As with previous editions of this textbook, we have attempted to provide useful information in a form that can be readily understood and applied by readers. In preparing this work, we have relied upon our own experiences and understanding of persons with severe disabilities and on a broad array of recent professional literature.

**New in This Edition**

This edition includes heightened emphasis on inclusive education and the presentation of research-based approaches for promoting successful inclusion. Several chapters include our most critical updates.

- **Chapter 2.** Here we expand the discussion philosophies and best practices with more of a focus on teaching academic skills aligned with the general curriculum to students with severe disabilities. This chapter also provides an overview of best practices for teaching students with Autism Spectrum Disorders.
- **Chapter 9.** In this chapter we have provided much more new information on the use of alternate assessments, in light of the most recent research and practices in this area.
- **Chapter 10.** This chapter extends our discussion of inclusion to address more specific strategies for providing instruction on the general curriculum in inclusive classrooms and the implications of this for the special educator.
- **Chapter 12.** We have updated our information on Positive Behavior Interventions and Supports because appropriate behavior of students with disabilities is important for successful inclusion. In this chapter we also include a discussion of seclusion and restraint.
- **Chapter 16.** This chapter includes new research-based information on improving peer relationships and addresses the roles of educators and families in fostering friendships among students with and without severe disabilities.
- **Chapter 17.** This chapter has been extensively revised and focuses on methods for teaching academics linked to the general curriculum to students with severe disabilities. It reflects the plethora of research that has recently emerged in this area.
- **Chapter 19.** Here we provide an update on the use of technology by persons with severe disabilities. Not only do we continue to see a wide variety of assistive technology devices, but we are now seeing a wide variety of apps designed and available for use on iPads or iPhones or iPods and many of these are discussed.
- **Chapter 20.** In this chapter we provide more guidance on early intervention services that support families and the inclusion of young children within early care and education programs. We also discuss how universal design can help create welcoming classrooms for young children.
- **Chapter 21.** In the last chapter, we have revised our information on transitioning to adulthood to reflect new developments and recommendations for supporting youth and their families as they approach life after high school.

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There are several areas that have received a significant amount of attention and revision throughout this edition.
edition. Most notably, in various chapters, we have deepened our discussion of how best to support students with severe disabilities to access meaningful opportunities for learning and relationships within inclusive school and community settings. Ensuring students with disabilities have the services and supports needed to participate fully in the life of their school alongside their peers remains a strong theme within recommended policy and practice. The field’s understanding of effective instructional and support strategies continues to grow rapidly. This edition includes heightened emphasis on quality indicators of inclusive education and presentation of research-based approaches for promoting successful participation in diverse settings.

An area that has received considerable attention in this revised edition is academic instruction and the use of alternate assessments to evaluate students in this area. Since the last edition of this textbook the amount of research on both alternate assessments (Chapter 9) and academic instruction (Chapter 17) has greatly increased and become an integral component of education for students with severe disabilities. Although some have been cautious about this change in curricular focus, it is an area that warrants a great deal of attention in a text of this nature. No doubt there are many issues still to be resolved, but participation in the general curriculum and in alternate assessments now resides as a central issue for students with severe disabilities, so in this edition we have provided information about the most recent practices in these areas.

Because the inclusion of students with severe disabilities continues to be a critical goal, we have extended our discussion of it to address more specific strategies on providing instruction on the general curriculum in inclusive classrooms (Chapter 10). We also address the implications this has for the role of special educators. Of course appropriate behavior of students with disabilities is often related to their success in inclusive settings, so addressing challenging behavior effectively is essential. Therefore we have updated our chapter on Positive Behavior Supports (Chapter 12) with current research on the application of individualized positive behavior support along with practical guidance on how to design and implement a behavior support plan. In this chapter we also include a discussion about issues related to seclusion and restraint.

Also related to successful inclusion, peer relationships has been given much more attention (Chapter 16). Meaningful peer relations have long been emphasized as an important outcome of inclusive schooling. Recognizing that fostering social relationships is as important as promoting access to rigorous instruction, we have developed a new focus addressing the roles of educators and families in fostering friendships among students with and without severe disabilities. Research-based interventions that build social skills, promote peer acceptance, strengthen social-related supports, and create opportunities for students with and without disabilities to meet and get to know one another are highlighted in this chapter.

Another topic which continues to grow in significance and which can greatly influence successful inclusion is the use of technology by persons with severe disabilities (Chapter 19). The current generation of readers have never known a world in which technology did not play a dominant role in day to day life, and technology tools are becoming more and more useful for persons with severe disabilities as well. Not only do we continue to see a wide variety of assistive technology devices, but we are now seeing a wide variety of apps designed and available for use on iPads or iPhones or iPods that can facilitate independent living and learning for many people with disabilities. We have attempted to present the most recent available information on these tools realizing that the reader will have access to information from various sources as new devices and tools appear.

The inclusion of students with severe disabilities begins as young children are first identified as eligible for intervention services provided through IDEA. During the early years, service and supports are delivered in the contexts of family, community, and early education programs. These early years are critically important to establishing the foundation for the child’s membership in community and learning trajectory. In this edition, we provide more guidance on the focus of early intervention services as they are provided in support of families and considerations for the inclusion of
young children within early care and education programs (Chapter 20). We have updated this chapter by providing principles for the provision of services and supports and guidance for universal design to create classrooms that can welcome and support young children with severe disabilities.

One certainty in the field of education is that students eventually grow up. And so the outcomes young people with severe disabilities attain after leaving high school offer a key marker of the success of educational services and supports. The knowledge base related to delivering effective transition education continues to grow rapidly. We have revised our information (Chapter 21) on transitioning to adulthood to reflect new developments and recommendations for supporting youth and their families as they approach life after high school.

**Acknowledgments**

As always, we would like to thank our friends and families, especially our spouses, for helping us once again to survive as we entered into the solitary world of textbook revision, 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. As with previous editions, 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 to support from our colleagues at Western Carolina University including Karena Cooper-Duffy, Kelly Kelley, Seb Prohn, and Cassie Coco; to our colleagues at the University of South Florida including Mario Hernandez, Glen Dunlap, and Don Kincaid (with special thanks to collaborative partners including Mary Louise Hemmeter, Barbara J. Smith, Patricia Snyder, and Phillip Strain); and to colleagues at Vanderbilt University including Alex da Fonte, Robert Hodapp, Elise McMillen, and to many exceptional graduate and undergraduate students. We are particularly grateful to the numerous educators, paraprofessionals, administrators, and families who have invited us into their classrooms, schools, and homes to learn alongside them about how best to educate students with severe disabilities. Thanks also to the reviewers for this edition: Brian Berry, Holy Family University; Mandy Rispoli, Texas A&M University; and Deborah E. Schadler, Gwynedd-Mercy College. Finally we would like to thank our editor at Pearson, Steve Dragin, for giving us the opportunity and guidance to move forward with this new edition; and also Katherine Wiley, editorial assistant at Pearson, for the support she provided.

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 for these persons often face challenges, 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.

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Part One

Important Considerations Prior to Teaching Persons with Severe Disabilities

Chapter 1
Students with Severe Disabilities: Definitions, Descriptions, Characteristics, and Potential

Chapter 2
Philosophies and Practices for Teaching Students with Severe Disabilities

Chapter 3
Collaboration among Professionals and Paraprofessionals

Chapter 4
Parents, Families, and Cultural Issues
Students with Severe Disabilities: Definitions, Descriptions, Characteristics, and Potential

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 potential of students with severe disabilities who are given appropriate forms of instruction and support.
Who Are People with Severe Disabilities?

The term severe disabilities implies a condition in which the development of typical abilities is in some way adversely affected. Unlike most other people, individuals with severe disabilities are often challenged by significant weaknesses in general learning abilities, personal and social skills, and/or sensory and physical development. The general ability to demonstrate the skills necessary to maintain oneself independently in typical life environments is reduced for persons with severe disabilities, and often the condition requires assistance and ongoing support from individuals without disabilities, including family members, friends, teachers, and professionals.

Traditional categories of persons usually referred to as having a severe disability include those who have been classified as having moderate, severe, or profound intellectual disabilities; those who have multiple disabilities, including physical or sensory disabilities as well as intellectual disabilities; and some who have autism spectrum disorders (ASDs).

TASH, an organization supporting “equity, opportunity and inclusion for people with disabilities” (formerly known as The Association for Persons with Severe Handicaps), described persons with severe disabilities in this way:

These people include individuals of all ages who require extensive ongoing support in more than one major life activity in order to participate in integrated community settings and to enjoy a quality of life that is available to citizens with fewer or no disabilities. Support may be required for life activities such as mobility, communication, self-care, and learning as necessary for independent living, employment and self-sufficiency. (Adopted by TASH, December 1985, revised November 1986; reprinted in Meyer, Peck, & Brown, 1991, p. 19)

Similarly, the American Association on Intellectual and Developmental Disabilities (AAIDD) characterizes an intellectual disability as a human manifestation in which different levels of support are required. According to the AAIDD: “Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18” (AAIDD, 2010, p. 1).

