Zingo, 1992). The use of collaborative teaming, including cross-disciplinary instruction and flexible scheduling, has often been recommended as a best practice for this population of students (Brown et al., 2016; Ryndak, 1996; Westling et al., 2015).

Evidence-Based Instructional Practices

Students with moderate and severe disabilities may acquire new skills through a variety of instructional methods, as described in Chapter 6. One of the most effective strategies found in the research is the use of systematic instruction. Systematic instruction has been defined as "teaching focused on specific, measurable responses that may either be discrete (singular) or a response chain (e.g., task analysis), and that are established through the use of defined methods of prompting and feedback based on the principles and research of applied behavior analysis" (Browder, 2001, p. 95). One aspect of systematic instruction is using a defined prompting and fading schedule to promote acquisition of a new response. For example, the system of least prompts refers to a hierarchy in which a teacher presents a series of prompts from least to most intrusive. If there is no response or an incorrect response, prompts are then given, from the least to the most intrusive, until the student gives the correct response (Ault, Wolery, Doyle, & Gast, 1989). Doyle, Wolery, Ault, and Gast (1988) found that the system of least prompts was successful in teaching students with a variety of ages and diagnoses, as well as with tasks across various domains. Demchak's (1990) review identified four methods for prompt fading that included not only the system of least prompts but also most-to-least prompts, graduated guidance, and time delay. Each of these systems is described in detail in Chapter 6.

Positive Behavior Support Strategies

Positive behavior support (PBS) has been used as an effective practice for managing challenging behaviors in students with disabilities, including students with severe intellectual disabilities (Cooper, Heron, & Heward, 2007). In general, PBS involves using educative strategies to decrease inappropriate behaviors and increase appropriate behaviors (O'Neill & Jameson, 2016). PBS strategies have been proven to be effective with students with developmental disabilities (Carr, Horner, et al., 1999) including students with severe intellectual disabilities (Brown et al., 2016) and students with autism (Horner, Carr, Strain, Todd, & Reed, 2002). Snell (2005) reported that although PBS has experienced success, there is still a research-to-practice gap for students with severe disabilities.

Carr, Horner, et al. (1999) conducted a comprehensive review of 107 studies involving PBS. In the studies done between the years 1985 and 1996, 222 participants, with the largest percentage having mental retardation, were identified. The investigation focused on the following variables: (1) demographics, (2) assessment, (3) interventions, and (4) outcomes. Results of the comprehensive review indicated that the field has been growing over the years, primarily in the areas of assessment and interventions focused on remediating environmental deficiencies. PBS strategies can be utilized for people with serious behavioral problems and are effective in reducing behavioral problems in one-half to two-thirds of cases. Success rates appear to improve to almost double when the intervention is predicated upon the functional assessment. Chapter 14 provides more information on PBS.

Self-Determination

The importance of self-determination for students with disabilities has been substantiated in the literature, although students with severe disabilities have not always had the opportunity to learn these skills (Algozzine, Browder, Karvonen, Test, & Wood, 2001; Martin, Van Dycke, Greene, et al., 2006; Wehmeyer & Schwartz, 1998; Wood, Fowler, Uphold, & Test, 2005). Self-determination has been defined as "a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior" (Field, Martin, Miller, Ward, & Wehmeyer, 1998, p. 2). These skills include (1) choice making, (2) decision making, (3) goal setting and attainment, (4) problem solving, (5) self-awareness, (6) self-regulation, and (7) participation in the IEP process (Agran, Blanchard, Wehmeyer, & Hughes, 2001; Allen, Smith, Test, Flowers, &

Wood, 2001; Van Reusen & Bos, 1990). Wehmeyer (2005) has proposed that the definition of self-determination for students with severe disabilities be that "self-determined behavior refers to volitional acts that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (p. 117).

