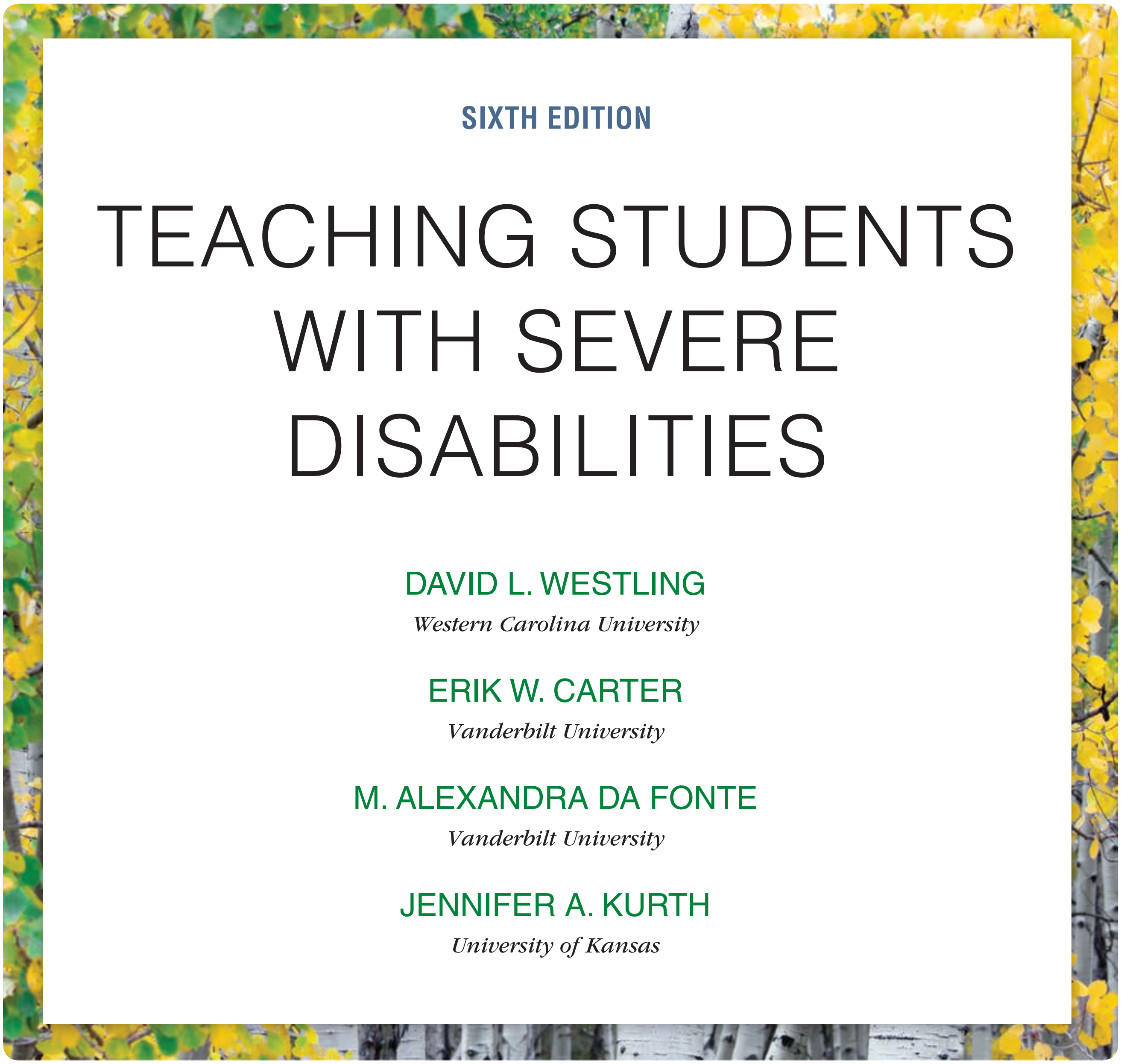
Teaching Students with Severe Disabilities

SIXTH EDITION

David L. Westling | Erik W. Carter
Alexandra Da Fonte | Jennifer A. Kurth



SIXTH EDITION

TEACHING STUDENTS WITH SEVERE DISABILITIES

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PREFACE

As with the previous editions of this textbook, we have attempted to provide useful information about a complex topic in a form that can be readily consumed and applied. In preparing the sixth edition of this comprehensive textbook, we have drawn upon the current research literature, best practices, strong values, and our own experiences working with students with severe disabilities. We are active researchers, teacher educators, and former teachers who have personally enjoyed the rewards and challenges of educating students with severe disabilities.

There are many notable changes in this edition, beginning with the addition of two new authors: Dr. M. Alexandra Da Fonte of Vanderbilt University and Dr. Jennifer A. Kurth of the University of Kansas. They have made significant contributions to this edition and their expertise is well represented in its pages.

Our primary goal in this edition has been to present concise information that helps readers develop an understanding of the strengths and needs of individuals with severe disabilities, current service philosophies, and effective instructional practices for teaching these students. In comparison to previous editions, we have tried to reduce unessential narrative and increase material that can be applied by current and future professionals. The result has been to shorten some chapters and combine others, with a final product consisting of 17 chapters, a reduction of four chapters from the previous edition. We made this change without sacrificing critical information while preserving the content that would be of the greatest value to readers.

As in previous editions, this book is divided into four major parts. In Part 1 (Chapters 1–3), we provide important considerations for teaching students with severe disabilities, including descriptions of students with disabilities and their potentials; philosophies that direct services and instructional practices; and the importance of and effective procedures for collaboration. In Part 2 (Chapters 4–7), we present general procedures that are relevant to all aspects of instruction, including assessing and planning for instruction, instructional methods (with a focus on systematic instruction), evaluating student progress, and supporting students in inclusive classrooms.

Part 3 (Chapters 8–14) drills deeper into instructional strategies for specific areas, including addressing health and medical needs of students and teaching communication skills; personal care skills; academics; home and community skills; and social, leisure, and recreational skills. The final chapter in Part 3 discusses providing supports to improve challenging behavior. In Part 4 (Chapters 15–17), we provide information about three key topics: using assistive technology, meeting the needs of young children, and transition planning and adult issues.

We would like to thank our families for helping us once again to survive as we entered the solitary world of textbook revision and hunkered down over our notes, journals, and keyboards. They were faithful and understanding enough to stay with us until we finally broke the surface and shared their worlds once again.

We are also grateful to our colleagues, students, and readers who have given us their opinions about earlier editions and suggestions for this revision. We are especially thankful for support from our colleagues at Western Carolina University (including Karena Cooper-Duffy, Kelly Kelley, David Shapiro, and Bill Ogletree), to our colleagues at Vanderbilt University (including Elizabeth Biggs, Robert Hodapp, Paul Yoder, and Joseph Lambert), and to our colleagues at the University of Kansas (including Michael Wehmeyer, Karrie Shogren, and Mary Morningstar).

At Pearson, we thank Kevin Davis, our editor, for providing insight, direction, and assistance for this new edition. We hope this textbook will be helpful to those who read it. The lives of people with severe disabilities, as well as those of their parents and families, can be complex and difficult for others to understand. Similarly, teachers and other service providers often face challenges and considerable rewards, many of which cannot be fully appreciated by their friends or even some of their coworkers. Helping to make life better for other people doesn't necessarily make one's own life worse, but it also doesn't make it simpler or easier. We don't expect this book to achieve this outcome either, but if it moves readers in a positive direction and helps them expend their energy more effectively, we will have been successful.

D. L. W.
E. W. C.
M. A. D.
J. A. K.

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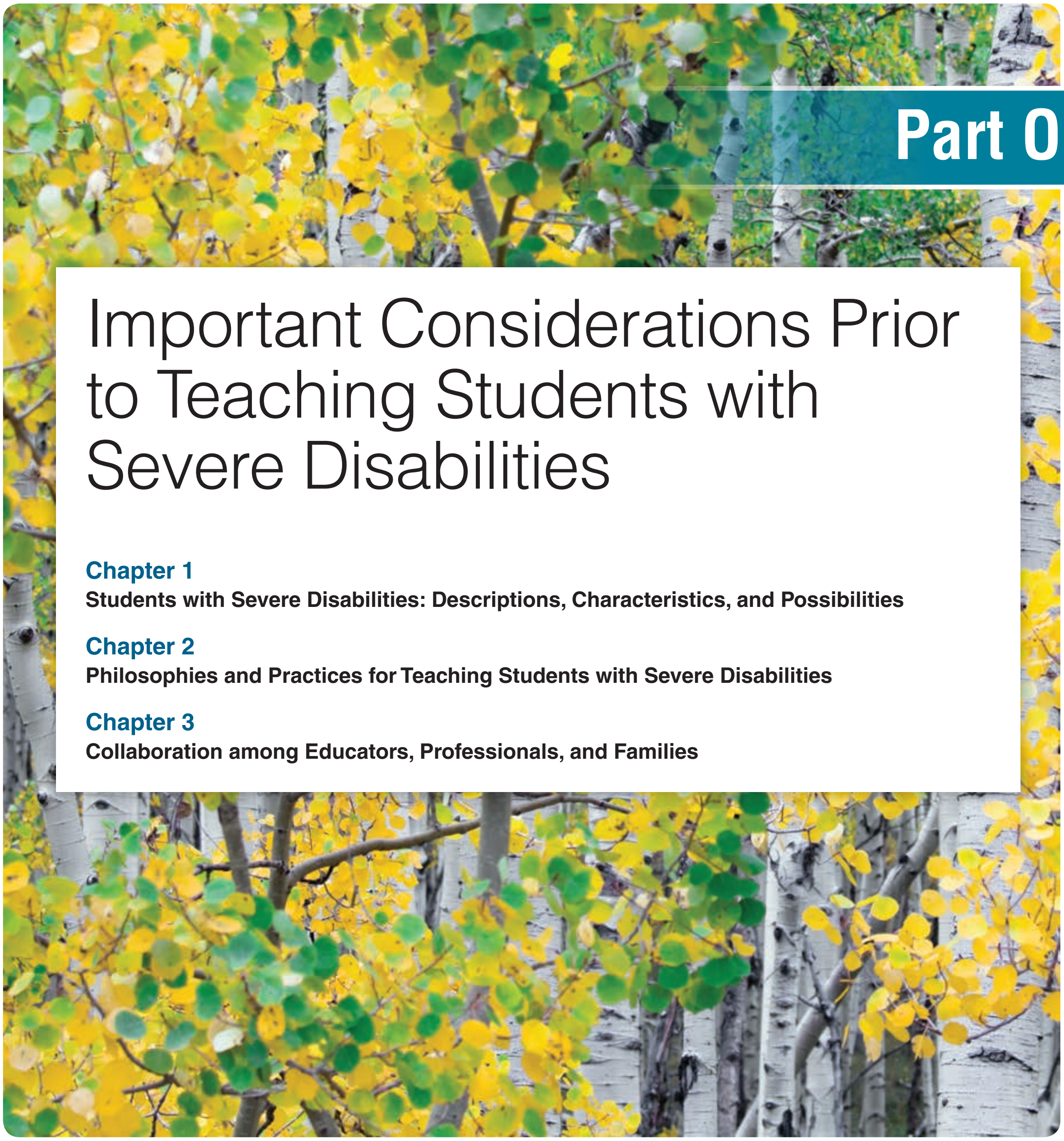

Part One

Important Considerations Prior to Teaching Students with Severe Disabilities

Chapter 1
Students with Severe Disabilities: Descriptions, Characteristics, and Possibilities

Chapter 2
Philosophies and Practices for Teaching Students with Severe Disabilities

Chapter 3
Collaboration among Educators, Professionals, and Families

1

Students with Severe Disabilities: Descriptions, Characteristics, and Possibilities

BL/BSIPSA/Alamy Stock Photo

In this chapter, definitions and concepts of severe disabilities and the traditional categories covered by this term are discussed. In addition, descriptions of learning characteristics, personal-social characteristics, and physical conditions often associated with severe disabilities are provided. We conclude with a discussion of the possibilities that await students with severe disabilities who are given strong instruction and individualized supports.

DEFINING SEVERE DISABILITIES

Disability has long been defined using the language of deficits and differences. It is common for college textbooks and research articles to begin with descriptions of individuals with disabilities that place the emphasis on all of the things that someone cannot do or struggles to do. Societal attitudes related to disability also tend to reflect a perspective of perceived limitations and diminished capacities (Scior & Werner, 2016). Yet it is more important to recognize—indeed to emphasize—the strengths, talents, abilities, passions, interests, and other positive traits that individuals with severe disabilities possess. For example, studies asking parents, siblings, staff, and special educators about the positive qualities and characteristics of individuals with intellectual disability and autism reveal a positive portrait of young people known for their optimism, joy, resilience, kindness, courage, empathy, gratitude, friendliness, skills, and enviable character (e.g., Carter et al., 2016; Carter, Brock, & Trainor, 2014; Carter, Carlton, and Travers, in press; Woodard, 2012). As is true for anyone else, individuals with severe disabilities possess a multitude of strengths that exist right alongside their challenges. Educators and other professionals should be careful not to perseverate on those challenges to the omission of these strengths. No person can be fully known when seen only through a single lens—especially a lens of limitations.