The AAIDD states five assumptions “essential” to the application of its definition:

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 disabilities generally will improve. (AAIDD, 2010, p. 1)

The theoretical model of intellectual disability (ID) developed by AAIDD (2010) has five dimensions: (1) intellectual abilities, (2) adaptive behavior, (3) health, (4) participation, and (5) context. These are mediated by a support system to affect an individual’s functioning. That is, the impact of all the dimensions on the individual is influenced by the support that buffers the person’s life. Furthermore, in a reciprocal manner, the functioning level of the individual may affect the supports that are required for successful functioning. The model implies that a person’s functioning is not due solely to characteristics of the individual, but also to the supportive context in which the person must operate. Thus AAIDD looks at intellectual disability not as a deficiency, but in terms of needed supports, similar to the concept presented by TASH.

Professionals have often found it useful to classify persons with an ID according to their level of intellectual development (Shapiro & Batshaw, 2013). Although the AAIDD eliminated categories of IDs based on levels of measured intelligence in 1992, these categories are still maintained in the American Psychiatric Association’s (APA) Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR, 2000) and are used in most school districts and in other
Important Considerations Prior to Teaching Persons with Severe Disabilities

Agencies and organizations. Commonly used levels of intellectual disability and their corresponding approximate IQ ranges include mild (50–70), moderate (35–50), severe (20–35), and profound (below 20–25). As noted previously, persons classified as having a moderate, severe, or profound level of intellectual disability are often considered to have a “severe” disability. Mild levels of intellectual disability are not usually categorized as severe.

Beyond IQ level or other characteristics, note that persons with severe disabilities are an extremely heterogeneous group with a diverse range of personal characteristics, abilities, strengths, and weaknesses (Giangreco, 2006). There is not a homogeneous population of students with severe disabilities. Instead, many individuals who may be characterized as having severe disabilities are, in fact, quite different from each other. With this caveat in mind, the following sections of this chapter provide more detail about the nature of severe disabilities by looking at the traditional categories and groupings of students with severe disabilities, and by examining significant characteristics that are displayed by many members of this population. There is a danger of negative stereotypes being associated with these descriptions; do not make assumptions about the potential of these individuals. These descriptions are not intended to be demeaning or derogatory, nor to overlook the many positive qualities possessed by people with severe disabilities.

Intellectual Disability: Categories and Syndromes

Moderate, Severe, and Profound Intellectual Disabilities

Persons referred to as having a moderate intellectual disability score above 35 to 40 and below 50 to 55 on traditional intelligence tests. Generally, individuals who fall within this classification are capable of learning many basic communication, self-help, academic, and domestic skills and can function adequately in many community and vocational environments. Many adults with a moderate intellectual disability are able to manage all their own daily self-care needs; prepare some foods for themselves and others; demonstrate adequate body control, including good gross and fine motor development; participate in common conversations; demonstrate some basic reading skills; interact cooperatively or competitively with others; make purchases in a grocery store; use money with fair accuracy; and carry out many occupational routines. An individual classified as moderately intellectually disabled might also be capable of self-initiation and show an ability to assume a degree of responsibility. Based on some concepts of severe disabilities, not all persons who have a moderate intellectual disability would be considered to have a severe disability as they may be able to function in various life areas without support.

Usually individuals have been classified as having a severe intellectual disability if their level of adaptive behavior is relatively lower than that described for persons with moderate intellectual disabilities and if their measured IQ is between 20 to 25 and 35 to 40. Ability examples of adults with severe intellectual disabilities include being able to eat adequately with a fork or spoon (but may need help with cutting); dressing and bathing with some supervision; using the toilet independently; and washing hands and face without help (but may have to be told or reminded to do so). The individual’s physical ability is generally good. He or she will usually not possess many academic skills, such as reading, but may be able to recognize some words and common signs or symbols. The person may know that money is of value, but may not be able to state the specific value of coins.

An individual diagnosed as having a profound intellectual disability falls within the most severe range of intellectual disability. Often these individuals are referred to as having “the most severe” disabilities or “significant disabilities” and have IQs below 20 to 25 points and developmental ages under 12 months on a standardized test of intelligence or on developmental scales. It is difficult to provide a typical profile of an individual with a profound intellectual disability because there is such an extreme degree of variability among the individuals so classified. Some persons are capable of relatively independent functioning in common self-care activities, such as eating and toileting, and may also possess functional skills in other domains of development, such as vocational and domestic skills. Others in this group do not speak, have very limiting sensory and motor impairments, are non-ambulatory, and tend not to be very attentive or...
responsive to environmental stimuli. Their physical disabilities often include quadriplegia, scoliosis, and bone malformations which often impairs their ability to sit, stand, or move without support and limits the use of their arms and hands (Petry & Maes, 2007).

Individuals with very severe or profound disabilities have sometimes been described according to their “behavior states” or alertness levels. These states include sleep states (asleep-inactive, asleep-active), indeterminate states (drowsy, daze), preferred awake states (awake inactive-alert, awake active-alert), and other awake states (awake-active/stereotypy, crying/agitated). Using these states, researchers have been able to develop individual profiles and have noted the consistency of state patterns of individuals across observations (Guess et al., 1988, 1990), although some persons have been shown to advance to higher behavior state levels as they get older (Guess, Roberts, & Rues, 2002). Researchers have suggested that further study of behavior states could lead to improved understanding of students with profound intellectual disabilities (e.g., Arthur-Kelly, Foreman, Bennett, & Pascoe, 2008; Roberts, Arthur-Kelly, Foreman, & Pascoe, 2005).

Most common causes of moderate, severe, and profound intellectual disabilities are biologically based, occurring between the time of conception and birth, and 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 problems. 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 a moderate, severe, or profound intellectual disability (Shapiro & Batshaw, 2013).

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 specific intellectual disability syndromes can help us understand relative strengths and weaknesses of individuals affected by the syndromes and may be useful in designing educational interventions (Di Nuovo & Buono, 2011; Fidler, Hodapp, & Dykens, 2002; Hodapp & Dykens, 2009). Please note that not all individuals who manifest the syndromes discussed below would be considered to have severe disabilities. Some may have mild intellectual disabilities or may even fall in the range of normal intelligence, although this would not be very common.

The reader interested in detailed information about certain syndromes should turn to more complete references on this topic (e.g., Batshaw, Roizen, & Lotrecchiano, 2013; Dykens, Hodapp, & Finucane, 2000). There is also information available on websites devoted to specific syndromes as well as the websites for government-sponsored organizations such as the Centers for Disease Control and Prevention (cdc.gov) or the National Institutes of Health (nih.gov).

Down Syndrome

Down syndrome (DS) is one of the most common syndromes associated with intellectual disability. It has an incidence of about 1 per 691 live births (National Down Syndrome Society, 2012). However, the risk of DS varies with the age of the mother, with older mothers at much greater risk. A woman giving birth at 20 years of age has only a 1 in 1,600 chance of having a child with DS, but a woman who is 45 years old has a 1 in 50 chance (Roizen, 2013). More than 90% of the time, DS occurs due to the presence of an extra chromosome 21 (trisomy 21). Children with DS are usually smaller than average and have slower physical, motor, language, and mental development. Some do not fall within the range of intellectual disabilities, but most are in the mild to moderate range and some are classified as severely intellectually disabled (Pueschel, 1992). Although, as Pueschel points out, persons with DS are like people without disabilities in many ways.
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. According to Roizen (2013), children with Down syndrome have an increased risk of abnormalities in almost every organ in the system. They often have congenital heart problems, disorders of the eyes, hearing loss, endocrine disorders, growth disorders, orthopedic disorders, and dental disorders.

Children with DS have language delays that become apparent between 18 months and 2 years of age, but receptive language is generally better than their expressive language. Although children with DS are often 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 a lesser extent, aggression; disobedience; and ADHD. About 10% of children with DS fall on the autism spectrum (Roizen, 2013).

Persons with DS 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 when compared to other persons with developmental delays (Fidler, Hodapp, & Dykens, 2002), but they may become more frustrated in difficult situations and have fewer coping strategies than other individuals with intellectual disability or those without disabilities (Jahromi, Gulsrud, & Kasari, 2008).