Regardless of the severity of disability, all individuals should be active participants as much as possible in exercising choice over the decisions affecting their lives (Brown, Belz, Corsi, & Wenig, 1993). According to Wehmeyer and Schwartz (1998), people who are self-determined have better outcomes related to their quality of life. Research has demonstrated that students of varying age ranges and disabilities can be taught self-determination and self-advocacy skills (Algozzine et al., 2001; Wood et al., 2005). Self-determination is considered an evidence-based practice that promotes a student's access to the general education curriculum (Agran & Hughes, 2014) and is associated with positive outcomes for students in academic, social, and postsecondary domains (Fowler, Konrad, Walker, Test, & Wood, 2007; Wehmeyer & Palmer, 2003).

General Curriculum Access

For students to learn general curriculum content, the instructional plan will need to have a strong focus on academic domains such as language arts, mathematics, science, and social studies. The overarching topic of general curriculum access was addressed by Spooner, Dymond, and Kennedy (2006) in a special issue of *Research and Practice for Persons with Severe Disabilities*. In that issue, Spooner, Dymond, Smith, and Kennedy (2006) described some of what we knew at that point in time and needed to know about accessing the general curriculum. They delineated approaches (i.e., peer supports, self-determination, universal design for learning [UDL] and teaching and assessing content standards) in addition to benefits and pitfalls (e.g., promise, varying definitions, evolving approaches, impact on postschool outcomes). As Browder, Wakeman, Spooner, Ahlgrim-Delzell, and Algozzine (2006) note, teaching academics simply because students can learn them is not the primary rationale. Instead, it is important to realize that these educational opportunities increase competence for adult living. Students with disabilities can learn and do much more than we once believed. With this increased learning, students have increased opportunities. For example, having some reading ability increases job options. Providing academic content instruction also promotes educational equality. Students who are nondisabled do not have to master skills such as making their beds before learning skills such as how to read. Similarly, students with severe disabilities should not be held to a double standard of learning all life skills before learning academic content. Gaining skills in general curriculum content can also increase opportunities for self-determination by providing students with more tools to gain information and demonstrate ability.

In teaching academic content, the focus is on teaching the standards for the students' age and grade level, such as aligning instruction with age-appropriate academic content (Browder, Spooner, Wakeman, Trela, & Baker, 2006). Although students may lack many basic skills, by applying what skills they do have, they may be able to access the grade-appropriate content and continue to develop literacy and numeracy. For example, students who cannot yet read may experience a 6th-grade novel through a read-aloud of a text summary. The student might use existing picture identification skills to indicate his or her understanding of the passage (Browder, Trela, & Jimenez, 2007). The use of peer supports may promote a student's access to academic courses (Jimenez, Browder, Spooner, & DiBiase, 2012).

Unfortunately, students with moderate and severe disabilities have sometimes lacked the educational opportunity to learn any academics. Koppenhaver and Yoder (1993) reported that students with moderate and severe disabilities did not have sufficient opportunities to participate in literacy activities in school. The reasons for this could be the low expectations about children with moderate and severe disabilities being able to learn to read and the difficulty in making reading materials accessible for this population of students. Much of the research in math instruction for students with moderate to severe disabilities also has reflected low expectations for students to be able to learn a few functional skills of money management. Models for teaching grade-level content, especially in science and social studies, are only now emerging. This book includes chapters in each of the major content domains—language arts (Chapters 7, 8, 9), mathematics (Chapters 10, 11), science (Chapter 12), and social studies (Chapter 13).

Functional Life Skills

Life skills, formally referred to as "functional skills" in the literature, are those that are used in daily living in the home, community, and job. Westling and colleagues (2015) recommend that the teaching of functional skills occur on a daily basis and that functional objectives be incorporated into a student's IEP. Functional skills promote the "criterion of ultimate functioning" for students to become as independent as possible. Brown and colleagues (1976) delineated four domains for functional curriculum planning, including community, domestic, vocational, and recreational skills. As students get older, home and community skills grow in importance as the focus becomes increased independence in the home and community (Bambara, Koger, Burns, & Singley, 2016). Some recommended practices for teaching functional skills include the following: (1) Objectives should be focused on increasing independence or self-determination while teaching integrated skills. (2) Skills should be taught in the home, school, or community environment (naturalistic settings) within functional contexts. (3) Skills should be taught that focus not only on initial acquisition of skills but also on maintenance and generalization of skills. (4) Data should be kept on student performance, and the results of the data should drive the decisions to change instruction (Westling et al., 2015).