At the same time, individuals with severe disabilities do experience considerable challenges—both personal and in their communities and cultures—that can substantially limit the opportunities they have to flourish in important areas of life. The term *severe disabilities* is used to describe a condition in which the development of typical abilities is both adversely and substantially affected across multiple domains. Individuals with severe disabilities experience significant difficulties across such areas as general learning, personal and social skills, and/or sensory and physical development. Moreover, their capacity to participate independently across school, home, work, and community settings can be considerably reduced. As a result, students with severe disabilities typically require assistance and support from others (e.g., family members, friends, classmates, teachers, and other professionals) to participate fully in the activities and relationships that make up everyday life. Finally, their need for support is likely to be ongoing and lifelong.

The term *severe disabilities* has been defined and applied in a wide variety of ways over time and across disciplines. Within the context of special education, students with severe disabilities are often classified by the primary disability categories of intellectual disability, autism, multiple disabilities, or deaf-blindness (see Figure 1.1). In other

FIGURE 1.1
Special Education Category Definitions Sometimes Associated with Severe Disabilities.

Category	Definition
Autism	A developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.
Deaf-blindness	Concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.
Intellectual disability	Significantly sub-average general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance.
Multiple disabilities	Concomitant impairments (such as intellectual disability-blindness or intellectual disability-orthopedic impairment), the combination of which causes such severe educational needs that they cannot be accommodated in special education programs solely for one of the impairments. The category of multiple disabilities does not include deaf-blindness.

Source: Individuals with Disabilities Education Improvement Act (IDEA) of 2004.

words, they are not represented within a single disability category. Moreover, within these categories, they comprise the subset of students whose disabilities substantially affect their intellectual functioning and adaptive behavior (Kleinert et al., 2015). Many of these students are eligible for their state's alternate assessment and would be described as needing "extensive repeated individualized instruction and support that is not of a temporary or transient nature" and using "substantially adapted materials and individualized methods of accessing information in alternative ways to acquire, maintain, generalize, demonstrate and transfer skills across multiple settings" (National Center and State Collaborative, 2014, p. 4). In other words, they represent the 1–2% of students in a school who have the most extensive instructional, behavioral, or other support needs.

Although most descriptions of severe disabilities emphasize the characteristics or traits of individuals, an environmental element is also important to acknowledge. TASH, an international organization focused on human rights and inclusion for people with severe disabilities, describes the persons they advocate for as those individuals who are:

> *most at risk for being excluded from society; perceived by traditional service 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; least likely to have the tools and opportunities necessary to advocate on their behalf; and are most likely to need ongoing, individualized supports to participate in inclusive communities and enjoy a quality of life similar to that available to all people. (TASH, 2019)*

Such a description places the emphasis on the attitudes and actions of communities and cultures that limit the opportunities and supports people with severe disabilities receive. In other words, the severity of any disability is amplified when society fails to encourage and support the presence and participation of this segment of the community.

Similarly, the American Association on Intellectual and Developmental Disabilities (AAIDD) emphasizes the importance of supports in its conceptualization of intellectual disability. According to the AAIDD, an intellectual disability is (a) characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills; and (b) originates before the age of 18. However, this definition is accompanied by five core assumptions (Schalock et al., 2010, p. 1):

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age, peers, and culture.
2. Valid assessment considers cultural and linguistic diversity, as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve.

This conceptualization of intellectual disability emphasizes the provision of individualized supports as a way of bridging the gap between a person's capacities and the relevant demands of the various environments in which they wish to participate. For individuals with severe disabilities, the intensity of needed supports will be extensive or pervasive. As with TASH's depiction, disability is not viewed as a deficiency but, rather, in terms of needed supports and opportunities.

Historically, professionals often referenced levels of intellectual disability on the basis of intelligence test scores. For example, the label of mild disability corresponded with IQ scores in the range of 50–70, moderate disability with scores in the range of 35–50, severe disability with scores in the range of 20–35, and profound disability with scores below 25 (Wehmeyer, 2013). However, the AAIDD eliminated such categorization of intellectual disability more than two decades ago, and the American Psychiatric Association's (APA) current definition also omits these distinctions (APA, 2013). In part, these changes reflect growing recognition of the limitations of intelligence testing, the importance of understanding context, and the need for more holistic considerations when defining disability.

What these distinctions did emphasize was that students with severe disabilities could have a wide range of instructional and support needs. For example, many children and adults with severe disabilities are able to manage some of their own daily self-care needs; demonstrate adequate body control, including good gross and fine motor development; prepare some foods for themselves and others; participate in conversations; learn practical reading skills; make purchases in a store; and carry out many aspects of a community job. Others may need more extensive help with activities like eating, dressing, bathing, toileting, making purchases, and navigating their environment. Still others may have more profound disabilities and cannot speak, have very limiting sensory and motor impairments, are not ambulatory, and tend not to be very attentive or responsive to environmental stimuli (Orlove, Sobsey, & Gilles, 2017).

Although students with severe disabilities share a common label and are talked about as a group throughout this textbook, it is important to emphasize that they represent an extremely heterogeneous group of individuals. Students with this label are highly diverse in the goals they are pursuing, the challenges they experience, the talents they possess, the opportunities they encounter, the supports they require, and the dreams they hold. For example, in their study addressing the strengths and needs of adolescents with severe disabilities across nine transition-related domains, Carter et al. (2014) found that no two students were found to have exactly the same profiles. Every student with severe disabilities is an individual whose strengths, needs, interests, and preferences should be discerned one person at a time. With this important caveat in mind, the next section examines the characteristics associated with different types of disabilities often associated with students with severe disabilities.

DISABILITY CONDITIONS AND SYNDROMES

The most common causes of severe disabilities are biologically based, occurring between the time of conception and birth. Moreover, about 75% of the causes can be linked to a specific origin, including genetic disorders, chromosomal anomalies, abnormalities of brain development, substance abuse, maternal infections, and other pregnancy difficulties. The most common identifiable causes for individuals with severe disabilities are Down syndrome, fragile X syndrome, and fetal alcohol spectrum disorders, which together account for about one third of all persons with intellectual disability (Shapiro & Batshaw, 2019).

Many individuals who have an intellectual disability exhibit clusters of similar physical and behavioral characteristics and have common genetic or physiological etiologies. When this occurs, these people are said to have a certain syndrome of intellectual disability. There are hundreds of recognized syndromes and obviously not all can be discussed here. However, several that are likely to be encountered by professionals working with individuals with severe disabilities are briefly described. Knowledge about such syndromes can provide general understanding of the relative strengths and weaknesses of individuals affected by the syndromes and may be useful in informing educational interventions. The reader interested in detailed information about certain syndromes should turn to more complete references on this topic (e.g., Batshaw, Roizen, & Pelligrino, 2019; Burack, Hodapp, Iarocci, & Zigler, 2012; Gentile, Cowan, & Dixon, 2019), agencies like the Centers for Disease Control and Prevention (**www.cdc.gov**) and the National Institutes of Health (**www.nih.gov**), or the organizations

FIGURE 1.2
Resources for Additional Information on Disability-Related Syndromes.

Syndrome	Website
22q11.2 deletion syndrome	**https://22qfamilyfoundation.org**
Angelman syndrome	**https://www.angelman.org**
CHARGE syndrome	**https://www.chargesyndrome.org**
Cornelia de Lange syndrome	**https://www.cdlsusa.org**
Cri-du-chat syndrome	**https://fivepminus.org**
Down syndrome	**https://www.ndss.org**
Fragile X syndrome	**https://fragilex.org**
Hunter syndrome	**https://mpssociety.org**
Klinefelter syndrome	**http://www.aaksis.org**
Lesch-Nyhan syndrome	**http://www.lesch-nyhan.org**
Mabry syndrome	**https://ghr.nlm.nih.gov/condition/mabry-syndrome**
Noonan syndrome	**https://www.teamnoonan.org**
Phenylketonuria syndrome	**https://npkua.org**
Prader-Willi syndrome	**https://www.pwsausa.org**
Rett syndrome	**https://www.rettsyndrome.org**
Smith-Magenis syndrome	**https://www.prisms.org**
Sturge-Weber syndrome	**https://sturge-weber.org**
Tourette syndrome	**https://tourette.org**
Turner syndrome	**https://www.turnersyndrome.org**
Usher syndrome	**https://www.usher-syndrome.org**
Williams syndrome	**https://williams-syndrome.org**

listed in Figure 1.2. Note that not all individuals who manifest the syndromes discussed next would be considered to have severe disabilities. Some may not have an intellectual disability or may only have intermittent or limited support needs.

Down syndrome. Down syndrome is one of the most common syndromes associated with intellectual disability. It has an incidence of about one per every 700 live births. However, the likelihood of having a child with Down syndrome varies with the age of the mother, with older mothers having a much greater likelihood. A woman giving birth at 30 years of age has a 1 in 1,000 chance of having a child with Down syndrome, whereas a woman who is 45 years old has a 1 in 50 chance (Ebensen & McLean, 2017). More than 90% of the time, Down syndrome occurs due to the presence of an extra chromosome 21 (*trisomy 21*).

Children with Down syndrome may be somewhat smaller in size than average and have slower physical, motor, language, and cognitive development. Although most children with Down syndrome have an intellectual disability, some do not. Certain physical features are characteristic of the syndrome and can be used for clinical diagnosis. These characteristics usually include a flattening of the back of the head; slanting eyelids; small folds of skin at the inner corners of the eyes; depressed nasal bridge; smaller ears, mouth, hands, and feet; and decreased muscle tone. A variety of health conditions are associated with Down syndrome. For example, individuals may have a heightened risk of congenital heart problems, gastrointestinal conditions, orthopedic problems, visual difficulties, hearing loss, seizures, obesity, diabetes, and dementia relative to the general public (Ebensen & McLean, 2017).

Children with Down syndrome typically have language delays that become apparent between 18 months and two years of age, but receptive language is generally better than their expressive language. Although children with Down syndrome are sometimes characterized as being amiable and happy, they actually have temperament profiles much like those of other children. Nevertheless, small percentages may demonstrate behavioral, emotional, and psychiatric problems; provocative behavior and, to less extent, aggression; and ADHD. About 16% of children with Down syndrome fall on the autism spectrum (Richards, Jones, Groves, Moss, & Oliver, 2015). Individuals with Down syndrome tend to perform better on visual versus auditory processing tasks. Their visual memory is better than their auditory memory, and they can generally do well on learning sight word reading, even when they are young. They have relatively lower rates of maladaptive behavior compared to other persons with developmental delays (Ebensen & McLean, 2017).

Fragile X syndrome. In recent years, fragile X syndrome has been recognized as the most commonly inherited genetic syndrome that results in an intellectual disability and is one of a large number of X-linked chromosomal causes of intellectual disability (Forster-Gibson & Holden, 2017). The overall prevalence of fragile X syndrome is estimated at approximately 1.4 in 10,000 males and 0.9 in 10,000 females (Hunter et al., 2014). Fragile X syndrome and other X-linked conditions are transmitted from a mother to a child on the sex-linked (or X-linked) chromosome and are manifested more often by boys than by girls. Fragile X syndrome is caused by an inactivation of the FMR1 gene that results in the loss of a protein that is vital for learning and memory. Among boys who inherit this condition, about 80% will have intellectual disability; girls are affected less often and usually their disabilities are less extensive.

Physical characteristics of males with fragile X syndrome include a long, narrow face; prominent jaw and forehead; large, protruding ears; high, arched palate; hyperextensible joints; flat feet; and enlarged testicles. Many affected boys tend to be hypotonic and lack coordination. They may grow rapidly, but tend to have short stature as adults. Individuals with fragile X syndrome have various medical conditions, including disorders of the eyes, orthopedic disorders, otitis media, mitral valve prolapse, and seizure disorders (Schwarte, 2008).

Learning may be easier for students with fragile X syndrome when the whole task is presented at once, instead of teaching separate parts of a task. Difficulties in communication and social skills may be accompanied by strong daily living skills and a great sense of humor. There are usually speech and language delays, and often echolalia occurs. Their speech is often cluttered and perseverative. They also tend to have difficulty with auditory memory and receptive language. Individuals with fragile X syndrome also tend to have stereotyped behaviors, such as hand flapping, lack of eye contact, tactile defensiveness, hyperactivity, and inattention. Some may exhibit aggression and anxiety. The behaviors of children with fragile X syndrome are often considered similar to those who are classified as having autism. Indeed, about 30% meet the diagnostic criteria for autism (Gabis, Baruch, Jokel, & Raz, 2011).