Fragile X Syndrome

In recent years, fragile X syndrome (FXS) 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 (Batshaw, Gropman, & Lanpher, 2013). The overall prevalence of FXS is estimated at approximately 1 in 4,000 males and 1 in 8,000 females (Schwarte, 2008). FXS 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. FXS is caused by an inactivation of the FMR1 gene that results in the loss of the fragile X mental retardation protein (FMRP), which is vital for learning and memory (Schwarte, 2008). Among boys who inherit this condition, about 80% will have intellectual disabilities ranging from mild to severe; girls are affected less often and usually their disabilities are mild learning disabilities or mild general intellectual disabilities (National Fragile X Foundation, 2012).

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

Learning is easier for persons with FXS when the whole task is presented at once, instead of teaching separate parts of a task. They are weak in communication and social skills, but relatively strong in daily living skills. They often have a delightful 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 (Schwarte, 2008). Price, Roberts, Vandergrift, and Martin (2007) found that boys with FXS had lower levels of language comprehension than typically developing boys, but higher levels than boys with Down syndrome.

These individuals 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 FXS are often considered similar to those who are classified as having ASD, and a significant percentage of individuals with FXS (as many as 25% to 30%) meet the diagnostic criteria for ASD (Schwarte, 2008). Individuals with FXS often benefit from a structured learning environment, with instructions that are concrete, clear, and accompanied by visual cues and prompts. Medication,
including stimulants and selective serotonin uptake inhibitors (SSRIs), has been used successfully to increase attention and decrease hyperactivity and to reduce anxiety and aggression (Schwarte, 2008).

**Fetal Alcohol Spectrum Disorders (FASDs)**

FASDs are a range of disorders that result from prenatal alcohol exposure. FASDs include fetal alcohol syndrome (FAS), which is the most serious condition on the spectrum, as well as alcohol-related neurodevelopmental disorders (ARNDs), and alcohol-related birth defects (ARBDs). According to the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC, 2011), FASDs form the largest class of birth impairments that can be 100% prevented by not drinking alcohol during pregnancy.

The CDC (2011) reports that FAS occurs in 0.2 to 1.5 per 1,000 live births in different areas of the United States and that other FASDs are thought to occur approximately three times as often as FAS. The diagnosis of FAS is defined by four criteria, according to the CDC: 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).

Wunsch, Conlon, and Scheidt (2001) note that although FAS and related conditions result from mothers consuming alcohol during pregnancy, the precise amount of alcohol consumption necessary to cause the condition is not known. Wunsch et al. also point out that it is difficult to isolate the influence of specific substances on fetal development, because often multiple influences are possible. However, Kodituwakku (2007) noted that some studies have shown that increased levels of alcohol consumption during pregnancy correlate with greater degrees of intellectual deficit, even when all FAS symptoms were not present.

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 problems 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 deficits in adaptive behavior may occur. Behavioral and emotional problems may also occur (Carpenter, 2011; Cone-Wesson, 2005; Kodituwakku, 2007; Wunsch et al., 2001). Based on an extensive review of research literature, Kodituwakku (2007) concluded that “the essence of the cognitive–behavioral phenotype associated with FASD can be defined as a generalized deficit in processing complex information” (p. 199).

**Prader–Willi Syndrome**

The most commonly recognized characteristics of individuals with Prader–Willi syndrome (PWS) are their propensity for overeating, low muscle tone, and obesity (Batshaw, Roizen, & Lotrecchiano, 2013; Scott, Smith, Hendricks, & Polloway, 1999; U.S. National Library of Medicine, 2012). In addition, they may exhibit obsessive-compulsive behavior and various other maladaptive behaviors that may become more serious during adolescence (Fidler et al., 2002; Steinhausen, Eiholzer, Hauffa, & Malin, 2004). Wigren and Hansen (2005) reported that some individuals with PWS also had characteristics of ADHD and an insistence on sameness. Efforts to inhibit their eating and access to food often spur temperamental outbursts by persons with PWS and they may also be stubborn and sometimes depressed (Scott et al., 1999).

PWS is not inherited, but is due to a chromosomal anomaly on chromosome number 15 and occurs in about 1 of every 10,000 births. Shortly after birth,
infants with PWS will show extreme hypotonia (weak muscle tone), a weak cry, poor sucking and swallowing, and little interest in food. Between ages 1 and 3 years, they will develop insatiable appetites, become very preoccupied with food, will 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 (Kundert, 2008; Scott et al., 1999).

The syndrome often results in a moderate intellectual disability, but measured IQs have ranged from 40 to over 100. In addition to being overweight, individuals with PWS are short, have small hands and feet, and have underdeveloped sexual organs. The child with PWS is likely to have delayed motor development and will walk later than most children. Speech and language problems are also common, with articulation often being noted as a problem (Scott et al., 1999). Fidler et al. (2002) noted that many children with PWS are weak on 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 preservation, stubbornness, obsessions, temper tantrums, and impulsivity (Kundert, 2008).

Intervention for individuals with PWS should focus on 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. It must be understood that weight management can be very challenging. Individuals with PWS 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. Weight gain is caused not only by overeating, but by a low metabolic rate, lethargy, and a low energy level. It is important to establish early control of food during the childhood years. Moderate exercises are also recommended. Because the individual typically has poor muscle tone and weak muscles, low-impact exercises such as walking, swimming, and jumping rope are recommended (Kundert, 2008; Prader–Willi Syndrome Association—USA, 2012).

**Angelman Syndrome**

Individuals with Angelman syndrome (AS) usually are severely to profoundly intellectually disabled. As with Prader–Willi syndrome, AS 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 1 in 10,000 and 20,000. Some characteristics of the syndrome include jerky body movements and stiff-legged walking. Individuals with AS 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 AS also have epilepsy (Williams, Peters, & Calculator, 2009).

Diagnosis of AS 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 (Walz, 2007).

In a review of 64 studies, Horsler and Oliver (2006) found that the following characteristics were most often identified among children with AS: laughing, feeding and eating problems, sleep disturbances, restlessness/hyperactivity/attention problems, excessive mouthing and chewing, hand flapping, attraction to water, aggression, and stereotyped behavior. Most often they are considered to be very sociable, happy, and affectionate (Williams et al., 2009). Although most people with AS 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 or devices (Williams et al., 2009).

**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...
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For example, a student may have severe to profound intellectual disability, be visually impaired, hearing impaired, and/or have a physical disability such as cerebral palsy. The term does not refer to a specific syndrome such as discussed above, but is a classification, like “intellectual disability” that is recognized under the Individuals with Disabilities Education Act. Virtually all individuals who have multiple disabilities would fall under the umbrella term “severe disabilities.”

Students with multiple disabilities usually have various health problems that complicate and worsen 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 (Heller, 2004; Thuppal & Sobsey, 2004).

Students with multiple disabilities are 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. Many times 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 the use of AAC systems (Kleinert, Holman, McSheehan & Kearns, 2010; Snell et al. 2010; Snell, Chen, & Hoover, 2006).

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 (Individuals with Disabilities Education Act, 1997, 34 CFR 300.7 (c) (2)). Compared to other disabilities, deaf-blindness is an extremely low-incidence disability. In 2010, there were only 9,612 public school age students in the United States who were classified as deaf-blind (National Consortium on Deaf-Blindness, 2011). Nevertheless, it is one of the most complex disabilities, and those who are classified as deaf-blind can show a great deal of variability in their conditions and the supports they require.

Most persons who are deaf-blind have some functional vision and/or hearing, and many are of average or above average intelligence, as was Helen Keller. In other words, not all persons classified as deaf-blind are considered to have a severe disability. 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.

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, often the child not only has 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 (Van Dijk, Janssen, & Nelson, 2001).

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 severe to profound intellectual disabilities, may show higher ability levels with some intellectual disabilities, or may develop without intellectual disabilities (Van Dijk et al., 2001).

Many causes of deaf-blindness cannot be readily identified, but several can. One of the best known is CHARGE syndrome, a congenital cause of deaf-blindness. Babies born with this condition have multiple physical and medical challenges, including heart abnormalities, breathing problems, and swallowing problems. Besides hearing and vision loss, they also have problems with balance, and significant delays in overall development and communication. CHARGE is often
caused by a mutation on chromosome number 8, which occurs new within the child (is not detected within the parents) (CHARGE Syndrome Foundation, 2012).

Another commonly identifiable cause of deaf–blindness is Usher syndrome, considered to be an acquired cause of deaf–blindness because complete deaf–blindness does not occur until later in life. This syndrome is a genetically transmitted condition characterized by a hearing impairment at birth and the later development of retinitis pigmentosa, a disorder that causes a person’s vision to worsen over time. Usher syndrome does not generally lead to intellectual disabilities or severe disabilities as we have defined them. There are three types of Usher syndrome; type 1 and type 2 are the most common in the United States. In Usher syndrome type 1, the child is born with a profound hearing loss and often with a problem balancing. These children usually begin to lose their vision by the time they are 10. With type 2 Usher syndrome, children are born with a moderate to severe hearing loss, but with no balancing problem and the onset of vision loss is usually later, during the adolescent years (National Institute on Deafness and Other Communication Disorders, 2008).