Teaching life skills is one way to prepare students to transition to adult living. A high-quality program for students with severe disabilities will also include other areas of transition planning. Although the unemployment rate for students with severe disabilities is extremely high (Newman, Wagner, Cameto, & Knokey, 2009; Wehman, Kregel, & Seyfarth, 1985), and although there is limited empirical evidence suggesting that transition practices lead to successful adult outcomes for students with the most severe disabilities (Baer, McMahan, & Flexer, 2004; Mazzotti & Test, 2016), individuals with severe disabilities have demonstrated that they can work community jobs (Wagner, Marder, et al., 2003; Wagner, Cadwallader, & Marder, 2003; Wehman, Hill, Wood, & Parent, 1987; White & Weiner, 2004). A high-quality transition plan will include instruction in job skills, including community-based experiences for older students. Wehman, Moon, Everson, Wood, and Barcus (1988) recommend that, in addition to employment, transition planning include consideration of postsecondary education, residential plans, financial income needs, recreation/leisure needs, medical needs, transportation, advocacy/legal needs, personal/home/money management, and personal counseling needs (e.g., sex education). Planning across these areas includes not only considering skills needed for the IEP, as described in Chapter 4, but also creating opportunities to learn to apply skills in real-life contexts (Chapter 16).

LEGAL REQUIREMENTS FOR EDUCATION OF STUDENTS WITH SEVERE DISABILITIES

The opinions of advocates and experts about what characterizes high-quality programs for students with disabilities have helped to shape current federal law and policy. Federal law governing students with disabilities has guaranteed all students with disabilities a free appropriate public education since the Education for All Handicapped Children Act was passed in 1975. The Individuals with Disabilities Education Improvement Act of 2004 (IDEA) continued to guarantee this right. The special education services to be provided are outlined through the development of an IEP (described in Chapter 4). Like earlier versions of this federal law, IDEA (2004) provided procedural safeguard provisions for parents (20 U.S.C. §615). Parents have recourse, through dispute resolution, to file a petition for an administrative hearing if they believe a school district did not follow legal procedures of if they disagreed with district decisions involving identification, evaluation, or placement of the child (Yell, 2006).

School districts enter into litigation with parents of students with disabilities for a variety of reasons (Yell & Drasgow, 2000). A major area of dispute tends to occur when a parent believes that his or her child has been denied a free appropriate public education (FAPE; Drasgow, Yell, & Robinson, 2001). Many of these disputes can be addressed by developing high-quality programs for students. According to IDEA (2004), FAPE is defined as

> special education and related services that (A) have been provided at public expense, under public supervision and without charge; (B) meet the standards of the state educational agency; (C) include an appropriate preschool, elementary school, or secondary school education in the State involved; and (D) are provided in conformity with the individualized education program required under 614(d).[20 U.S.C. § 602 (9)(A–D)]

The FAPE standard was first defined in the *Rowley* case as being "reasonably calculated to enable a child to receive educational benefit" (*Board of Education of the Hendrick Hudson Central School District v. Rowley,* 1982). This standard has been tested repeatedly in cases involving students with moderate and severe disabilities and the provision of both special education and related services. In 2017, the U.S. Supreme Court ruled that school divisions, when providing special educational services to students with disabilities, cannot simply ensure that a student makes minimal or trivial progress from year to year but instead must ensure that students make meaningful progress given the students' circumstances (*Endrew F. v. Douglas County School District RE-1,* 2017; Prince, Yell, & Katsiannis, 2017). This ruling has broad implications for students with moderate to severe disabilities such as Jane and for how meaningful progress is individualized, defined, and measured.