Fetal alcohol spectrum disorders. Fetal alcohol spectrum disorders (FASDs) comprise a range of disorders that result from prenatal alcohol exposure. FASDs include fetal alcohol syndrome, which is the most serious condition on the spectrum, as well as alcohol-related neurodevelopmental disorders and alcohol-related birth defects. The Centers for Disease Control (2014) reports that FASDs occur in about nine per 1,000 live births in the United States. Although it is clear these conditions result from mothers consuming alcohol during pregnancy, the precise amount of alcohol consumption necessary to cause the condition is not known.

The diagnosis of fetal alcohol syndrome is defined by four criteria: abnormal facial features (e.g., smooth ridge between nose and upper lip); lower-than-average height, weight, or both; central nervous system problems (e.g., small head size, hyperactivity and problems with attention, poor coordination); and prenatal alcohol exposure (although confirmation is not required to make a diagnosis). The most critical impact on the unborn child occurs during the first trimester of pregnancy when the alcohol may affect the way cells grow and are organized. During this time the developing brain will be particularly sensitive, and the alcohol can diminish the number of brain cells that develop. Consumed in the later stages of pregnancy, alcohol can result in fetal distress, reduced growth, poor central nervous system development, or miscarriage.

Developmental delays of children with FASDs may first be seen when babies have sleeping problems, are restless and irritable, and have sucking problems. Further developmental delays generally become apparent in the first two years of life, particularly in the areas of speech and language. Verbal learning may be most impaired. Intellectual challenges may also be seen in planning, sequencing, self-monitoring, and goal-directed behavior. Math skills are particularly difficult for students with FASDs. Developing appropriate social interactions can be a problem, and difficulties in adaptive behavior may occur. Behavioral and emotional problems may also occur (McClain, Kodituwakku, & Kodituwakku, 2017).

Prader-Willi syndrome. Prader-Willi syndrome is a complex genetic disorder known to affect appetite, metabolism, behavior, and cognitive functioning. Individuals with this syndrome have a propensity for excessive eating, low muscle tone, and obesity (National Institutes of Health, 2018b). In addition, they may exhibit obsessive-compulsive behavior and various other maladaptive behaviors that may become more serious during adolescence (Percy et al., 2017). Individuals with Prader-Willi syndrome may have characteristics of ADHD, an insistence on sameness, behavioral and personality problems, and obsessive-compulsive disorders.

Prader-Willi syndrome is not inherited, but is due to a chromosomal anomaly on chromosome number 15 and occurs in about one of every 10,000 births. Shortly after birth, infants with Prader-Willi syndrome will show extreme hypotonia (weak muscle tone), a weak cry, poor sucking and swallowing, and little interest in food. Between ages one and three years, they can develop insatiable appetites, become very preoccupied with food, want to eat continuously, and develop life-threatening obesity. At this time, they will start to show delayed psychomotor activity, cognitive delay, and emotional-behavioral problems.

The syndrome often results in an intellectual disability, but cognitive impairments can range widely. In addition to being overweight, individuals with Prader-Willi syndrome tend to be short, have small hands and feet, and have underdeveloped sexual organs. The child with Prader-Willi syndrome is likely to have delayed motor development and will walk later than most children. Speech and language problems are also common (Percey et al., 2017). Many children have difficulties with sequential processing (i.e., following a consecutive order in problem solving) but are stronger on tasks requiring simultaneous processing. Common behavioral issues include compulsive behavior, especially skin-picking, excessive sleeping, verbal preservations, stubbornness, obsessions, temper tantrums, and impulsivity.

Intervention for individuals with Prader-Willi syndrome often emphasize weight management, behavior management using positive behavior supports, and educational development, with a later focus on transition planning. If weight can be managed, a normal life expectancy may be possible. If weight is not adequately managed, obesity may lead to lung and heart disease, diabetes, high blood pressure, and other disorders. Individuals with Prader-Willi syndrome experience uncontrollable hunger and have been known to obtain food in a number of ways, including stealing, raiding the refrigerator in the middle of the night, taking food from classmates, and searching through waste containers. Their hunger is painful and constant, and leads to an unceasing pursuit of food. It is important to establish early control of food during the childhood years and to establish patterns of moderate exercise.

Angelman syndrome. Individuals with Angelman syndrome often have significant cognitive impairments. As with Prader-Willi syndrome, Angelman syndrome occurs due to a chromosomal anomaly in which a portion of chromosome 15 is missing. The prevalence of this condition is estimated to be between one in 12,000 and one in 20,000 (National Institutes of Health, 2018a). Some characteristics of the syndrome include jerky body movements and stiff-legged walking. Individuals with Angelman syndrome tend to have characteristic facial features, such as a wide, smiling mouth, a thin upper lip, and deep-set eyes. They often have fair hair and skin and light blue eyes. About 80% of people with Angelman syndrome also have epilepsy (Percy et al., 2017).

Diagnosis of Angelman syndrome often occurs during infancy when feeding problems and poor sleeping patterns begin. Individuals with Angelman syndrome sometimes exhibit behaviors that are similar to individuals with autism, such as little or no speech, hand flapping, short attention spans, and motor delays. Many children are considered to be very sociable, happy, and affectionate. Although most people with Angelman syndrome have little verbal expression and speak no or only a few words, their comprehension is more advanced. Many learn to communicate using alternative or augmentative communication (AAC) systems.

Multiple Disabilities

Individuals may be classified as having multiple disabilities if, in addition to having an intellectual disability, they have at least one additional sensory or physical disability. For example, a student may have a significant cognitive impairment, a visual impairment, a hearing impairment, and/or a physical disability such as cerebral palsy. The term does not refer to a specific syndrome such as discussed earlier, but is a classification that is recognized under the Individuals with Disabilities Education Improvement Act (2004). Almost all students served under the special education category of multiple disabilities would fall under the umbrella term *severe disabilities*. In 2017, there were approximately 122,000 public school-age students in the United States who were classified as having multiple disabilities (U.S. Department of Education).

Students with multiple disabilities usually have various health problems that complicate and exacerbate their disabilities. They often develop conditions such as high blood pressure, obesity, brittle bones, depression, and general tiredness. Other conditions include cardiovascular (heart) diseases, respiratory diseases, eating disorders, and growth impairments (Orlove, Sobsey, & Gilles, 2017). Students with multiple disabilities may be prone to engage in various uncommon behaviors, including repetitive movements, stereotypical movements such as hand flapping, or self-injurious behaviors such as head banging or making loud and atypical vocalizations. Often, these behaviors can be improved through the use of positive behavior support principles, and often the behaviors are determined to be communicative behaviors. Often these students will benefit from instruction in and access to AAC systems.

Deaf-blindness. Persons with deaf-blindness have both hearing and visual impairments that together cause severe communication and developmental delays, and their educational needs typically extend beyond those of persons who are either only deaf or only blind. Compared to other disabilities, deaf-blindness is an extremely low-incidence disability. In 2017, there were only about 1,300 public school-age students in the United States who were classified as deaf-blind (U.S. Department of Education). There are two major causes of deaf-blindness in school-age children and adolescents. The first is viral infections such as rubella or other viral diseases, particularly from infections during the first trimester of pregnancy. When this happens, the child may not only have congenital deaf-blindness (i.e., is born with the condition), but also often has other physical or medical conditions. The second cause results from a genetic condition. Either the child inherits the condition, such as Usher syndrome, or a genetic mutation occurs within the child, as is often the case with CHARGE syndrome.

Most persons who are deaf-blind have some functional vision and/or hearing, and many are of average or above average intelligence. In other words, not all persons classified as deaf-blind are considered to have a severe disability. Nevertheless, it is one of the most complex disabilities, and students who are classified as deaf-blind can show a great deal of variability in their conditions and the supports they require. Those who are classified as having severe disabilities have greater degrees of hearing and vision loss, usually have had the dual sensory impairments from birth, and have some degree of intellectual disability. These individuals have very limited social and communicative abilities and will require many structured learning opportunities to acquire various daily living skills.

The effects of deaf-blindness will be influenced by the time of onset of the condition as well as the degree of loss in each of the sensory systems. Children who experience damage to their auditory and visual organs during early pregnancy will often have neurological impairments as well. The child not only has difficulties learning due to disabilities in both sensory systems but also because of neurological impairments. Depending on the extent of the conditions, the child may have significant cognitive impairments, limited cognitive impairments, or no intellectual disability. There are important differences between persons who are congenitally deaf-blind, such as due to CHARGE syndrome, and those who acquire deaf-blindness, such as due to Usher syndrome. The former tend to have more severe impairments. For example, individuals with congenital deaf-blindness often engage in self-stimulation or stereotyped behaviors (such as hand flapping, finger flicking, or head rocking) because normal sources of environmental stimulation are lost or diminished. They may also be more likely to have an intellectual disability, mental illness, behavior disorders, and characteristics of autism spectrum disorder (Dammeyer, 2011).

It is not appropriate to treat a student with deaf-blindness as a blind person who also has a hearing loss or as a deaf person who also has a visual loss. The unique condition of this disability requires that the individual be considered holistically and that a transdisciplinary model of intervention be developed (Orelove, Sobsey, & Gilles, 2017). Consideration needs to be given to the degree of residual vision and hearing that exists in order to maximize the functional use of these abilities.

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is characterized by impairments in two broad areas: (a) persistent deficits in social communication and interaction and (b) restricted, repetitive patterns of behavior, interests, or activities (APA, 2013). This broader umbrella term encompasses individuals with a wide range of profiles that had previously been referred to using the labels of Autistic Disorder, Asperger's Disorder, PDD-NOS, and Childhood Disintegrative Disorder. The most recent prevalence estimates for individuals with ASD in the United States are 1 in 59 children (CDC, 2012). ASD can sometimes be identified in children who are younger than 18 months, but more often diagnosis occurs between two and four years of age.

The primary characteristics associated with ASD are challenges related to social communication and interaction, which manifests in the areas of social-emotional reciprocity, nonverbal communicative behaviors, and the development and maintaining of relationships (APA, 2013). In addition, individuals with ASD engage in repetitive or stereotyped behaviors such as rocking, hand flapping, echolalia, spinning, or tapping. Possible early indicators of autism include not babbling, pointing, or making meaningful gestures by one year of age; not speaking one word by 16 months; not combining two words by two years; not responding to name; and losing previously acquired language or social skills.

Other early indicators are poor eye contact, not knowing how to play with toys, excessively lining up toys or other objects, being attached to a particular toy or object, not smiling, and at times seeming unable to hear (Perry, Koudys, Dunlap, & Black, 2017).

Most individuals with ASD would not be considered to have a severe disability. Although about one third of persons with ASD also have an intellectual disability, the degree of cognitive impairment varies considerably (Baio et al., 2018). Individuals with ASD who do have severe disabilities can exhibit wide-ranging challenges. For example, two core communication deficits—joint attention and symbol use—are common. Joint attention involves actions such as orienting and attending to another person, shifting attention between people and objects, sharing emotional expressions with another person, following the gaze of another person who is looking at something of interest, and drawing the attention of someone to share an object of interest. Symbol use involves using conventional gestures (such as pointing, waving goodbye, or demonstrating with actions), learning the meaning of words, and using objects functionally and symbolically.

The verbal communications of students with ASD who have severe disabilities can also vary. Some students may not use any speech. Among those who do communicate verbally, many do so in a limited or abbreviated fashion, usually showing various abnormal speech and language characteristics. Echolalia, or the imitation of speech of others, often precedes more typical forms of speech. It often is used by children with ASD as a purposeful form of communication. Many children with ASD progress beyond echolalia and use more common grammatical forms, generally progressing in the development of grammar in the same order as other children, although more slowly. Even though their grammatical abilities may advance, they often are impaired by problems following social communication rules, referred to as pragmatics, indicated by difficulties in switching roles between speaking and listening.

Individuals with ASD who have severe disabilities may also exhibit atypical characteristics in the production, form, and content of their speech. Speech sounds may have inappropriate volume, pitch, rate, rhythm, or tone; be monotonous; have a melodic quality; or be high pitched. The speech that is produced may be stereotyped or repetitive, and the individual may use inappropriate parts of speech. In other cases, the meaning of the speech that is produced may be difficult to interpret, especially for someone who does not know the individual. Sometimes these individuals say particular sentences or phrases over and over, which the context of the statements does not appear to warrant.