There are important differences in persons who are congenitally deaf–blind, such as due to CHARGE syndrome, versus those who acquire deaf–blindness, such as due to Usher syndrome: Persons with congenital deaf–blindness often have more severe conditions. 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 (Van Dijk, 1985; Van Dijk et al., 2001). Individuals with congenital deaf–blindness are also more likely to have intellectual disabilities, mental illness, behavior disorders, and characteristics of ASD (Dammeyer, 2011). Dalby et al. (2009) found important differences between adults with congenital deaf–blindness and those who had become deaf–blind in later life. Persons in the congenital deaf–blind group had greater challenges in communication, social interactions, orientation and mobility, and activities of daily living. Those who had acquired deaf–blindness, often through aging, had more functional skills, but experienced greater loss of social interactions and, consequently, more loneliness.

It is not adequate 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 (Orelse, Sobsey, & Silberman, 2004). 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.

### Dual Diagnosis (Intellectual Disabilities and Mental Illness)

Intellectual disability is defined by the existence of reduced intellectual abilities and limited adaptive behavior that originates during the developmental period. Mental illness, on the other hand, is a medical condition that affects a person’s “thinking, feeling, mood, ability to relate to others and daily functioning” (National Alliance on Mental Illness [NAMI], 2011). When an individual with an ID experiences mental illness, this is often referred to as a “dual diagnosis.”

The cause of most psychiatric disorders among individuals with IDs is likely a complex interaction of biological (including genetic), environmental, and psychosocial factors (Robb, 2013). Although biological factors undoubtedly play a significant role, conditions such as family disturbances or social adversity have a greater impact on individuals with cognitive limitations because of their inability to understand the circumstances of the situation, weaker problem-solving abilities, greater need for support, and less ability to cope with stress.

According to Robb (2013) and Reiss (1993), various types of mental illness may affect people with intellectual disabilities. These include:

- **Anxiety disorders.** Anxiety disorders include generalized anxiety disorder, panic disorder, social phobia, obsessive–compulsive disorder (OCD), and post-traumatic stress disorder (PTSD). The prevalence of anxiety disorders may be as high as 25% among persons with intellectual disabilities. These disorders are
characterized by displays of emotional uneasiness, arousal, fear, and a need to escape.

- **Mood disorders.** Mood disorders include major depression and bipolar disorder. Symptoms of mood disorders can include sleep or appetite problems, noncompliance, social withdrawal, aggression, irritability, self-injury, or crying spells. It is estimated that 5% to 15% of persons with IDs are affected by mood disorders.

- **Psychotic disorders.** Psychotic disorders are characterized by changes in thinking and perceptions that are not linked to reality. Schizophrenia represents the most common psychotic disorder. Symptoms include delusions, hallucinations, and disorganized speech and behavior.

A major difficulty with the determination of mental illness among persons with intellectual disabilities is differentiating whether the problem observed is a function of the ID or if a mental illness exists. This is particularly true when the ID is more severe and the person lacks adequate communication abilities. If an individual does not have adequate verbal abilities to describe or explain his or her symptoms, interviews with family members and caregivers and careful observation are often required to reach a diagnosis of a particular psychiatric disorder. Standardized rating scales that indicate the occurrence of atypical behaviors, along with functional behavioral assessments, are useful for determining the behavioral patterns of the individual and then for developing an intervention plan. Interventions address both the developmental level of the individual and the specific psychiatric diagnosis. Comprehensive interventions may incorporate one or more forms of intervention, including an appropriate educational program, communication or language therapy, psychotherapy, behavioral intervention, and the use of different medications (Robb, 2013).

Several studies have found that individuals with IDs experience a higher rate of psychiatric disorders than do persons with typical development, but other studies have found that the prevalence is about the same as in the general population. Estimations of the prevalence of persons with dual diagnosis range from about 10% to 40% of persons with intellectual disabilities (Borthwick-Duffy & Eyman, 1990; Deb, Thomas, & Bright, 2001; Reiss, 1990, 1993). However, as noted above, diagnosing a mental illness in a person with an ID may sometimes be difficult; this fact will cause a variation in estimates of the prevalence. Individuals with an ID and mental illness form a very heterogeneous group, making an accurate identification very difficult (Robb, 2013). Furthermore, the methods used in epidemiological studies to determine prevalence also vary and thus can affect the reliability of the outcomes.

Robb (2013) stated that “children with intellectual disabilities have a 4–5 fold higher rate of psychiatric disorders and that higher rate does not diminish as the children grow into adolescence” (p. 524). However, when different or more stringent criteria and procedures are used, prevalence rates of mental illness among people with intellectual disabilities tend to be closer to rates found in the general population. For example, Deb et al. (2001) studied intellectual disabilities in adults between 16 and 64 years of age living in the community. The researchers first screened subjects using a quick, mini-assessment of their characteristics through a brief interview and found that 22.2% of them (20/90) met the criteria for having a psychiatric disorder. The screening was followed by a face-to-face assessment. This second assessment resulted in 14.2% (13/90) being classified as having a psychiatric disorder: 4.4% had schizophrenia, 2.2% had depressive disorder, 2.2% had generalized anxiety disorder, 4.4% phobic disorder, and 1% delusional disorder. It is important to note that Deb et al. excluded certain conditions from their list of psychiatric illnesses, including ADHD, behavior disorders, dementia, and personality disorder. It is also important to note that their subjects lived in the community as opposed to an institution, which is where many studies of mental illness among people with ID have occurred.

Deb et al. stated that their findings indicated the overall rate of mental illness in their sample was similar to that found in the general population, but the rates of schizophrenia and phobic disorders were significantly higher. They also found that increasing age and the presence of physical disability were significantly associated with the occurrence of psychiatric disorders. Others have reported that most persons who are dually diagnosed fall into the range of mild to moderate intellectual disabilities, are about equally male
and female, and come from different ethnic and racial backgrounds (Holden & Gitlesen, 2004; Reiss, 1993).

**Autism Spectrum Disorders**

Autism spectrum disorders (ASDs) are neurodevelopmental disorders characterized by impaired social reciprocity, atypical communication skills, and repetitive behaviors (Hyman & Levy, 2013). On the autism spectrum, the disorders vary in the nature and degree of their manifestation. The most recent prevalence estimate for individuals with ASD is 1 in 88 in the population (CDC, 2012). Some persons with ASD would not be considered to have a severe disability, but others would, primarily because of challenges they face in caring for their personal needs and interacting with other persons. ASD can be identified sometimes as young as 18 months, but more often between 2 and 3 years of age (National Institute of Mental Health [NIMH], 2012). Autism (also referred to as “autistic disorder” or “classical autism”) is the most common condition of ASD.

Besides autism, other forms of ASD (also referred to as Pervasive Developmental Disorders or PDD) have included Asperger’s syndrome, Rett syndrome, childhood disintegrative disorder, and “pervasive developmental disorder not otherwise specified” (PDD-NOS) (NIMH, 2012). However, these categories are changing. The forthcoming revision of the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM-5), will not include Rett syndrome and childhood disintegrative disorder as part of the spectrum. Hyman and Levy (2013) stated “Rett syndrome is now known to be one of a number of genetic syndromes that have a high risk for manifesting symptoms of ASD. Regarding childhood disintegrative disorder, it is not clear if this is a discrete entity or rather a term that has been used as a place holder for individuals with a neurodegenerative disorder with autistic features for which a specific genetic diagnosis has not yet been made” (p. 346).

The cause of autism and other ASDs is developmental brain abnormalities that are genetically based, although the precise genetic source is not known. It is also now assumed that environmental factors interact with genetic conditions to influence the occurrence of ASDs, although the environmental factors also are not clearly identified (Hyman & Levy, 2013; NIMH, 2012).

Only three medications taken by mothers when pregnant have been associated with the later occurrence of ASDs. Thalidomide was a drug used in the 1960s to control nausea in pregnant women and was later found to cause limb deficiencies. Some of these children also exhibited a high prevalence of ASDs. Additionally, high rates of ASD have been found to occur in children whose mothers used valproic acid (to control seizures) or mesoprostol (which may fail when used to induce early termination of pregnancy) (Hyman & Levy, 2013). Research has not supported other causes that have been speculated including infections, adverse nutrition, the environment, and vaccines containing thimerosal (Hyman & Levy, 2013; NIMH, 2012). Hyman and Levy (2013) stated, “No known environmental or chemical exposures have been associated with an increased risk of ASD to date” (p. 351), but they also state: “Although existing data do not implicate specific chemical agents, it is possible that substances to which mothers and newborns are exposed may affect brain development in a way that leads to ASDs in susceptible individuals. This needs to be further explored” (p. 351).