A second major area of dispute may occur when parents disagree with school districts regarding a child's placement in the least restrictive environment (LRE; DeMitchell & Kerns, 1997; Thomas & Rapport, 1998; Yell & Drasgow, 1999). According to IDEA (2004), LRE is defined as "to the maximum extent appropriate, children with disabilities, including children in public or private institutions and other care facilities, are educated with children who are not disabled." The law also reflects that students should not be removed from the regular education environment except "only when the nature and severity of the disability of the child is such that education in regular classes with supplementary aids and services cannot be achieved satisfactorily" [20 U.S.C.§ 612 (a)(5)(A)].

According to Yell (1995), five elements related to inclusion are grounded in federal regulations: (1) The individual needs of the student determines his or her least restrictive environment. (2) Districts are not required to place a student in an integrated setting before recommending a segregated placement. (3) Each district should make a continuum of alternative placements available to students. (4) If students are placed in segregated placements, then they should be integrated to the maximum extent appropriate to meet their individual needs. (5) The potential disruptive effect on the students without disabilities should be considered.

The courts have considered many of these elements when making decisions in LRE cases involving students with severe disabilities. For example, in *Oberti v. Board of Education of the Borough of Clementon School District* (1993), the Third U.S. Circuit Court of Appeals ordered full inclusion of a young child with Down syndrome because, it claimed, the district had reached the decision regarding a segregated placement without considering the range of supplemental aids and services. The court concluded that the use of the supplemental aids and services may have assisted the student to be successful in a general education placement. In this case, the court considered three factors in making its decision. First, it considered whether or not the district made a reasonable effort to accommodate the child in a general education classroom. Second, it investigated what educational benefits were available to the child in the general educational classroom if appropriate supplemental aids and services were provided, as compared with the potential benefits that would have been provided in a segregated class. Third, it questioned whether there would be any possible negative effects on the education of students in the class if the child were included. In addition, the court considered the young age of the student (age 8) as a significant factor in favor of inclusion.

In *Sacramento City Unified School District Board of Education v. Rachel H.* (1994), the court considered similar factors as in *Oberti,* but it also considered the cost of including a student in a general education classroom. In this case, the district was unable to demonstrate that placing the student in general education classes would burden the district financially. A key concept in the literature is that following the legal tenants of LRE and FAPE may not be all that is required of districts to prevent disputes. Researchers in the field of special education and special education law suggest that validated, or evidence-based, practices should be followed by school districts as well (Agran & Hughes, 2014; Etscheidt, 2003; Westling et al., 2015; Yell & Drasgow, 2000). Chapter 6 provides information on evidence-based practices for students with severe disabilities.

Another area of litigation may occur in the area of related services (Bartlett, 2000). According to IDEA (2004), "the term related services mean transportation, and such developmental, corrective, and other supportive services . . . as may be required to assist a child to benefit from special education." Some examples of related services outlined in the statute are speech–language pathology, audiology, interpreting services, psychological services, occupational and physical therapy, therapeutic recreation services, social work, nursing, counseling, orientation and mobility, and medical services designed for evaluative purposes [20 U.S.C.§ 602(26)(A)]. The list of related services is not exhaustive. In *Irving Independent School District v. Tatro* (1984), the U.S. Supreme Court ruled that clean, intermittent catheterization for a child with spina bifida was considered a related service and not an excluded medical service under federal law. In this landmark case, the

U.S. Supreme Court established a "bright line" test stating that districts must provide health care–related services if the child needs these services during the day so that he or she may attend school and benefit from his or her education. The services must be able to be performed by nonphysicians and would therefore be considered related services under IDEA rather than medical services (Norlin, 2007).

The Every Student Succeeds Act of 2015 (ESSA) replaced No Child Left Behind (NCLB; 2002). Although the two laws are different, there are several key tenets in ESSA (2015) that are similar in nature to NCLB (2002) in that they protect access to the general curriculum and state assessments for students with disabilities, including those with the most significant cognitive disabilities. ESSA (2015) requires states to develop challenging academic standards and annual alternate academic achievement standards for students with the most significant cognitive disabilities. In addition, alternate assessments must be developed based on these standards. Whenever possible, assessments must be developed using the principles of UDL, and accommodations must be provided. Computer adaptive tests are allowed. School districts must disaggregate assessment results by subgroups, including students with disabilities. States must establish long-term goals with measures of interim progress. States can define alternate diplomas that are standards based. School improvement support and improved conditions for teaching and learning are also included in this federal legislation.