Some individuals with ASD may exhibit behavioral characteristics that functionally increase the severity of their disability. Among the more serious challenging behaviors that they may exhibit are tantrums, crying and shouting, aggression, stereotyped behaviors, and self-injury. Such behaviors have a communicative function. Another behavioral characteristic that may occur is an uncommon preoccupation with some particular item or items (or parts of items) for which there does not seem to be any reason. They may, for example, insist on carrying around a piece of blanket or a particular book, or they may show unusual fascination with items by continuously touching them, feeling them, spinning them, or smelling them. Following strict routines or being rigid in many daily activities may also be important to individuals with ASD. As a part of this *insistence on sameness,* they tend to want aspects of their environment to be arranged in a certain order and daily events to proceed in a predictable manner. In their regular activities their interests and attention do not vary. For example, they may insist on eating a certain food or watching a certain television show at a set time. If there is some variation in this routine, the person may become very upset, even to the point of having a temper tantrum.

KEY CHARACTERISTICS OF PERSONS WITH SEVERE DISABILITIES

The descriptions offered in the previous sections clearly indicate that individuals with severe disabilities comprise a diverse group of students with widely varied characteristics, abilities, and needs. This is true both within and between different traditional categories. However, some characteristics tend to be common across these students and deserve additional attention. These themes can help educators and other professionals better understand the potential instructional, support, and service needs of individuals with severe disabilities.

Learning Characteristics and Abilities

Although it is important not to over-generalize about individual skills and abilities, most persons classified as having severe disabilities have substantially more difficulty learning new skills and applying what they learn to real-life situations than do individuals without or with other disabilities. As a result, it may take these students more time to learn basic skills, they may encounter more difficulty acquiring complex skills, and they may learn fewer skills overall. Yet it is important to emphasize here that students with severe disabilities can learn when provided rigorous and relevant instruction (Browder & Spooner, 2014; Gilson, Carter, & Biggs, 2017).

Learning characteristics and abilities of persons with severe disabilities are related to the degree of cognitive impairment, life experiences, and sensory and physical conditions of the individuals. Because there will be variations in each of these personal dimensions, there will be variations in what individuals are able to learn, and how they are best able to learn. Figure 1.3 provides general descriptors of characteristics and abilities and their implications for teaching and learning. More detailed information on instructional approaches is presented throughout the chapters in this textbook.

Personal–Social Characteristics

It is important to stress again the individuality of students with severe disabilities when we consider issues related to their personal behavior and their relations with others. Some individuals with severe disabilities have strong networks of friends and are embedded in their community; others have more limited social connections and rarely participate in community activities. Although it is true that social skills deficits and the presence of complex communication challenges, mobility difficulties, and cognitive impairments can have an impact on the interpersonal aspects of one's life, the barriers in this area do not always reside within the student. Societal barriers like community awareness and attitudes, architectural and transportation barriers, and the absence of needed invitations and supports can also hinder the degree to which students with severe disabilities have opportunities to meet, get to know, and develop relationships with others.

The quality of any person's life—including individuals who have severe disabilities—is affected by the quality of their social interactions and relationships with others. Someone whose personal behavior is considered to be unusual, undesirable, or even offensive is likely to have fewer friendships and other relationships, will participate in fewer shared activities with others, and will be more isolated within their community. Individuals with challenging behaviors are much more likely to be placed in separate schools or classrooms, segregated work environments, and more restrictive living arrangements. On the other hand, persons with severe disabilities with more appropriate personal and social skills are likely to be more successful in different life areas, such as community living and employment, *even if* their intellectual ability is significantly limited. People tend to accept or reject each other based more on personal interactions than on the other person's abilities.

Therefore, increasing appropriate behavior and reducing inappropriate behavior will be a critical outcome for many persons with severe disabilities. Figure 1.4 presents some of the common personal–social characteristics of individuals with severe disabilities and ways those characteristics can be improved.

FIGURE 1.3

Common Learning Characteristics and Implications.

Learning Characteristic	Implications
Language Skills Some individuals with severe disabilities may experience difficulties in articulation, grammar, vocabulary, and general expressive ability. Some may also have difficulty comprehending and conversing with others.	Many students can improve their communication skills, and many will do so using augmentative and alternative communication (AAC) devices. Many will require specific communication skills to be targeted on their individualized education programs (IEPs), and many will require support by a speech/language pathologist (SLP).
Attentional Ability Attending to the right person, item, or condition in the environment may be difficult for some individuals with severe disabilities. They may not learn quickly about what requires their attention, or what they need to attend and respond to.	Using visual highlighting, visual symbols, or other very apparent stimuli will better enable many students to focus on what is relevant. Color-coding is often useful. Some students work better when visual schedules or other symbols are used to direct them through routines.
Observational and Incidental Learning Because of attentional weakness, many individuals with severe disabilities do not learn simply through observation unless additional instruction is incorporated.	Many varied observational opportunities should be planned. Important skills should be taught through direct and systematic instruction. Goals and objectives must be stated, systematic instruction provided, and performance measures taken.
Memory Short-term memory may be more limited among students with severe disabilities. Once something is learned, however, it may be retained for a long time. However, some individuals do not use executive functions well to help them recall information.	To improve memory, initial learning should focus on meaningful and functional information, teaching should occur for a sufficient length of time, and periodic rehearsal should occur. Some individuals can also learn to use strategies to help with recall.
Skill Synthesis Bringing together disparate skills to use in unique situations, such as using reading and math to shop for groceries, can be difficult for some individuals with severe disabilities. They may not easily see the relationship between different skills or to use them together.	Students may learn and apply new skills better if they are taught and practiced in relevant clusters. Although skills like reading and math may be taught separately, they may need to be re-taught together to be applied in unique situations.
Generalization Many individuals with severe disabilities have difficulty learning skills in one setting and then demonstrating them with different people, at different times, in different locations, and under different conditions.	Because a goal or objective has been achieved in one setting or condition does not mean it will occur elsewhere. Instruction and skill demonstration must occur for all situations in which the skill is expected to occur, including those outside of the classroom.
Self-Management Many individuals with severe disabilities have few opportunities to learn the skills of monitoring what they are doing, engaging in correct action, and reinforcing themselves to do so.	Not only should the opportunity to learn to manage one's own behavior be provided, but it should be provided often, under different circumstances. Continuously making decisions for an individual will make it difficult for that person to become more independent.

Physical Characteristics

Students with severe disabilities typically have health care problems that are more frequent and substantial than individuals without disabilities. Many have specific physical disabilities or health disorders that occur alongside a significant cognitive impairment (i.e., multiple disabilities). The existence of health disorders has several implications. They may make mobility more difficult and thus restrict opportunities to participate in activities and be part of important social networks. They may interfere with a student's ability to stay focused, exacerbating existing learning problems. Health disorders may require medications and medical treatments that come at inopportune times. Some illnesses may result in fatigue and cause a student to miss some activities during the day, or even miss entire days of school. Most concerning is that they may result in more isolation from other students, be a turn-off for some students, or result in teasing, bullying, or other reprehensible behavior.

The unique physical characteristics of students require individualized interventions. However, a primary objective will be to reduce the impact of their physical and health

FIGURE 1.4

Common Personal–Social Characteristics and Implications.

Personal–Social Characteristics	Implications
Challenging Behaviors Some individuals with severe disabilities may exhibit repetitive behaviors (stereotypies), aggression, self-injury, non-compliance, elopement (running away), and other inappropriate behaviors. The behaviors may occur for a number of reasons, including the need to communicate a wish or desire, escape from an undesirable situation, gain attention, gain access to tangible reinforcement, like food or a toy, or gain sensory stimulation.	Positive behavioral interventions and supports (PBIS) can be very useful in improving inappropriate behavior. This process first seeks to hypothesize the cause or function of the behavior through interviews with key persons and direct observation. Based on the results of a functional behavior assessment (FBA), a Behavior Intervention Plan (BIP) is developed to address conditions that set the occasion for behavior, to teach more appropriate replacement behaviors, and to reinforce appropriate behavior.
Friendships and Peer Relationships Individuals with severe disabilities often have more restricted social networks. This means they may not be invited to social activities, may not have close friends, and may not engage in conversations very often. A combination of factors can blend to limit these relationships, including the skills of students, the attitudes of others, and the opportunities and supports made available.	Fostering friendship and other supportive relationships should be a central focus of educational and community services. Opportunities to interact with others and to discuss issues of common interest are the seeds for any relationship. Improvement of communication skills, including social conversations using AAC devices if necessary, and inclusion in school and the community can provide the means and opportunity for friendships and relationships to develop.
Love and Intimacy Most individuals with severe disabilities are provided limited information and support related to the physical and emotional aspects of intimacy. Some with more severe disabilities do not recognize boundaries and the need for privacy, so they engage in inappropriate acts (e.g., public masturbation, touching others). Others have been taught that physical feelings are bad and should be ignored. Still others are bound by misinformation and a lack of knowledge.	Understanding basic aspects about love and sexuality as a part of life should begin early and be an ongoing part of learning for people with severe disabilities. Factual information, like names of body parts and how women get pregnant, should be presented as individuals are able to understand it. Issues like boundaries, privacy, and different types of relationships should also be addressed early. As persons mature and approach adolescence and adulthood, they should be presented with opportunities to make their own decisions about their feelings about another person and how they wish to relate to them.

conditions on their inclusion and learning opportunities, increase their mobilization and participation, provide any appropriate prescribed interventions or medications as required under school policy, and monitor their progress. To achieve these objectives, teachers need to collaborate closely with related services providers, such as speech/language pathologists (SLPs), physical therapists (PTs), and occupational therapists (OTs).

Figure 1.5 lists some of the more common physical disabilities and health conditions associated with severe disabilities. In addition to these specific conditions, persons with severe disabilities may have various other physical challenges. These may include recurring infections, growth impairments, bowel and bladder control problems, chronic constipation, partial or complete loss of hearing or visual ability, congenital limb malformations or absences, and juvenile rheumatoid arthritis. Like the other physical conditions discussed earlier, these present substantial challenges to persons with severe disabilities.

NEW POSSIBILITIES FOR INDIVIDUALS WITH SEVERE DISABILITIES

Despite the challenges described earlier in this chapter, individuals with severe disabilities can experience meaningful and fulfilling lives. Indeed, they are deserving of the instruction, supports, relationships, and opportunities that can contribute to a flourishing life. Expectations for students with severe disabilities have changed dramatically over the past 50 years. Whereas it was once assumed the individuals with severe disabilities could not learn, we now have decades of research and practice demonstrating that these students can make substantial progress across curricular domains and a broad range of everyday life skills. Whereas it was once assumed that individuals with severe disabilities needed to be served in segregated settings, we now have decades of research and practice demonstrating that these students can thrive

FIGURE 1.5

Common Health Conditions and Implications.