The predominant characteristics associated with autism are impaired social interactions and relations between the individual with autism and others. The person with autism often demonstrates weaknesses in communication, engages in repetitive behaviors (such as stereotypic or self-injurious behaviors), and has very narrow interests, limited imagination or play behavior, and ritualistic behaviors. Possible early indicators of autism include not babbling, pointing, or making meaningful gestures by 1 year of age; not speaking one word by 16 months; not combining two words by 2 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 (Hyman & Levy, 2013; National Research Council, 2001; NIMH, 2012; Wetherby & Prizant, 2000).

Many individuals who are diagnosed with autism are often considered to have a severe disability, but the range of abilities is broad, especially if considering all ASDs. Many individuals with ASD are considered
intellectually disabled (because of a low measured IQ), but some individuals with autism have average or above average intellectual abilities. In a report from the CDC (2009), estimates of persons with ASD who also had an intellectual disability ranged between 29% and 51%, averaging 41%. On tests of intelligence, children with autism tend to show difficulties in the areas of information processing, acquired knowledge, and using verbally mediated skills. Better performance tends to occur on skills that require less verbal ability such as block design, organization, and short-term memory. Persons with ASD also tend to not do well when applying concepts and generalizing skills (National Research Council, 2001).

Several studies have been conducted to examine the relationships between intelligence, adaptive behavior, functional skills, and other related conditions of persons with ASD. For example, Kraijer (2000) found that persons with intellectual disabilities and autism scored lower in the areas of communication, socialization, and maladaptive behavior than did persons with intellectual disabilities without autism. The two groups scored equally well in daily living skills and motor skills. Keen and Ward (2004) studied the occurrence of autism spectrum disorders during two separate years (1997 and 2001) in an industrial area of England. They found that the number of students with ASD doubled during that period of time and that students with higher functioning skills were being identified at later ages, often with a pre-identified condition of ADHD. The range of intellectual abilities they found were between moderate intellectual disability and above average intellectual ability, but only 27% fell into the range of intellectual disability. In a study of over 1,000 persons with “high functioning” autism, Kanne et al. (2011) found that there were deficits in adaptive behavior, especially in the areas of socialization, communication, and daily living skills. Interestingly, these deficits did not correlate with the severity of autism symptoms, but did correlate with intelligence measures. Further, the deficits in adaptive behavior, in relation to mental age, decreased with an increase in age. Kanne et al. stated: “…the trends are worrisome and pose important implications for intervention, as older school-age and adolescent individuals with ASD are presenting with greater deficits in their functional independence compared to younger school-age individuals, despite no difference in presenting autistic symptomatology or intellectual ability.” (p. 1016).

A severe lack of language development is often a characteristic of persons with autism. Research in this area has focused on two core communication deficits: joint attention and symbol use. 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 bye-bye, or demonstrating with actions), learning the meaning of words, and using objects functionally and symbolically. An early lack of joint attention is a predictor of a later lack of language development (National Research Council, 2001).

The vocal communications of persons with autism are varied. Those with the most severe degree of disability may not verbalize at all, although these are the minority. However, even those who do communicate 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.

Persons with autism also generally show 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 melody-like quality; or be high pitched. The speech that is produced may be stereotyped or repetitive, and the individual may use inappropriate parts of speech, saying, for example, “You go to the store?” when he means “I want to go to the store.” 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. Usually, persons with autism will not participate in conversations of normal length and quality and seem to be unable to “read” the social situation or participate actively in it.

Some persons who are diagnosed as having autism demonstrate 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 (National Research Council, 2001). Often such behaviors are viewed as having a communicative function, that is, they are used to convey a meaning that cannot be expressed in a more conventional manner. 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 autism. 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.

Individuals with autism often do not interact with others with the type and degree of emotionalism that typically occurs between two people. They appear to lack an awareness of the existence or the feelings of others and do not look to others for comfort during times of distress or discomfort. One explanation for this characteristic is called the theory of mind (Baron-Cohen, 1995; Frith, 1997). According to this theory, people with autism have difficulty understanding the perspective of other people, that is they have “mind blindness.” They do not understand that others have different plans, thoughts, and points of view. They also have difficulty understanding that others have beliefs, attitudes, and emotions. Furthermore, according to this theory, people with autism cannot comprehend that someone might not know the answer to a question and therefore they become upset when they ask a question that cannot be answered.

**Key Characteristics of Persons with Severe Disabilities**

The descriptions presented in the previous sections should clearly indicate that individuals with severe disabilities have diverse characteristics, abilities, and needs. This is true both within and between different traditional categories. However, some traits occur with relatively high frequency and these deserve close attention because understanding them will help us to better understand the needs of individuals with severe disabilities and how to address these needs.

**Learning Characteristics and Abilities**

While we must be careful not to over-generalize about individual skills and abilities, most persons classified as having severe disabilities have significantly more difficulty learning new skills and applying what they learn to real-life situations than do other individuals. They are weak in certain learning characteristics and abilities, which will result in more time being required to learn skills, more difficulty in learning more complex skills, and learning fewer skills overall as compared to others. While it must be stressed that it is possible for many skills to be learned, the number and types of skills will not be comparable to those learned by most individuals (Beirne-Smith, Patton, & Kim, 2006). By examining discrete characteristics and abilities, we may be able to develop better approaches for instruction and support.

Learning characteristics and abilities of persons with severe disabilities are related to intellectual levels, life experiences, and sensory and physiological conditions of individuals. As 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. Table 1–1 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.

### Table 1–1 Learning Characteristics and Abilities and Teaching Implications

<table>
<thead>
<tr>
<th>Learning Characteristic or Abilities</th>
<th>Teaching Implications</th>
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<tr>
<td><strong>Language Skills</strong></td>
<td>Many students can improve their communication skills, and many will do so using AAC devices. Many will require specific communication skills to be targeted on their IEPs, and many will require support by a speech/language pathologist (SLP).</td>
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<tr>
<td><strong>Attentional Ability</strong></td>
<td>Using visual highlighting, visual symbols, or other very apparent stimuli will better allow many students to focus on what is relevant. Color-coding is often useful. Students with ASD work better when visual symbols are used to direct them through routines.</td>
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<td><strong>Observational and Incidental Learning</strong></td>
<td>Many varied observational opportunities should be planned. Also, important skills should be taught through direct and systematic instruction. Goals and objectives must be stated, systematic instruction provided, and performance measures must be taken.</td>
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<td><strong>Memory</strong></td>
<td>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.</td>
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<td><strong>Skill Synthesis</strong></td>
<td>People with ID and with ASD will learn and operate better if skills are taught and practiced in relevant clusters. Although skills like reading and arithmetic may be taught separately, they may need to be re-taught together to be applied in unique situations.</td>
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<td><strong>Generalization</strong></td>
<td>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.</td>
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<td><strong>Self-Management</strong></td>
<td>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.</td>
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### 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. There are many who have relatively normal lives, replete with friends and social activities, while
others may have fewer social relations and more personal difficulties. Some personal problems experienced by persons with severe disabilities may be closely related to their limited intellectual development or to the nature of autism, their lack of knowledge about how to interact with others, or their physical development. But many of their personal–social challenges may also be explained by their learning history, environmental influences, and the attitudes of others in society.

The quality of a person’s life, especially a person with an ID or an ASD, is tied to the ability to engage in socially acceptable behavior and to interact with people in appropriate ways. Someone whose personal behavior is undesirable or offensive will have fewer friendships and other relationships, will participate in fewer social activities, and will be more isolated. They will be more likely placed in separate schools or classrooms, separate work environments, and more restrictive living arrangements, even though these are not desirable outcomes. 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. Table 1–2 presents some of the common personal–social characteristics of persons with severe disabilities and ways those characteristics can be improved.

### TABLE 1–2  Personal–Social Characteristics and Intervention Implications

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<th>Personal–Social Characteristics</th>
<th>Interventions</th>
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<tr>
<td><strong>Challenging Behaviors</strong></td>
<td>Positive Behavior Supports and Interventions (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 (Functional Behavior Assessments, FBA). Based on the results of the FBA, a Behavior Intervention Plan (BIP) is developed to remove conditions that trigger the behavior, teach more appropriate behavior (like communication skills), and reinforce appropriate behavior.</td>
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<td><strong>Friendships and Personal Relations</strong></td>
<td>Friendships and relationships for people with severe disabilities can be formed in the same way as they are for others. 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. Even if development is at first slow, there is a good chance it will occur.</td>
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<td><strong>Love and Sexuality</strong></td>
<td>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.</td>
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Chapter 1  Students with Severe Disabilities: Definitions, Descriptions, Characteristics, and Potential

Physical Characteristics

Students with severe disabilities typically have health care problems that are more frequent and severe than individuals without disabilities. Many times they have specific physical disabilities or health disorders concurrently with an ID and may be referred to as having multiple disabilities, as explained previously. The existence of health disorders has several implications. They may make mobility more difficult and thus threaten the opportunity to participate in activities and be part of a social network. They may interfere with a student's ability to stay focused, adding to 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. Worst of all, they may result in more isolation from other students, be a “turn off” for some students, and occasionally result in teasing, bullying, or other reprehensible behavior.