Educators who are planning for students with disabilities need to remember three important points about the law and potential for litigation. First, the best way to avoid litigation is to provide a high-quality evidence-based program that is an example of collaborative team planning, including parents, students, and professional staff. Goals should be reasonably calculated to confer educational benefit in the students' LRE as determined by a qualified IEP team. Second, when disputes with parents occur, the optimal starting point is to resolve differences through a well-implemented IEP meeting with all required members present. If the issues cannot be resolved, school systems still have dispute resolution options prior to an administrative hearing. Under IDEA (2004), there are three distinct types of dispute resolution, including *resolution, mediation,* or an *administrative hearing* [20 U.S.C § 615 (2)(b)(5–7); (2)(e)(2)(a); (2)(f)(2)(1)(A)]. Both resolution and mediation are legislative processes designed to settle disagreements between parents and school districts before a hearing occurs. Hazelkorn, Packard, and Douvanis (2008) found that 76% of districts surveyed believed that mediation permits a better discussion of the issues than an administrative hearing. The third point is that both educators and parents can benefit from training in team collaboration. Communication breakdowns may be avoided if trust is established that all are committed to the student's education and if participants have specific skills in conflict resolution. If differences cannot be resolved, there may still be the increased likelihood of both parties accepting a third party's assistance in resolution.

SUMMARY

Although special education, at some level, has been around for approximately 200 years, the first legal requirements for public educational services were enacted only a little more than 40 years ago. Prior to 1975, students with moderate and severe disabilities were categorically excluded from public school programs. With the new federal law came labels, and labels have been viewed by many as a double-edged sword, as people are individuals and unique. With the new federal law came minimal funding and regulations that many states were required to follow. With subsequent federal legislation (NCLB, 2002) and IDEA (2004) came access to instruction aligned with general education standards for students with moderate to severe disabilities, as well as increased accountability for school districts to provide appropriate services. With subsequent case law and increased research in the field on evidence-based practices and quality indicators came higher quality education and better postschool outcomes for students with moderate to severe disabilities.

All individuals with moderate to severe disabilities will need the best quality educational services to function as independently as possible as adults. For Jane to receive an FAPE in her LRE, the quality indicators of educational programming discussed in this chapter will need to be implemented across the school staff. Staff will need to collaborate with various instructional and related services personnel, as well as with Jane's family. School district administrators will require professional development in creating an inclusive school culture. Jane will need to be given access to the latest principles of UDL, and appropriate assistive technology will need to be provided to aid her in communication and accessing the general curriculum. Her specific program will need to be individualized and reasonably calculated to confer educational benefit, and meaningful progress will need to be monitored closely. Research will need to continue to identify the very best evidence-based practices that will afford Jane and other students with moderate to severe disabilities the opportunity to improve their independence and quality of life.

APPLICATIONS

1. Go to your state department of education's website and find out what terms are used to classify students with disabilities under your state's regulations. Which of these disability categories may apply to students with moderate and severe disabilities? To what extent does your state use the most current terminology?
2. Examine how the media, including social media, describe individuals with disabilities. To what extent do the media use the most current terms? How might you influence the media's portrayal of individuals with disabilities?
3. Interview the parents of a student with moderate and severe disabilities about their child. What have been their challenges and joys? How did they discover the child had a disability? What are the most important qualities and abilities of their child they want others to recognize? If possible, choose a family whose culture differs from your own.
4. Interview a school administrator about the goal of inclusion for students with moderate and severe disabilities. What does he or she believe to be the factors that influence successful inclusion practices in his or her school? What are some of the barriers he or she may face to including students with moderate and severe disabilities in the general education curriculum?

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