Health Conditions	Implications
Cerebral Palsy This neurological disorder results from the inability of the brain to control the voluntary muscles in a normal fashion, thus interfering with normal movement and posturing abilities. The four major forms of cerebral palsy (CP) are spastic CP (characterized by stiff muscles and exaggerated reflexes), dyskinetic CP (characterized by involuntary, non-purposeful movements), ataxic CP (characterized by lack of balance and uncoordinated movements), and mixed CP, meaning that more than one form of the condition occurs in the same person.	A student's participation in different class activities may be affected by the severity and extent of the CP. Many students will require adaptations or accommodations. PTs and OTs can help teachers design ways to include the student with CP in various learning activities. Educators and peers sometimes inaccurately presume that a student with CP also has an intellectual disability. The motor limitations of students with CP often mask their intellectual ability, and any assumptions should be avoided.
Epilepsy Epilepsy is a disorder of the brain that results in recurrent seizures. There are different types of seizures, but the most severe form, generalized tonic-clonic seizures, occurs most often among persons with severe disabilities. Epilepsy is a symptom of irregular activity within the brain and is one of the most common disorders of the nervous system.	When a seizure occurs, there is an abnormal electrical discharge in the brain. When a student has a seizure, the teacher should help him lie down, turn him to one side to prevent choking on saliva or vomit, loosen clothing around the neck, and place something soft under his head to prevent it from hitting a hard surface. The teacher should not insert anything into the mouth. If the seizure lasts for more than five minutes, the teacher should call for emergency assistance. The teacher should note when the seizure occurred and how long it lasted.
Cardiovascular Disorders Such disorders occur in many persons with severe disabilities and are often associated with specific syndromes. Children with Down syndrome are known to have various congenital defects, including endocardial cushion defect, ventricular septal defect, atrial septal defect, and mitral valve prolapse. Other cardiac conditions may affect persons with severe disabilities, including narrowed valves within the heart; a hole in a wall of the heart; a lack of separation of the heart's chambers; narrowed arteries; underdevelopment of part of the heart; the mixture of deoxygenated with oxygenated blood; abnormal development of major veins; and attachment of arteries to the wrong part of the heart.	Most persons with heart defects must avoid too much activity, although otherwise normal involvement and participation in life are encouraged. The particular problem for persons with severe disabilities who have a congenital heart disease may be the degree of tiredness or fatigue that they experience during the normal routine of the day. The opportunity for frequent rest periods should help alleviate this problem while still allowing involvement in many typical activities.
Respiratory Disorders Asthma, bronchitis, apnea, bronchopulmonary dysplasia, cystic fibrosis, respiratory distress syndrome, and chronic colds, flu, or pneumonia may occur among persons with severe disabilities. In addition, breathing difficulties may occur due to weakened muscles that result from cerebral palsy, muscular dystrophy, or spinal muscular atrophy. Various respiratory disorders result in wheezing, breathing difficulties, and excess mucus.	Persons with these conditions may require postural drainage, suctioning, and oxygen therapy and receive prescribed medications. Some students with chronic respiratory problems should avoid high activity levels. It may be necessary to use special equipment to assist in breathing. The types of equipment used include continuous or periodic ventilation to assist breathing; the provision of concentrated oxygen, using an oxygen tank or oxygen concentrator; and using an electric suctioning machine to remove excess mucus from the lungs. Some persons will have a tracheotomy (an opening in the trachea), which allows breathing to occur more easily or accommodates the ventilator or suctioning device.
Eating Problems Persons with severe disabilities might develop eating problems that call for special attention if they are to consume enough nutrients to ensure adequate growth and maximum cognitive development. A variety of problems can occur, including poor oral-motor functioning, causing a weak suck, poor lip closure, jaw thrusting, lack of tongue control, and difficulty in chewing and swallowing. A child who has a respiratory disorder or a cardiac disease may lack the energy to participate in the feeding process. Other children exhibit resistance to eating by tantrums, gagging, or regurgitating.	Gastroesophageal reflux (vomiting because of a weak muscle connecting the stomach and the esophagus) can be corrected by surgery. In other cases, these behaviors may occur as a response to an unpleasant eating experience, because of a strong preference or dislike for different foods, because of changes in the environment or the routine, or because of hunger. In these cases, behavior may be improved by changing the food, the eating environment, or other conditions aversively associated with eating. Occupational therapy can help improve oral-motor functioning during eating sessions.
Spina Bifida and **Hydrocephaly** The most serious and most common form of spina bifida is *myelomeningocele.* When this occurs, the spinal cord (myelo) and its covering membrane (meninges) pouch out of the opening in the vertebrae. It is often accompanied by hydrocephalus, which occurs when the cerebrospinal fluid is not absorbed normally by the body and instead is trapped in the ventricles of the brain and causes the brain, and thus the head, to become enlarged.	Spina bifida results in paralysis of the lower trunk. Besides lacking leg use, the person who has a myelomeningocele may lack bladder and bowel control, lack skin sensation in the lower body, and may have scoliosis. To reduce the impact of hydrocephaly, a shunt may be inserted into the ventricles, allowing the fluid to drain. Hydrocephalus often results in motor, language, or perceptual disabilities and seizure disorders. Usually, the condition is treated during the first year of life, using the shunting procedure. Delayed treatment results in the condition becoming more serious, including a more serious degree of intellectual disability.

in inclusive classrooms, schools, workplaces, community activities, and colleges. Whereas it was once assumed that individuals with severe disabilities could not make substantive contributions to the lives of others, we now have decades of research and practice demonstrating that these students can enrich the lives of families, affect peers in positive ways through their friendships, enhance the culture of workplaces, and share their gifts and talents in ways that benefit their communities. Parents, professionals, and advocates working together have made significant progress. Consider three example areas where noteworthy progress has been made.

School Inclusion and Access to the General Curriculum

Although they were once excluded entirely from public education, the majority of students with severe disabilities now attend their neighborhood schools and many are included in one or more general education classes (Brock, 2018; Kleinert et al., 2015). Through the support of administrators, teachers, and parents, many schools now provide the necessary accommodations and supports so that students with severe disabilities are valued and active members of their school communities. This shift toward inclusive practices has been beneficial for students with and without severe disabilities alike. The opening sections of the Individuals with Disabilities Education Improvement Act summarizes well what we know as a field: "Almost 30 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by ... having high expectations for such children and ensuring their access to the general education curriculum in the regular classroom, to the maximum extent possible... ." (2004). More time spent in general education classes alongside peers is associated with higher-quality individualized education programs (IEPs), more time engaged in the general curriculum, better learning outcomes in areas like reading and math, increased social interactions, and stronger communication skills. Likewise, longitudinal studies suggest that more time spent in general education classes during school is a key predictor of better post-school outcomes for young adults with disabilities in the areas of employment and postsecondary education (Mazzotti et al., 2016). The prevailing expectation is now that students with severe disabilities will learn the academic knowledge and skills aligned with those of their peers in general education classes (Olson, Leko, & Roberts, 2016). Research shows that—with appropriate accommodations, curriculum modifications, and systematic instructional methods—students with severe disabilities can learn relevant and challenging content (e.g., Hudson, Browder, & Wood, 2013; Spooner, Knight, Browder, & Smith, 2012; Spooner, Root, Saunders, & Browder, 2018).

At the same time, peers who have had the opportunity to learn alongside and get to know their classmates with severe disabilities are often quite articulate about the substantive personal benefits they derive from these relationships and shared learning opportunities (Carter, 2015). These include a deeper appreciation of diversity and individual differences, greater understanding of the value of inclusion, improved attitudes, acquisition of advocacy and support skills, increased knowledge about specific disabilities, greater self-confidence, a strengthened commitment to social justice principles, and personal growth. Perhaps most important, peers speak of the enjoyment they receive and the friendships that emerge from opportunities to spend time with and learn alongside one another. Inclusive practices can also have a long-term impact on the attitudes and commitments of young people without disabilities who will eventually become employers, neighbors, community leaders, and fellow citizens.

Addressing Challenging Behaviors

The presence of challenging behavior continues to be a primary concern for educators, families, and other professionals involved in the lives of individuals with severe disabilities. Self-injurious, aggressive, and inappropriate behaviors can contribute to substantial stress within families, rejection by peers, and social isolation. Although these problems remain serious and extensive, we know more today about how to approach them than ever before. Research on the use of positive behavioral interventions and supports (PBIS) has become more extensive. PBIS stresses the importance of creating supportive learning environments, the use of functional behavior assessments (FBAs), the adoption of non-aversive interventions, and the provision of individualized instruction and supports (e.g., Goh & Bambara, 2012; Kurth & Enyart, 2016). PBIS does not seek simply to eliminate undesirable or challenging behaviors, but to spur long-term and sustainable change. This is achieved by using an FBA to develop a hypothesis (or hypotheses) about the behavior's purpose and then to develop a comprehensive behavior intervention plan to address the behavioral deficiencies (such as improving communication skills, social skills, or academic skills) or address environmental factors thought to be related to the behavior (such as antecedents or consequences that maintain the behavior, or setting events that affect common responding to the environment).

Support for PBIS is based both on values and research (Horner & Dunlap, 2012). Many educators and professionals support this approach because it uses a non-aversive, comprehensive orientation, and is considered to be a more ethical way to address behavior change. However, there is also a strong body of evidence, primarily drawing upon applied behavior analytic approaches, that offers an empirical defense for many of the components of PBIS. In a classic review, Carr et al. (1999) analyzed 109 research publications, which included 366 measured outcomes on 230 participants with intellectual disability or autism. They reported that when a 90% reduction in the problem behavior was used as a criterion, the PBIS interventions were effective in about half of the cases, and when an 80% reduction rate was used as the criterion, two thirds of the interventions were judged effective.

Living, Learning, and Working in the Community

Individuals with severe disabilities are also gaining greater access to different aspects of community life. The Americans with Disabilities Act, the Olmstead decision, and other legislative and policy initiatives have spurred more rapid movements toward community inclusion. For example, trends in residential placements continue in the direction of smaller, more natural settings (Braddock, Hemp, Tanis, Wu, & Haffer, 2017). Instead of living in congregate living facilities, such as group homes or large residential institutions, persons with severe disabilities are now more likely to live in their own homes or apartments, either with roommates or with other sources of support. By using Medicaid waiver funds, community-based organizations can provide services that let people with severe disabilities enjoy life like everyone else.

In the area of postsecondary education, new learning opportunities are opening up for students with severe disabilities. Inclusive education has now expanded to the two- and four-year college campus across the United States. The Higher Education Opportunities Act of 2008 introduced new provisions to increase access to inclusive postsecondary education. Indeed, more than 270 colleges and universities host programs specifically focused on supporting the enrollment of young adults with intellectual disability (see **www.thinkcollege.net**). Although not all of these programs support students with severe disabilities, new contexts for inclusion now exist. With support, students with disabilities can access interesting courses across the college curriculum, become active members of clubs and student organizations that pull upon their passions, participate in orientation events and campus programs that expose them to new perspectives and possibilities, access internships and campus jobs that inform their career trajectories, experience life in the dorms alongside others, and enjoy the social aspects of college life that help them forge lifelong relationships (Carter, 2018).

Individuals with severe disabilities are also making important contributions within the workplace. A good job can be the gateway to many other valued outcomes by contributing to someone's financial well-being, sense of accomplishment and self-worth, independence, self-determination, relationships, and valued roles. Thousands of youths and adults with severe disabilities are participating in the workforce and enjoying jobs that align with their interests and passions (Carter, Austin, & Trainor, 2012; Winsor et al., 2017). Multiple approaches now exist to elevate the employment of individuals with severe disabilities, including supported employment, customized employment, strategic internships, and micro-enterprises. Moreover, employers are discovering the business case for hiring people with severe disabilities and the myriad ways they can enhance workplace culture and productivity (Kendall & Karns, 2018).

CONCLUSION

Individuals with severe disabilities have wonderful strengths and positive traits that exist alongside their limitations and needs. Although these students experience substantial limitations across multiple areas of life and require ongoing supports, they also have interests, passions, talents, and other enviable qualities that are worth knowing about and communicating to others. Perhaps more so than any other group of students, individuals with severe disabilities are heterogenous and diverse. Individualization is essential when working to identify and address their learning, social, health, and other needs. Although it is valuable to understand the different disability categories and syndromes these young people often experience, such information neither defines nor fully describes them. Every student with severe disabilities is an individual.

The landscape has changed dramatically over the past 50 years. People with severe disabilities were once denied the opportunity to attend school; they resided in large institutions, and they were excluded from most aspects of community life. Today, opportunities and supports in the areas of education, employment, residential living, relationships, and community participation have substantially improved. But there is much more work to do. Looking backward at the history of this field, it is clear that we have almost always been shortsighted or wrong about what individuals with severe disabilities could accomplish or contribute. When provided the right combination of individualized instruction, supports, relationships, and opportunities, students with severe disabilities can flourish in their homes, schools, workplaces, and communities. Moving forward, educators, families, and other professionals should remain both optimistic and humble as they continue to advocate for better services and supports for individuals with severe disabilities.

QUESTIONS FOR REFLECTION

1. Students with severe disabilities are individuals who possess diverse strengths, needs, preferences, and interests. To what extent is it helpful to group these students together under the label of “severe disabilities”? What are the advantages and disadvantages of using such a label?
2. Why might it be important to consider someone’s strengths and positive qualities alongside their needs and challenges? How might a strengths-based perspective facilitate the inclusion of students with severe disabilities in school and community settings?
3. Given the learning characteristics and abilities shared by many students with severe disabilities, what would be one way to improve their outcomes in school and beyond?
4. The social networks of many individuals with severe disabilities are dominated more by professionals than by peers. What steps could be taken to facilitate friendships and other peer relationships?
5. Recent research and practice have demonstrated that students with severe disabilities have much more potential than once thought. In what areas do you think we may be presently falling short in our expectations of what individuals with disabilities can accomplish or experience?

2

Philosophies and Practices for Teaching Students with Severe Disabilities

Jaren Wicklund/Fotolia

This chapter presents different philosophies and practices for educating students with severe disabilities. Although there is overlap in some areas, in other ways they diverge. You are likely to see these philosophies and practices in action, at least to some degree, when you observe or participate in educational programs for students with severe disabilities.

A HISTORICAL OVERVIEW OF PHILOSOPHIES AND PRACTICES

As we begin to consider the nature of the appropriate educational services for students with severe disabilities, we should do so in light of the type of life we believe they should have. When we look back through history, we can only conclude that the quality of life for people with severe disabilities has often been poor, even unacceptable. So, if nothing else, the philosophy that anyone has about how to teach and provide services to people with severe disabilities should have at its core a desire to improve the quality of life for these individuals.

Early Philosophies and Practices

Since educational and related services began to be offered to persons with severe disabilities about two centuries ago, the philosophies that have guided professional practices have varied. Early in the 19th century, because practitioners thought that intellectual disabilities could be cured by exercising the nervous system, their instructions consisted primarily of sensory and motor exercises. Later, toward the end of the century, professionals began to change their opinions. Deciding that cures were not possible, they felt that it would be better to protect and care for the needs of people with severe disabilities, and the focus shifted from instruction to care and management.