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

Table 1–3 lists some of the more common physical disabilities and health conditions associated with severe disabilities. More detailed information about most of these conditions can be found in Batshaw, Roizen, and Lotrecchiano (2013); Best, Heller, and Bigge (2010); and Orelove, Sobsey, and Silberman (2004) as well as on disability-specific websites.

In addition to the specific conditions described in Table 1–3, persons with severe disabilities may have various other physical problems. These may include recurring infections, growth impairments, bowel and bladder control problems, chronic constipation, partial or complete loss of hearing or visual ability, congenital

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<tr>
<th>Physical and Health Conditions</th>
<th>Teaching and Management Implications</th>
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<td>Cerebral Palsy (CP) is a neurological disorder resulting 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 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.</td>
<td>A student’s ability to physically engage in class activities will depend on the severity and extent of the CP. Many can participate, but some will require adaptations or accommodations. The PT and OT can help teachers design ways to include the student with CP in various learning activities. Sometimes it is assumed that the student with CP also has a severe intellectual disability. While this may be true in some cases, it would be a mistake for teachers to approach the student with this assumption. The motor limitations of students with CP often mask their intellectual ability.</td>
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<td>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. Although the tonic–clonic seizure is the most common among persons with severe disabilities who have seizures, other types may also occur including complex partial seizures and absence seizures. Epilepsy is one of the most common disorders of the nervous system.</td>
<td>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 5 minutes, the teacher should call for emergency assistance. The teacher should note when the seizure occurred and how long it lasted.</td>
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TABLE 1—3  Continued

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<th>Physical and Health Conditions</th>
<th>Teaching and Management Implications</th>
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<td><strong>Cardiovascular Disorders</strong> 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.</td>
<td>These conditions result in shortness of breath, fatigue, poor growth and development, chest pain, blueness of the lips and nail beds (cyanosis), fainting, chest deformity, and rapid heartbeat. 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.</td>
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<tr>
<td><strong>Respiratory Disorders</strong> such as asthma, bronchitis, apnea, bronchopulmonary dysplasia, cystic fibrosis, respiratory distress syndrome, and chronic colds, flu, or pneumonia may occur among persons with severe disabilities. Additionally, 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.</td>
<td>Some individuals who have severe disabilities and 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.</td>
</tr>
<tr>
<td><strong>Eating Problems</strong> 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.</td>
<td>Gastroesophageal (GE) 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.</td>
</tr>
<tr>
<td><strong>Spina Bifida and Hydrocephaly</strong> 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.</td>
<td>Spina bifida results in paralysis of the lower trunk. Besides lacking leg use, the person who has a myelomeningocele will 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.</td>
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</tbody>
</table>
limb malformations or absences, and juvenile rheumatoid arthritis. Like the other physical conditions discussed above, these present substantial challenges to persons with severe disabilities.

**Potential for Success by Persons with Severe Disabilities**

Despite their many challenges, persons with severe disabilities have the potential to have very meaningful, fulfilled lives. Parents, professionals, and advocates working together have made significant progress. From experience and research, we have learned that, given adequate opportunities, supports, and appropriate forms of instruction, many persons with severe disabilities can learn and participate in typical life activities. To conclude this chapter, consider four key areas where progress has been made and where there is clearly potential for more progress.

**Use of Adaptive Technology Devices to Improve Participation**

More and more studies demonstrate how technology can increase participation by persons with severe disabilities and improve their quality of life. In some cases these devices are allowing individuals to develop participation or communication skills, and in other cases they are facilitating learning new material. Assistive technology (AT) devices commonly used by students with severe disabilities include augmentative and alternative communication (AAC) devices to facilitate communication, and devices for daily living such as powered wheelchairs or scooters, or adaptive eating utensils, or toothbrushes. Additionally, more and more apps are also becoming available for iPods and iPads that allow these devices to function as effective AT devices (Shah, 2011).

Studies involving students with severe disabilities have demonstrated that AT devices can assist them in learning to communicate and control their environment. For example, Lancioni et al. (2002) taught two persons with profound intellectual disabilities and multiple disabilities to use simple hand movements to activate optic microswitches. Because of the extent of their disabilities, active participation by the participants in the study was very challenging. The researchers were looking for a way for the participants to engage in some voluntary movement in order that they might have more control over their own environment. Although they had little bodily control, they were able to move their hands intentionally. In the study, when they moved their hands purposefully to activate the optic microswitches, they received different forms of sensory or tactile positive reinforcement. The researchers found that the hand movements of the individuals increased when the stimulation devices were activated and reinforcement was delivered. This study demonstrated a possible way to increase student participation.

In another study, Cosbey and Johnston (2006) taught three children between 3 and 6 years of age with severe and multiple disabilities to use a single-switch voice output communication aid (VOCA) to gain access to a desired toy or to express social statements in a regular classroom. The researchers used physical prompts, a time delay strategy, and natural reinforcers to get the children to communicate using the VOCAs. Two children learned to activate the switch with their hands, and the third learned to turn her head to hit the switch with her cheek. The study not only demonstrated that the children could learn the responses to activate the VOCA, but that their peers without disabilities would respond to them when they did. The single-switch VOCAs proved to be a useful device for fostering social interactions between children with severe disabilities and those without severe disabilities.

Additional research has shown the utility of iPads and iPods for teaching functional skills such as work skills, transitioning, and pedestrian navigation (e.g., Cihak, Fahrenkrog, Ayres, & Smith, 2010; Kelley, Test, & Cooke, 2013; Van Laarhoven et al., 2009). In these studies, the devices are used to present the learners with visual and/or auditory cues that direct them through a series of steps so that they may perform a task independently. For example, Kelley, Test, and Cooke taught young adults with moderate intellectual disabilities to use picture cues presented on an iPod to learn to find their way around a college campus. The participants learned to click the iPod to see a picture of a landmark and the direction they should walk to the next landmark.
Improvement of Challenging Behavior

There may be no greater challenge for teachers and parents than that presented by students who exhibit challenging behavior. Students with severe disabilities, including students with ASD; moderate, severe, and profound intellectual disabilities; and multiple disabilities often exhibit challenging behavior including stereotypes, self-injury, non-compliance, and other inappropriate behaviors that cause stress within families, rejection by peers, and social isolation.

Although these problems are serious and extensive, we know more today about how to approach them than ever before. Researchers have developed an approach that has come to be known as positive behavior interventions and support (PBIS). PBIS stresses the need to conduct functional behavior assessments (FBAs), use “non-aversive” environmental interventions, and promote comprehensive changes in lifestyles and environments in order to achieve long-term changes (Carr et al., 2002; Horner et al., 1990). PBIS does not seek simply to eliminate undesirable behavior, but to achieve long-term change. This is achieved by using an FBA to develop a hypothesis (or hypotheses) about the behavior’s purpose 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. Many support it because it uses a non-aversive, comprehensive orientation, and is considered to be a humane approach to behavior change. However, there is also a strong body of evidence, primarily using ABA research methodology, that offers an empirical defense for many of the components of PBIS, especially the value of basing interventions on FBAs (e.g., Carr et al., 1999; Hanley, Iwata, & McCord, 2003; Pellios, Morren, Tesch, & Axelrod, 1999). For example, Carr et al. analyzed 109 research publications, which included 366 measured outcomes on 230 participants with intellectual disabilities 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 PBIS interventions were judged effective.

Inclusion in Regular Schools and Classrooms and Participation in the General Curriculum

Many students with severe disabilities have been successfully included in regular schools and classrooms. Through the support of administrators, teachers, and parents, many schools have provided necessary accommodations and supports so that students with severe disabilities can be considered valued members of schools and classrooms. The result has been that students with and without disabilities have benefited. Studies have shown that students with severe disabilities can benefit from inclusion in general education classrooms in several ways. They can become more attentive, develop better social and communication skills, become more socially accepted, and demonstrate academic progress (Fisher & Meyer, 2002; Foreman, Arthur-Kelly, Pascoe, & King, 2004; Ryndak, Morrison, & Sommerstein, 1999). Studies have also shown that students without disabilities can benefit from the presence of students with severe disabilities. Classmates of students with severe disabilities often find that spending time with their peers with disabilities improves their understanding of people with disabilities, improves their own self-concept, and improves their self-understanding. Furthermore, there is no evidence that having students with severe disabilities included in regular classrooms adversely affects grades or social behavior of students without disabilities (Carter, Hughes, Copeland & Breen, 2001; Cole, Waldron, & Majd, 2004; Hughes et al., 2001).

Although inclusion was initially considered an opportunity for improving social skills, research has also demonstrated that students with severe disabilities can meaningfully participate in the general curriculum and benefit from their participation. Today there is an expectation that students with severe disabilities will
learn the academic knowledge and skills outlined in the Common Core State Standards (Common Core State Standards Initiative, 2012). Research shows that, with appropriate accommodations, curriculum modifications, and systematic instructional methods, students with various, even multiple, disabilities can learn material in the general curriculum. Examples of research in this area have focused on teaching emergent literacy and literacy skills, including more complex reading skills (e.g., Baker, Spooner, Ahlgrim-Delzell, Flowers, & Browder, 2010; Downing, 2005, 2006; Erickson & Kopenhaver, 1995; Spooner, Rivera, Browder, Baker, & Salas, 2009); teaching math skills (Browder et al., 2012; Collins, Kleinert, & Land 2006); and teaching science (Cooper-Duffy & Perlmutter, 2006; Courtade, Spooner, & Browder, 2007; Courtade, Browder, Spooner, & Di Biase, 2010).

Living and Working in the Community

Besides experiencing success in regular classrooms and schools, research shows that people with severe disabilities are enjoying living in their own homes and communities and being accepted by other people. For the past 25 years, thanks to the Americans with Disabilities Act and the Olmstead decision, there has been a clear trend for persons with severe disabilities to live in smaller, more natural settings (Salmi, Scott, Webster, Larson, & Lakin, 2010). 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 their families or with other sources of support. Using Medicaid waiver funds, community-based organizations can provide services that let people with severe disabilities enjoy life like everyone else. One such organization, KFI Maine, provides “flexible supports to individuals to meet their unique needs while living in their own homes and apartments.” According to their website, “KFI’s supported living services are designed for people who require minimal assistance or those who require up to 24 hours of support each day. Areas of support provided may include shopping and cooking, budgeting, leisure time activity and friendship development, volunteerism and community participation, personal hygiene, etc.” (KFI Maine, 2012).

Persons with disabilities who are living in a community may develop true friendships, given appropriate circumstances and contexts. Pottie and Sumarah (2004) studied the relationships of four pairs of adult friends—each pair included an adult with intellectual disabilities and another without disabilities. The adults all lived together in a “caregiving community” where they “lived, worked, and shared their lives together” (Pottie & Sumarah, 2004, p. 56). In contrast to some research, they found that “friendships between persons with and without a developmental disability do occur and can be meaningful and reciprocal” (p. 63). They attributed this outcome to individuals making a choice to recognize strengths in others and to offer each other goodwill in the form of respect, concern, emotional and practical support, and affection. Although the friends could not offer each other the same types of “gifts,” they were able to develop meaningful relationships that continued for 7 to 15 years.

Many people with severe disabilities are also able to work in community jobs through either supported employment or customized employment (Callahan, 2009). Brown, Shiraga, and Kessler (2006) reported on the successful working experiences of 50 adults with significant disabilities who had been employed in integrated work settings for more than 20 years. At the time of the study, the adults were between the ages of 23 and 45 years and had various disabilities, including moderate to severe intellectual disabilities, cerebral palsy, behavioral challenges, and sensory–motor disabilities. They all needed assistance in every area of their daily lives, yet all had been working in integrated work settings—alongside co-workers without disabilities—from 2 months to 27 years. Most of the individuals who were studied worked primarily in office settings, with a smaller number in food service settings, and all were provided with the support of job coaches and the natural support of co-workers and employers. Brown et al. reported that along with their jobs in the community, most of the individuals also enjoyed community-based living arrangements and full social lives.
Conclusion

People with severe disabilities are a heterogeneous population that has traditionally been described based on various categories of disability. Regardless of the categorical placement, these individuals differ from one another just as much as any two people without disabilities differ—perhaps even more. This variability makes it difficult to draw many general truths about people with severe disabilities. Nevertheless, certain characteristics and conditions seem to describe their strengths and weaknesses, although the specific needs of individuals can only be individually determined. Knowing the challenges experienced by people with severe disabilities makes it possible to develop better ways to provide instruction and support, and to evaluate the effectiveness of these approaches. An understanding of some problems that individuals with disabilities face when interacting with others as well as when they are alone, guides efforts to encourage the individuals with disabilities as well as more typical members of society to improve their behavior and accept each other with mutual respect. And an awareness of the many physical conditions that challenge persons with severe disabilities enables professionals and general members of the community to assist them with their needs and find ways for them to have a fuller degree of participation and a better quality of life.

Prior to the past 40 years, most people with severe disabilities were, in fact, denied the opportunity to participate in the world. They resided in institutions or were segregated in separate schools. But today in the United States and many other parts of the world, these conditions are rapidly changing. The past 20 to 25 years have seen tremendous advances in the knowledge regarding people with severe disabilities and how to educate them and assist them in learning to live. The supportive community is now better equipped to improve their functioning in many areas, which offers a hope, if not a promise, that their lives will be better today and tomorrow than were the lives of persons with severe disabilities in years past.

Questions for Reflection

1. Because people with severe disabilities are unique persons, is it appropriate to group them all together under one label? Why or why not?

2. Does the most recent definition of intellectual disabilities by the American Association on Intellectual and Developmental Disabilities improve the concept of this condition or make it more difficult to understand?

3. Given the learning characteristics and abilities shared by many people with severe disabilities, what would be one way to improve their learning potential?

4. Many people with severe disabilities have significant physical or health problems. Should we assume that people with very severe physical disabilities also have cognitive disabilities?

5. Unfortunately, some people with severe disabilities have relatively few friends. What could be done to improve this situation?

6. Research shows that individuals with severe disabilities have much more potential for learning than was previously thought. What additional areas of research might be important, if you were planning to expand this knowledge?
This chapter presents different philosophies for educating students with severe disabilities and how those philosophies have been implemented. While the philosophies overlap in some areas, in other ways they diverge. At the conclusion of this chapter we offer our own definition of special education for students with severe disabilities.
When considering the nature of appropriate educational services for students with severe disabilities, it should be done in light of the type of life we as a society believe they should have. Looking back through history, it is clear 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 their quality of life. This is the background for examining how philosophies and practices have emerged.

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. 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. 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 the gene pool of society. Beginning with the turn of the century, then, the guiding philosophy was not to teach and not 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 began to receive public school services. This first occurred when Public Law (P.L.) 94-142 (now called the Individuals with Disabilities Education Act, IDEA) was passed in 1975, mandating 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 an ability-level philosophy. Students’ developmental levels (mental ages, IQs, social quotients) were determined, 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, preacademic and primary-level academic skills, language development, self-care skills, gross and fine motor skills, and prevocational skills. Regardless of the students’ ages, most classrooms resembled kindergarten or nursery school classes.

When programs were developed for students with the most severe intellectual disabilities, instructional programming was intended to inch them forward on scales of normal human development. 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 step in typical 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 the student’s life.

Precursors to Modern Practices

More current practices for providing services to persons with severe disabilities evolved from different sources of influence. During the late 1960s, the concept
of *normalization* was introduced (Nirje, 1969, 1972; Wolfensberger, 1972). This policy called for agencies to provide persons with intellectual disabilities with living and learning experiences that were as normal as possible. Skills to be taught were those that would allow greater independence and life patterns that were like those of people without disabilities. Under the normalization principle, it was intended that the instructional procedures for teaching these skills also were to be as close to normal as possible.

At about the same time, the *deinstitutionalization* period began. This period was characterized by a decline in the number of persons with intellectual disabilities living in large residential institutions and an increase in the number living with their families and in smaller community-based residences. Efforts were made by states to move individuals out of large institutions into smaller facilities located in regular communities (foster homes, group homes, intermediate-care facilities, and sheltered apartments).

As normalization and deinstitutionalization were occurring and public school programs were emerging, the focus gradually began to shift from simply providing services to improving the quality of instruction and related services. Many educational programs lagged behind the philosophies of normalization and deinstitutionalization. Students were *not* being educated for lives that were to be as normal as possible or for living with their families and in their own communities. Often they were being taught activities that would be of no use to them and in the worst cases, teachers were simply providing baby-sitting or custodial care and not teaching anything at all.

The question of the value and relevance of much special education was first raised in the 1960s about special education for students with mild intellectual disabilities. Lloyd Dunn (1968), a prominent professor of special education, wrote that too many minority children were being placed in self-contained special classes for students with mild intellectual disabilities. Dunn proposed that many of these students should not be considered intellectually disabled, that general education should be able to serve them, and that much of special education was not justifiable. Following Dunn’s paper, special education programs and related practices for students with mild intellectual disabilities started to change. But similar concerns about the practices of educating students with more severe disabilities did not begin to surface until a few years later, after the passage of P.L. 94-142.