Moving into the 20th Century

As the 20th century approached, Western society was swept by what has been referred to as the "genetic scare." There was great concern that persons with "inferior genes" would have a degrading effect on the quality of the human race. As a result of this type of thinking, people with intellectual and other disabilities were warehoused in large residential institutions so that they would not pose a threat to society or the gene pool. At the beginning of the 20th century (the 1900s), then, the guiding philosophy was not to teach or even to care for persons with intellectual disabilities, but to protect society from them.

Before the 1950s, there was little in the way of services for most persons with intellectual disabilities besides placing them in institutions. Other services that were available were provided by parents' organizations and private groups. It was not until the 1950s and 1960s that public schools began to provide instruction for persons with moderate and severe intellectual disabilities, and it was not until several years later, during the mid-to-late 1970s, that children and youth with the most severe disabilities—often called profound disabilities—began to receive public school services. This first occurred when Public Law (P.L.) 94–142 (now called the *Individuals with Disabilities Education Act* or *IDEA*) was passed in 1975, which mandated a "free and appropriate education" for *all* students with disabilities.

When students with severe disabilities were finally accepted into public school systems, instructional practices were often guided by a developmental-level philosophy. Students' mental ages or IQs were assessed, and they were taught skills that were considered to be attainable within these levels. Instructional activities for students with moderate and severe intellectual disabilities, even those in their adolescent years, consisted of arts and crafts, pre-academic and primary-level academic skills, language development, self-care skills, gross and fine motor skills, and prevocational skills. Regardless of the students' ages, the décor in most special schools and classrooms resembled kindergarten or nursery schools.

When programs were developed for students with the most severe disabilities, instructional programming was intended to inch them forward on scales of typical human development. For example, teachers would attempt to increase a student's eye contact or his or her ability to put a block in a box, because this was the next milestone of normal human development. Positive reinforcement (usually a small amount of food) was used to reinforce correct responses, and behavioral performances were recorded and charted on graph paper. Little thought was given to the usefulness of the behavior or how it would improve a student's life.

Precursors to Modern Practices

More current practices for providing services to persons with severe disabilities evolved from different sources of influence that originated in the 1960s. The human service concept of *normalization* was introduced, calling for schools and agencies to provide living and learning experiences that were as normal as possible (Nirje, 1969, 1972; Wolfensberger, 1972). Skills were taught that would allow life patterns like to those of people without disabilities, and procedures for teaching these skills were to be as normal as possible. At about the same time, the *deinstitutionalization* period began. Efforts were made by states to move individuals out of large institutions into smaller facilities located in regular communities (e.g., foster homes, group homes, intermediate-care facilities, and sheltered apartments). This period was characterized by a decline in the number of persons living in large residential institutions and an increase in the number living with their families or in smaller community-based residences.

CURRICULAR PHILOSOPHIES

As normalization and deinstitutionalization were occurring, public school programs gradually began to change, shifting from a developmental orientation to a focus on improving the relevance of instruction and related services. After the 1960s, three discernible themes emerged, each with its own set of recommended practices. The first to evolve was the *inclusion/functional instruction* approach championed by Lou Brown at the University of Wisconsin and other special educators (Brown, Nietupski, & Hamre-Nietupski, 1976). This philosophy called for the inclusion of individuals with severe disabilities in the mainstream of life, and recommended instructional approaches that taught functional, practical, and chronologically age-appropriate skills. The inclusion/functional instruction philosophy continues today and forms the basis for many current school and community practices.

The second theme, *self-determination*, promoted by Michael Wehmeyer at the University of Kansas and many other professionals, came to the forefront in the early 1990s and had at its core improving the abilities of people with intellectual and developmental disabilities to have greater control over their lives, including making their own decisions to the extent possible. This movement extended the inclusion/functional instruction philosophy and has also become a significant theme in the education of students with intellectual and developmental disabilities (Wehmeyer, 1992; 2014).

The third and most recent instructional theme, spurred by school reform movements and the 1997 and 2004 amendments to IDEA, is *access to the general curriculum*. This approach, championed by Diane Browder and Fred Spooner at the University of North Carolina, Charlotte, is meant to allow students with disabilities, including those with severe disabilities, an opportunity to participate in the general academic curriculum provided to students without disabilities. As part of this approach, students with severe disabilities are also required to be included in statewide accountability evaluations through the use of alternate assessments (Browder, Wood, Thompson, & Ribuffo 2014). The details and implications of the three themes are described in the following sections.

Inclusion and Functional Instruction

In the mid-1970s, many leaders in the field of special education proposed an educational model that had as its cornerstone inclusion and functional skills instruction.

They proposed that students with severe disabilities be educated in regular schools with students who do not have disabilities, and they eschewed homogeneously grouping students into segregated settings. They believed that learning is more likely to occur if there are sufficient opportunities to interact with persons of different ability levels. Brown et al. (1976) also promoted the use of direct instruction and said that students with severe disabilities should be taught in the actual settings in which they need to be performing meaningful skills, such as in domestic and community settings. They stated that "Teachers … can rarely, if ever, infer that because a student performs a particular skill in an artificial setting, he or she can also perform that skill in other more natural settings" (p. 6).

The inclusion/functional skill philosophy was based on a desire for persons with severe disabilities to participate as fully as possible in integrated adult environments, what Brown et al. (1976) called the "criterion of ultimate functioning" (p. 2). They felt that any instructional activity that does not contribute to this outcome should not be pursued. According to this philosophy, educators should ask: "Is this activity necessary to prepare students to ultimately function in complex heterogeneous community settings?" and "Could students function as adults if they did not acquire the skill?" (p. 9). Reflecting the tenets of the normalization principle, Brown et al. also promoted the idea that teaching procedures for students with severe disabilities should be as natural as possible. They proposed that skills should be taught, learned, and practiced in different settings, with different people, and under different conditions so that the learner would be able to generalize the skills into natural settings.

Almost a half century later, many authorities continue to support the value of this model (e.g., K. Ayres, Douglas, Lowrey, & Sievers, 2011; Brown, 2013). As a testament to the effectiveness of the inclusion/functional curriculum model to prepare students with severe disabilities for meaningful adult lives, Brown, Shiraga and Kessler (2006) published a paper reporting the status of 50 adults with moderate to severe intellectual disabilities who, as adults, were working in real community jobs, some for over 20 years. The features and implications of the inclusion/functional instruction philosophy are highlighted in Table 2.1.

TABLE 2.1
Features of the Inclusion/Functional Instruction Model

Feature	Implications
Inclusion	• Students with severe disabilities should attend regular, age-appropriate schools; the home school of the student is the most preferred school. • Students should be in regular classrooms, when possible, with supports; separate settings should be used only if necessary to achieve certain objectives. • Students with severe disabilities should comprise no more than 1% of a school to maintain natural proportions. • Tactics such as adapted curricula and materials, cooperative learning, and peer tutoring should be used to achieve success. • Activity-based instruction and experiential learning should be used to allow students to participate in the general curriculum. • Out-of-classroom instruction, such as community-based instruction (CBI), should include students without disabilities to be more inclusive. • General and special educators should collaborate in planning and teaching; students with disabilities do not "belong" to the special education teacher. • Friendships and relationships between students with and without disabilities should be encouraged. • Paraprofessionals should not be overused and should not be used to isolate students in the classroom. • Adequate planning time should be allocated for teachers and related services professionals to work together.

Continued

TABLE 2.1 Continued

Feature	Implications
Social Participation	• Social participation and engagement should be encouraged in the school, the home, and throughout the community, including in vocational settings. • Appropriate social skills should be targeted for instruction on the IEP; inappropriate social behavior should be replaced with appropriate behavior. • Social behavior should be incidentally taught whenever there is an opportunity to do so. • Individuals without disabilities should model, prompt, and reinforce appropriate social behavior. • Standards of appropriate social behavior should be enforced for students with disabilities. • Efforts should be made to increase the quantity and quality of social behavior.
Functional, Age-Appropriate Skills	• Functional, age-appropriate skills that allow a person to be more independent should be the focus of instruction and should be included in the IEP. • Instruction on skills should be embedded in the general curriculum and taught throughout the day as integrated skill clusters, not in isolated trials. • Skills should focus on increasing participation and making the individual more independent and/or less dependent and less isolated. • Meaningful partial participation should be encouraged if students cannot participate fully. • Systematic instruction should be used to teach the most important skills (those on the IEP) and individual performance data should be used to monitor progress. • Functional skills should be maintained over time and should be generalized to appropriate settings and conditions. • Natural materials and actual settings should be used during instruction of many key skills. Artificial materials and settings may impede generalization. • Language and communication, motor skills, mobility, and social skills should be embedded in the instruction of functional skills.
Non-school, Community-Based Instruction (CBI)	• Instruction outside school contexts is necessary for functional and age-appropriate skills to be learned and generalized to natural settings. • The student and his or her parents or family should be involved in identifying community settings for instruction. • Whenever possible, peers without disabilities should be involved in non-school instruction. • Instruction should occur in multiple community settings to meet individual objectives and help achieve generalization. • Teaching community skills in simulated settings or using technology such as video-based instruction can be helpful, but is not sufficient to achieve generalization. • Ecological inventories can identify skills necessary for operating in different community settings. • CBI will become more important as the student gets older but may also be appropriate for younger students, although the targeted skills may differ. • CBI is not the same as going on a field-trip; it is an instructional activity during which specific skills should be taught.

Self-Determination

The importance of self-determination as an educational outcome had its origins in the normalization movement and is related to other human service policies affecting the lives of people with disabilities, most notably self-advocacy and disability rights (Ward, 1996). The disabilities rights movement, which originated like other civil rights movements in the 1960s, has been led by people with disabilities who are concerned with gaining concrete benefits and opportunities in society (Ward, 1996). Wehmeyer (2014) referred to self-determination as being indicative of the "third wave of the disability movement: the self-advocacy era," during which people with disabilities began to "claim their own voices" (p. 6–7).

Self-determination can be (1) viewed as an educational outcome, (2) defined in relation to the characteristics of an individual's behavior, and (3) achieved through lifelong learning, opportunities, and experiences (Wehmeyer, 1996). Self-determination has been defined as "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life, free from undue external influence or interference" (Wehmeyer, 1992). For self-determination to occur, according to Wehmeyer (1996; and Wehmeyer, Kelchner, & Richards, 1996), an individual must exhibit four essential characteristics:

1. *Autonomy:* Acting according to one's own preferences, interests, and abilities, independently and free from undue external influences
2. *Self-regulation:* Deciding what strategies and tactics to use in particular situations, in setting goals for oneself and working to achieve these goals, in problem solving, and in monitoring one's own performance in these tasks
3. *Psychological empowerment:* Believing that one has control over important circumstances, that is, an internal locus of control, and a belief that one has the skills to achieve the desired outcomes and that by applying these skills the desired outcome will occur
4. *Self-realization:* Having a reasonably accurate knowledge of himself, his strengths, and his limitations and acts in a way that capitalizes on this knowledge

For these essential characteristics to develop within an individual and lead to self-determination, important experiences are necessary. Wehmeyer (1996) referred to these critical experiences as *component elements of self-determined behavior.* They include:

- Choice making
- Decision making
- Problem solving
- Goal setting and attainment
- Self-observation, evaluation, and reinforcement
- Internal locus of control
- Positive attributions of efficacy and outcome expectations
- Self-awareness
- Self-knowledge

Wehmeyer and Abery (2013) reviewed the research on self-determination and choice and reported several important findings:

- Many individuals with intellectual and developmental disabilities exhibit fewer self-determination characteristics than do their peers without disabilities. Research shows that this is not generally due to inherent ability, but due to fewer opportunities to practice the skills necessary to become more self-determined, such as making choices and expressing preferences.
- When adequate opportunities and supports are provided, persons with intellectual and developmental disabilities often have the capacity to exercise self-determination. Instruction in skills such as choice-making, decision-making, setting goals, self-advocacy, problem-solving, and self-awareness has been shown to improve the self-determination ability.
- Some characteristics are associated with being more self-determined, including: exhibiting better social skills, adaptive behavior, and less inappropriate behavior. Adolescents tend to increase their self-determination ability as they get older, and to some extent, persons with higher IQs tend to have higher levels of self-determination. This may be because they have more learning opportunities, because choice opportunity is a strong predictor of self-determination.
- Learning, living, and working environments bear on the development of self-determination. Students in inclusive school settings and individuals who live and work in non-congregate facilities tend to exhibit more self-determination. This is likely because more structured and controlled environments, such as special schools and group homes, allow less choice-making and fewer problem-solving opportunities.
- As adolescents with intellectual and developmental disabilities approach adulthood, those who have higher levels of self-determination tend to have better outcomes in employment, community living, and quality of life.

Based on the available research, Wehmeyer and Abery (2013) concluded that "Promoting self-determination and choice opportunities for people with intellectual and developmental disabilities has become best practice in the field" (p. 399). Unfortunately, many parents, teachers, and paraprofessionals do not have the knowledge, skills, or attitudes to promote the development of self-determination skills actively among students with intellectual and developmental disabilities (Carter, Owens, Trainor, Sun, & Swedeen, 2009; Carter, Sisco, & Lane, 2011; Wehmeyer, Agran, & Hughes, 2000). This has led many proponents of self-determination to maintain that because of the research findings previously presented, it is important for teachers, parents, and others to use strategies to enhance the development of self-determination skills (Agran, King-Sears, Wehmeyer, & Copeland, 2003; Doll, Sands, Wehmeyer, & Palmer, 1996). Table 2.2 summarizes some strategies recommended by Doll et al. that may be employed at different stages of life.

TABLE 2.2
Strategies to Improve Self-Determination

Life Stage	Self-Determination Strategies
Early Childhood (Ages 2 to 5)	• Teach the child to recognize personal preferences and to be aware of alternative options; let him or her pick between two alternatives. • Teach the child he or she has the freedom to make some choices in certain situations, and allow enough time for the choice to be made. • Help the child learn the consequences of different choices, including learning that some choices are dangerous; discuss what might happen if … • Help the child recognize the views of others about choices. • Help the child remember some consequences of past choices, some pleasant, some not. • Provide chances to plan for upcoming events in the near future. • Encourage the child to compare outcomes created by him or her with outcomes created by you or others.
Early Elementary (Ages 6 to 8)	• Prompt the child to identify more varied solutions to his or her problems and consider different strategies to accomplish a task. • Encourage the child to think about personal strengths and weaknesses and likes and dislikes before making decisions. • Encourage the child to follow through with decisions and stay on tasks related to choices made; give praise and attention for doing so. • Provide the child with feedback about decisions and what they've led to; evaluate their performance with them so they can make improvements. • Prompt the child to think out loud about possible choices and strategies that he or she might use. • Allow the child to talk about ways that he or she might best learn something. • Encourage the child to self-evaluate his or her work and discuss how it could be improved. • Let the child set some personal goals related to particular tasks or activities and then encourage reflection on whether they were achieved.
Late Elementary (Ages 9 to 11)	• Encourage the child to set personal goals and take actions to reach these goals; if possible, have him or her write down the goals and review them occasionally. • Teach the child to change his or her opinions or behavior when he gets new information. • Help the child learn that sometimes extra effort will help him or her reach a goal. • Show the child how others might react to his or her actions or activities; the use of visual displays, such as pictures, may be helpful. • Remind the child about past decisions he or she made and how they affected others; ask him or her to think of how some people might react to current decisions. • Support the child to undertake self-evaluation of completed tasks and what might be done to improve his or her performance.
Secondary (Ages 12 to 18)	• Encourage adolescents to think systematically and support their use of problem solving. • Encourage them to be more rational and less emotional when dealing with challenging situations. • Provide opportunities for them to make important decisions about their daily activities and about longer-term goals such as diet, academics, and career possibilities. • Encourage them to see the links between their daily decisions and their ability to achieve longer-term goals. • Help them see how long-term goals can be broken down into smaller tasks that will ultimately lead to the goals. • Help them recognize their strengths and weaknesses and how to set and achieve goals in light of this information. • Encourage students to recognize different sources of support and to seek it when necessary.

Supported decision-making. Many individuals with intellectual and developmental disabilities have cognitive difficulties that affect their ability to make decisions, and additionally, often have little practice in this area because many decisions are made for them. These conditions may be why they sometimes make decisions that can result in adverse or undesirable consequences. As a result, as individuals with intellectual disabilities approach adulthood, parents or caregivers often pursue legal guardianship, which allows for "substitute decision making," the antithesis of self-determination (Millar, 2007).

In response to this relatively common situation, scholars have recently proposed that instead of removing the opportunity for decision-making, *supported decision-making* should be used with the person with the disability to involve him or her as much as possible in making important life decisions (e.g., Shogren & Wehmeyer, 2015; Shogren, Wehmeyer, Lassman, & Forber-Pratt, in press; Shogren, Wehmeyer, Uyanik, & Heidrich, 2017).

If decision-making is considered to be deciding the best course of action to take given the various options possible while understanding the implications of the different options (Shogren et al., in press), supported decision-making is a process that employs one or more trusted family members, friends, advocates, or professionals to help the individual make an informed decision (Shogren et al., 2017). Although researchers are just beginning to explore the elements and procedures of supported decision-making, an important step forward is the development of the Supported Decision Making Inventory System (SDMIS). Shogren et al. (2017) described the system as including three domains:

1. *SDM Personal Factors Inventory*: Provides information about the individual's feelings about decision-making, his or her level of agency (skills related to reaching goals), and experiences making decisions;
2. *SDM Environmental Demands Inventory*: Determines the extent to which the individual is currently facing important decisions in key life areas, and;
3. *Decision Making Autonomy Inventory*: Measures the individual's autonomy in decision-making activities and the level of support needed for decision-making actions.

Shogren et al. (2017) pointed out that supported decision-making "empowers people with disabilities to utilize a combination of natural supports—friends, family, peers, community members—to provide supports for decision making as opposed to an appointed guardian speaking for the individual" (p. 434).

Preference assessments and students with very significant disabilities. Determining personal preferences is not something that we often think is possible for individuals with the most significant disabilities, commonly referred to as profound intellectual disabilities, but research demonstrates otherwise. Using different *preference assessment methods*, individuals with significant disabilities have been able to show preferences for different items and activities, and when given choices within different activities, tend to perform better on the activities for which they are able to select different components (Canella, O'Reilly, & Lancioni, 2005: Tullis et al., 2011). For example, Reid et al. (2001) offered adults with profound disabilities who were working in a small publishing shop the opportunity to choose whether to work with adaptive devices or to work without them. The devices helped them work more independently by requiring less assistance from a support person. The workers nearly consistently chose to use the devices and thus relied on less support from their supervisor.

There are several ways that individuals with very significant disabilities can show the items or activities that they prefer. The following are some commonly used preference assessments (Chazin & Ledford, 2016; Tullis et al., 2011):

- Single stimulus preference assessments: An individual item, such as a toy, is presented to the individual and the way he or she interacts with the item and the duration of interaction are recorded.

- Paired stimuli preference assessments: Two items are presented to an individual at once and a record is kept as different choices are presented over time.
- Multiple stimuli with (MSW) replacement or without (MSWO) replacement. For both methods, several items are presented at one time, and the individual is allowed to choose one. When using MSW, when one item is selected, it is replaced. With MSWO, selected items are not replaced.
- Free operant observations: With this assessment method, items or activities are presented or made available, and the individual can engage with any or all of them throughout the assessment session. An observer can then determine preferred items or activities.

A detailed explanation for conducting these preference assessments is provided by Chazin and Ledford (2016).

Studies have shown that preference assessments can reliably identify desired items or activities, and that incorporating preferred choices into instructional activities can result in improved learning and performance. More specifically, allowing students to engage with preferred items and in preferred activities may serve as effective reinforcement when learning important tasks, may reduce challenging behavior, and may increase more appropriate behavior (Canella et al., 2005; Tullis et al., 2011).

Participation in the General Curriculum

As stated previously, learning the content contained in the general curriculum followed by students without disabilities is the most recent philosophical shift to be applied to educating students with severe disabilities. We provide an overview of the main issues related to this practice.

Why participation in the general curriculum evolved. For many years, some students with severe disabilities demonstrated the ability to learn basic academic skills, primarily sight words and simple arithmetic skills. However, the skills that were taught were generally limited to those considered to be functional, such as basic sight words, money skills, and skills related to operating in the home and community (Browder, Spooner, Ahlgrim-Delzell, Harris, & Wakeman, 2008; Browder, Wakeman, Spooner, Ahlgrim-Delzell, & Algozzine, 2006). However, the 1997 and 2004 IDEA amendments, as well as the No Child Left Behind Act of 2001 (NCLB), changed the nature of academic skills that teachers were expected to teach. These laws called for students with disabilities, including those with severe disabilities, to participate in the general curriculum along with students without disabilities. Students with severe disabilities were also to be assessed annually by state education agencies, using alternate assessments if they could not participate meaningfully in the standard assessment system.

Besides the legal requirement, a second reason participation in the general curriculum became a dominant movement is because many special education professionals proposed that students with severe disabilities would be better educated if they were given the opportunity to engage in more traditional academic activities, such as literacy instruction and other areas of the general curriculum (Browder et al., 2007; Copeland & Cosbey, 2008/2009; Katims, 2000; Kliewer & Biklen, 2001; Kliewer & Landis, 1999; Ryndak, Morrison, & Sommerstein, 1999; Spooner & Browder, 2006; Spooner, Dymond, Smith, & Kennedy, 2006). This means that not only should students with severe disabilities be included in general education classrooms, but that they should participate and demonstrate progress in the same curricular areas as students without disabilities and not focus solely on functional skills (Browder et al., 2014; Wehmeyer, Lattin, & Agran, 2001; Wehmeyer, 2006). Spooner, Dymond, Smith, & Kennedy (2006) wrote:

> *The promise of NCLB (The No Child Left Behind Act) and IDEA (The Individuals with Disabilities Education Act) is that all students have potential to access, participate in, and process the general curriculum. Access to the general curriculum broadens the curriculum options available to students with significant cognitive disabilities; increases expectations for achievement; results in the development of academic skills, social relationships, and skills from other domains (e.g., home living, vocational); and promotes opportunities for students to engage in curriculum activities with their non-disabled peers in inclusive settings (p. 280).*

Learning areas included in the general curriculum for students with severe disabilities. When students with severe disabilities participate in the general curriculum, there is an expectation that they will learn academic knowledge and skills that are anchored to the academic standards developed for students without disabilities. This content will consist of the curricular elements such as those outlined in the Common Core State Standards (Common Core State Standards Initiative, 2012) now being implemented by many states, including English Language Arts and Mathematics, as well as individual states' standards in areas such as science and social studies.

The Common Core standards were developed under the leadership of the National Governors Association Center for Best Practices and the Council of Chief State School Officers in collaboration with school personnel and instructional experts (Common Core State Standards Initiative, 2012). Students with disabilities, including those with severe disabilities, are expected to learn skills that are linked to these standards. As was noted by the developers of the Common Core standards, "Some students with the most significant cognitive disabilities will require substantial supports and accommodations to have meaningful access to certain standards in both instruction and assessment, based on their communication and academic needs. These supports and accommodations should ensure that students receive access to multiple means of learning and opportunities to demonstrate knowledge, but retain the rigor and high expectations of the Common Core State Standards" (Common Core State Standards Initiative, 2012).

Research conducted in the past few years has resulted in the development of evidence-based practices for teaching students with severe disabilities in several academic areas (Browder et al., 2014; Spooner, Knight, Browder, & Smith, 2012). These include teaching reading (Browder, Ahlgrim-Delzell, Spooner, Mims, & Baker, 2009; Browder, Courtade-Little, Wakeman, & Rickelman, 2006; Browder, Wakeman, Spooner, Ahlgrim-Delzell, & Algozzine, 2006), math (Browder, Spooner, Ahlgrim-Delzell, Harris, & Wakeman, 2008; Browder et al., 2012; Collins, Kleinert, & Land 2006), and science (Courtade, Spooner, & Browder, 2007; Spooner, Di Biase, & Courtade-Little, 2006; Spooner, Knight, Browder, Jimenez, & DiBiase, 2011).

Instructional practices that help students participate in the general curriculum. In some cases, students with severe disabilities may be able to participate adequately in the general curriculum as it is presented for students without disabilities in the regular classroom. Most of the time, however, the instructional content of the general curriculum will be modified in a way that students with severe disabilities will be able to access it. In addition, more specialized instructional methods may be used to ensure successful learning (Browder et al., 2014; Copeland & Cosbey, 2008/2009). Several of these are described briefly in Table 2.3.

Alternate assessments for alternate academic standards (AA-AAS). In addition to participation in the general curriculum, educational reforms called for by NCLB and by IDEA 1997 and 2004 require students with disabilities to participate in annual statewide assessments. If the student has a disability that inhibits him or her from

TABLE 2.3
Strategies for Participation in the General Curriculum

Strategies	Implementation Descriptions
Developing curriculum extensions	This planning process begins with identifying the grade level or course learning goals and strategies for students without disabilities. Next, individualized goals and instructional strategies are developed for the students with severe disabilities. These should reflect the learning content for the students without disabilities. These curriculum extensions may be developed by the state education agency or they may be collaboratively planned by general and special education teachers.
Using UDL principles to design curriculum	Universal Design for Learning (UDL) is a planning process that is meant to make academic content accessible for learners with different abilities. This process may be incorporated into planning curriculum extensions. It takes into consideration how students may be presented with curricular material, how they express their knowledge, and how they might maintain their engagement in the learning process.
Using assistive technology	Assistive technology (AT) devices, such as augmentative and alternative communication (AAC) devices, are often useful in helping students access and participate in the general curriculum. They can fill gaps that occur as a result of a student's disability. For example, some computer apps can turn written words into verbal language, and some can turn symbols that are touched into spoken words. AT devices are often incorporated into UDL planning.
Using systematic instruction	Systematic instruction is a process for teaching that has long been used with students with severe disabilities. Its major components include clearly identifying learning targets as behavioral objectives; breaking these objectives into their components through a task analysis; using prompts, reinforcement, and error correction to facilitate learning; and collecting and recording performance data to monitor learning progress.
Using peers as instructors	Peers without disabilities can be used as tutors to help students with severe disabilities successfully engage in the general curriculum. Peers can be considered more natural instructors than paraprofessionals because they do not isolate the student with disabilities from the rest of the class but instead serve as important agents for both academic learning and communication and social skills learning.
Using the "self-determined learning model of instruction"	The use of self-determination strategies can be helpful in enabling students with severe disabilities to access the general curriculum in meaningful ways. This process asks students to identify key areas of the general curriculum they wish to focus on, identify a plan for learning, and then monitor their own learning to determine whether they have been successful.
Use embedded instruction	Embedded instruction means teaching academic skills embedded in other activities, for example, teaching sight words during other regular class activities or teaching vocabulary during functional skill learning.

participating meaningfully in the standard assessment process, even if accommodations are allowed, then the student must be assessed using an alternate means of assessment. According to the National Center on Educational Outcomes (NCEO, 2016), for students with severe intellectual disabilities, the most common type of alternate assessment is the Alternate Assessment for Alternate Academic Standards (AA-AAS). "These assessments are based on the grade-level content covered by the general assessment, but at reduced depth, breadth, and complexity. These assessments describe achievement based on what a state determines is a high expectation for these students" (NCEO).

According to the NCEO (2016), "The AA-AAS is intended to be used with students with significant cognitive disabilities as determined by each state's eligibility criteria. National data on who participates in AA-AAS show that participating students are those with the most severe intellectual disabilities and multiple disabilities—children who represent fewer than 1% of all students, or less than 10% of all students who have disabilities." In a study of nearly 40,000 students in 15 states who were assessed using an AA-AAS, Kleinert et al. (2015) found that 93% of the students were placed in separate classrooms or schools.

An AA-AAS may take different forms, including portfolios, rating scales, and item-based tests (NCEO, 2016). Portfolios include samples of student work linked to the general academic curriculum. Rating scales require teachers to rate a student's performance based on classroom observations. Item-based tests are administered in one-to-one arrangements, and the student is expected to perform on specific items such as pointing to a certain picture when prompted.

Issues related to participation in the general curriculum and alternate academic assessments. The pursuit of learning goals in the general curriculum by students with severe disabilities, and being evaluated using alternate assessments on general curriculum goals, has not occurred without debate. The main issues that have been discussed are these:

- Some authorities feel that students with severe disabilities should receive instruction primarily in a functional skills curriculum as has been the central focus of instruction for nearly 50 years (e.g., Ayres et al., 2011; Brown, 2013). Others, however, feel that students can benefit from instruction in both functional skills and the general curriculum (Collins, Hager, & Galloway, 2011; McDonnell, Hunt, Jackson, & Ryndak 2013).
- Studies have shown that some parents, teachers, and administrators have mixed feelings about instruction in the general curriculum and the use of alternate assessments, although acquiring more information about instructional procedures may improve their attitudes and understanding (Agran, Alper, & Wehmeyer, 2002; Courtade, Browder, Spooner, & Di Biase, 2010; Flowers, Ahlgrim-Delzell, Browder, & Spooner, 2005; Petersen, 2016; Roach, 2006; Timberlake, 2016; Towles-Reeves, Klienert, & Anderman, 2008).
- Some authorities have expressed concern that schools may place students with severe disabilities in more segregated (non-inclusive) classrooms and schools to provide instruction in the general curriculum and prepare them for alternate assessments. They have argued that the context of instruction is important and that instruction in the general curriculum should occur in the general education classroom (Jackson, Ryndak, & Wehmeyer, 2008/2009; Ryndak, Jackson, & White, 2013; Ryndak et al., 2014).
- As of yet, no one has been able to evaluate the long-term impact of students with severe disabilities participating in the general curriculum fully (Bouck, 2012), which has resulted in criticism of this approach (Brown, 2013). However, it is also true that we have little research about the long-term impact of any type of schooling for students with severe disabilities with the exception of a few studies (e.g., Brown et al., 2006; Ryndak, Ward, Alper, Montgomery, & Storch, 2010).

Related best practices

In addition to major curriculum philosophies, several other practices are important and should be considered components of quality programs for students with severe disabilities. In this section we focus on three important practices: (1) providing services early in the life of a child with severe disabilities, including support to his or her family to the extent necessary; (2) promoting a high level of collaboration and planning among professionals and between professionals and parents; and (3) offering related services so that the student may attain maximum benefits from his or her educational program.

Early intervention and preschool programs. An early intervention program is an extremely important service that should be provided to infants and toddlers with disabilities

TABLE 2.4
Key Components of Early Intervention and Preschool Programs

Components	Descriptions
Early start	Screening for children with disabilities, referral to programs, and initiation of services should all occur as soon as possible after atypical development has been identified.
Family-centered	Support of the family is an integral component of early intervention. The family's strengths and needs should be identified, and unique intervention plans should be developed accordingly.
Extended support system	In addition to family involvement, the extended family and other members of the family's social network should be considered part of the support system for the child.
Professional–family relations	Professional assistance should be provided to buttress the natural system of family support, not to supplant it.
Developmentally appropriate	The early intervention program should be developmentally based in that it encourages and fosters integrated development as opposed to training isolated skills. Children should be encouraged to make choices, be actively involved in the learning process, and learn how to influence what happens in their environment effectively.
Progress assessments	Frequent assessment should occur, and learning activities should be planned as a result of these assessments.
Transition planning	Because an important goal should be the introduction of the child into a normal kindergarten, the program should prepare the child for that environment and work with the family to plan a transition into the new program.
Program evaluation	Program evaluation should occur on a regular basis, with input from parents, teachers, and administrators on the satisfactory outcome of the program.

as soon as a delay is observed until the child turns three, when he or she should begin participation in a preschool program. Because most children with severe disabilities are identifiable at birth or very early in life, it is possible to begin intervention early, which is critical to maximizing later development. High-quality early intervention and preschool programs reduce the impact of the disability, enhance the child's development, help the family meet the child's needs, and coordinate available resources for the child and the family. Key components of early intervention and preschool programs are listed in Table 2.4.

Collaboration and comprehensive planning. During the school years, the effectiveness of services for students with severe disabilities will be maximized if professionals collaborate with each other, as well as with parents, to offer quality educational and related services. Professionals and parents should work as teams that focus on planning to ensure the student's progress. The more effective the team, the more likely the student will benefit. Key elements of collaboration and planning are listed in Table 2.5.

Related services. Related services are those that students receive, in addition to instruction, that enable them to benefit fully from their educational program. Typical related services for students with severe disabilities include speech/language services, physical therapy, and occupational therapy. Students may also require services from school psychologists or behavioral specialists, nurses, social workers, rehabilitation counselors, and job coaches. Table 2.6 provides a list of practices that should characterize the provision of related services that supplement those listed in Table 2-5.

TABLE 2.5
Key Components of Collaboration and Planning

Components	Key Practices
Team representation	Representatives of various disciplines, as well as parents, should participate in collaborative planning because of the complex needs of the student. When possible, the student should also participate.
Team awareness	Team members should be aware of the knowledge and expertise of one another. All disciplines should share knowledge and skills with all others to meet different needs and in different situations.
Decision making	Decisions should be made through a consensus of the group based on the best information available to the group.
Student focused	Specialists should focus not only on developing isolated skills within their specialty areas, but on how specific skills may be incorporated into daily routines and activities.
Parental involvement	Parents may wish to participate in different ways and their choice should be respected. Support should be provided to facilitate parent involvement. Parents should have frequent opportunities to visit the school and participate in activities with their child.
Communication	Parent–school communication is critical. Parents and professionals are a primary source of information for one another. Parents will often need information about school and community services that are available.
Holistic planning	Planning should allow the student to participate in all areas, including participating in the general curriculum and involvement in home, community, recreational, and work activities. Consideration should be given to future as well as present activities.
Targeting specific skills	The student's current skill level in different areas and his or her unique needs should prescribe specific skills that should be listed as objectives on the IEP.
Planning for transitions	Planning for major moves or transitions should occur well in advance of the transition, with attention being given to the needs of the person with disability and to the nature of the future setting or service.
Planning for inclusion	Special focus should be on planning to move the student to an inclusive classroom or setting if he or she is not already there.

TABLE 2.6
Best Practices for Providing Related Services

Components	Best Practices
Location of services	Services should be offered in the least restrictive environment possible. Providing services in restricted environments should be avoided except when the setting is necessary for new or particularly difficult tasks.
Therapy in the natural environment	If it is necessary to isolate the student for some aspect of a particular therapy, the therapy should continue in the most natural setting as soon as possible.
Integrating therapy	Therapy goals should be integrated with the student's other objectives, and vice versa. The more opportunity to practice a skill, the better the chance for it to be learned sooner.
Sharing knowledge	The therapist's expertise will be especially useful for explaining (1) a student's limitations and how to circumvent them, and (2) the student's level of development and how to improve it.

BEST PRACTICES FOR TEACHING INDIVIDUALS WITH ASD

Many of the practices we have discussed throughout this chapter can be considered appropriate for students with autism spectrum disorders (ASD) as much as they can for other students with severe disabilities. However, because of their unique characteristics, individuals with ASD have often been studied as a separate population, and unique evidence-based practices have been identified by various authors to address their needs (e.g., Machalicek et al., 2008; Martinez, Werch, & Conroy, 2016; National Autism Center, 2009, 2015; National Research Council, 2001; Odom, Boyd, Hall, & Hume, 2010; Reichow, 2012; Wong et al., 2014). In the following sections, we look at comprehensive treatment models and individual interventions that have been shown to be especially effective with students with ASD.

Comprehensive treatment models. There are a number of educational or therapeutic programs, referred to as comprehensive treatment models (CTMs, National Research Council, 2001; Odom et al., 2010). CTMs have been designed specifically for students with ASD. Each CTM has a set of practices (considered its brand) that are used in its various treatment centers. Odom et al. examined 30 CTMs and placed them into five categories: clinic or home-based applied behavior analysis (ABA) programs; special classroom ABA programs; inclusive classroom ABA programs; developmental/relationship-based programs; and idiosyncratic programs. They examined each CTM and rated them on five criteria: operationalization (how well procedures are defined), fidelity (how well the model can be implemented), replication (the extent to which the model has been replicated in different settings), outcome data (the extent to which the program has affected student outcomes as reported in refereed research), and quality (the quality of the research reported). Based on their analysis, Odom et al. found that five CTMs had high ratings in at least four areas. Three of these highly rated CTMs were clinic or home-based ABA programs, including Lovaas Institute, May Institute, and Princeton Child Development Institute. One was an inclusive ABA program: LEAP (learning experiences, an alternative program for preschoolers); and one was a developmental-relationship-based program, the Denver model. Odom et al. noted that several other programs also had strengths even though they did not meet the criteria for the higher ranking.

If we consider the specific characteristics of effective programs, such as those listed or others, we can find several that are in common. Based on its review of the research, the National Research Council (2001) suggested that the following practices within programs would lead to better outcomes for students with ASD:

- *Educational services should begin as soon as a child is suspected of having an ASD . . . [and] . . . should include a minimum of 25 hours per week, 12 months a year, in which the child should be engaged in systematically planned, developmentally appropriate activity aimed toward identified objectives;*
- *A child should receive sufficient individualized attention on a daily basis so that individual objectives can be effectively implemented . . .;*
- *Assessment of the child's progress in meeting objectives should be used on an ongoing basis to further refine the IEP . . . [and] . . . lack of . . . progress over a 3 month period should be taken to indicate a need to increase intensity . . .;*
- *. . . [C]hildren should receive specialized instruction in settings in which ongoing interactions occur with typically developing children* (National Research Council, 2001, pp. 220–221).

Individual interventions. Besides looking at the effects of comprehensive programs, researchers have examined instructional practices or interventions to determine their effectiveness with students with ASD (National Autism Center, 2009, 2015; Wong et al., 2014). In its first report, the National Autism Center (NAC; 2009) analyzed 775 studies in which various interventions were used to teach appropriate skills (e.g., academic skills, communication skills, self-regulation, etc.) or decrease challenging behaviors (e.g., problem behaviors, repetitive nonfunctional behaviors, etc.). In their second report, the NAC (2015) added 389 studies, including 361 studies for individuals between 0 and 21 years of age, and 28 studies of individuals 22 years of age or older.