### Curricular Philosophies

Approaches to educating individuals with severe disabilities have changed dramatically over the past several decades, and they are still changing today. Three discernible themes have emerged, each with clusters of recommended practices. The first to evolve was the call to include persons with severe disabilities in the mainstream of life and to teach them functional, practical, and chronologically age-appropriate skills so that they could be more successful in that mainstream (Brown, Nietupski, & Hamre-Nietupski, 1976). The *inclusion/functional instruction* approach has continued until the present and forms the basis for many of today’s practices.

The second theme, *self-determination*, came to the forefront in the early 1990s and had at its core improving the abilities of people with intellectual disabilities to have greater control over their own 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 disabilities (Wehmeyer, 1992).

The third and most recent development, spurred by school reform movements and the 1997 and 2004 amendments to IDEA, is *participation in the general curriculum*. It is meant to allow students with severe disabilities an opportunity to participate in the general academic curriculum in a meaningful way. As part of this process, students with severe disabilities are also required to be included in state-wide accountability evaluations through the use of alternate assessments (Browder & Spooner, 2003; Browder, Spooner, Wakeman, Trela, & Baker, 2006; Spooner & Browder, 2006; Spooner, Dymond, Smith, & Kennedy, 2006). The details and implications of the three philosophical themes are described in the following sections.
Inclusion and Functional Instruction

In the mid-1970s, Brown et al. (1976), among others, proposed an educational model for students with severe disabilities 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 the exclusive use of grouping students homogeneously 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. also promoted the use of direct instruction and said that students with severe disabilities should be taught in the settings in which they need to be able to perform particular skills. 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). Brown et al. also promoted the idea that teaching procedures for students with severe disabilities should be natural. They proposed that skills should be learned and practiced in different settings, with different people, and under different conditions so that the learner would be able to use the skills in natural settings.

Over a span of almost 40 years, the inclusion/functional instruction model has been supported and defended by many authorities (e.g., B. Ayres, Meyer, Erevelles, & Park-Lee, 1994; K. Ayres, Douglas, Lowrey, & Sievers, 2011; Billingsley & Albertson, 1999; Certo, Haring, & York, 1984; Downing & Eichinger, 2002, 2003; Ford, Davern, & Schnorr, 2001; Ford et al., 1989; Fox et al., 1986; Horner, Meyer, & Fredericks, 1986; McDonnell, Hardman, & McDonnell, 2002; Meyer, Eichinger, & Park-Lee, 1987; Rainforth & York-Barr, 1997; Sailor et al., 1989; Salisbury & Vincent, 1990; Snell, 1988; Strain, 1990; Williams, Fox, Thousand, & Fox, 1990). Recently Brown and Ahlgren (2012) re-emphasized the importance of its tenets. The features and implications of the inclusion/functional instruction philosophy are highlighted in Table 2–1.

<table>
<thead>
<tr>
<th>Feature</th>
<th>Implications</th>
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| 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 in order 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 will allow students to participate in the general curriculum  
- Out-of-classroom instruction, such as community-based instruction (CBI), should include students without disabilities  
- General and special educators should collaborate in planning and teaching; students with disabilities do not “belong” to the special education teacher |
### Feature Implications

<table>
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<tr>
<th>Feature</th>
<th>Implications</th>
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<tbody>
<tr>
<td><strong>Friendships and relationships between students with and without disabilities should be encouraged.</strong></td>
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<tr>
<td>Paraprofessionals should not be overused and should not be used to isolate students in the classroom</td>
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<tr>
<td>Adequate planning time should be allocated for teachers and related services professionals to work together</td>
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<tr>
<th><strong>Social Participation</strong></th>
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<td>Social participation and engagement should be encouraged in the school, the home, and throughout the community including in vocational settings</td>
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<tr>
<td>Appropriate social skills should be targeted for instruction on the IEP; inappropriate social behavior should be replaced with appropriate behavior</td>
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<td>Social behavior should be incidentally taught whenever there is an opportunity to do so</td>
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<tr>
<td>Individuals without disabilities should model, prompt, and reinforce appropriate social behavior</td>
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<tr>
<td>Standards of appropriate social behavior should be enforced for students with disabilities</td>
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<tr>
<td>Efforts should be made to increase the quantity and quality of social behavior</td>
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<tr>
<th><strong>Functional Age-Appropriate Skills</strong></th>
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<td>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</td>
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<tr>
<td>Instruction on skills should be embedded in the general curriculum and taught throughout the day as integrated skill clusters, not in isolated trials</td>
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<tr>
<td>Skills should focus on increasing participation and making the individual more independent and/or less dependent and less isolated</td>
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<td>Meaningful partial participation should be encouraged if students cannot participate fully</td>
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<tr>
<td>Systematic instruction should be used to teach the most important skills (those on the IEP) and behavioral data should be used to monitor progress</td>
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<tr>
<td>Functional skills should be maintained over time and should be generalized to appropriate settings and conditions</td>
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<tr>
<td>Natural materials and actual settings should be used during instruction of many key skills; artificial materials and settings may impede generalization</td>
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<tr>
<td>Language and communication, motor skills, mobility, and social skills should be embedded in the instruction of functional skills</td>
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<th><strong>Non-school, Community-Based Instruction (CBI)</strong></th>
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<tr>
<td>Instruction outside school contexts is necessary in order that functional and age-appropriate skills can be learned and generalized to natural settings</td>
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<td>The student and his parents or family should be involved in identifying community settings for instruction</td>
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<tr>
<td>Whenever possible, peers without disabilities should be involved in non-school instruction</td>
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<tr>
<td>Instruction should occur in multiple community settings to meet individual objectives and help achieve generalization</td>
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<tr>
<td>Teaching community skills in simulated settings or using video-based instruction can be helpful, but is not sufficient to achieve generalization</td>
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<tr>
<td>Ecological inventories can identify skills necessary for operating in different community settings</td>
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<tr>
<td>CBI will become more important as the student gets older, but may also be appropriate for younger students although the targeted skills may differ</td>
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<tr>
<td>Data should be maintained to determine if adequate learning has occurred</td>
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<td>CBI is not the same as going on a field trip; it is an instructional activity during which specific skills should be taught</td>
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As a testament to the effectiveness of the inclusion/functional curriculum model and to the preparation of 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 jobs in community settings, some for over 20 years. They pointed out the vocational and social successes of these individuals and concluded their paper by writing, “Those who opposed allowing opportunities for integrated vocational experiences in the 1970s and 1980s and predicted failure and harm were wrong. Those who oppose integration today are even more wrong because we now have an increasing body of evidence that, given authentic instruction and reasonable long-term and personalized support, individuals with significant disabilities can be engaged successfully and safely in integrated vocational settings over long periods” (p. 119).

Self-Determination

The importance of self-determination as an educational outcome had its origins in the normalization movement and is related to other social trends 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, is concerned with gaining concrete benefits and opportunities in society, such as equal employment opportunities and the right to be integrated as full members of society (Ward, 1996).

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 life-long 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**: a belief 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**: the individual has 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 thus lead to self-determination, important life experiences are necessary. Wehmeyer (1996) referred to these critical experiences as component elements of self-determined behavior. They include the following:

- 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

Research has led to a number of important findings about self-determination. For example:

- Not all students with intellectual disabilities have had sufficient experiences to develop the necessary psychological characteristics for self-determination. (Wehmeyer, 1994)
- Individuals with intellectual disabilities who have higher levels of self-determination also have higher measures of autonomy, self-awareness, self-regulation, and locus of control. (Wehmeyer et al., 1996)
- Very often persons with intellectual disabilities have little say in basic life events, even though decisions about these events directly affect their quality of life. (Wehmeyer & Metzler, 1995)
• Individuals with intellectual disabilities with more self-determination have a greater desire to leave home, are more likely to have jobs, and are more likely to maintain savings and checking accounts. (Wehmeyer & Schwartz, 1997)
• Many parents, teachers, and paraprofessionals do not have the knowledge, skills, or attitudes to actively promote the development of self-determination skills among students with intellectual disabilities. (Carter, Owens et al., 2009; Carter, Sisco et al., 2011; Wehmeyer, Agran, & Hughes, 2000)

Proponents of self-determination maintain that because of such findings, it is important that teachers, parents, and others use strategies to enhance the development of self-determination skills (Agran, King-Sears, Wehmeyer, & Copeland, 2003; Brotherson, Cook, Cunconan-Lahr, & Wehmeyer, 1995; Brown & Cohen, 1996; Doll, Sands, Wehmeyer, & Palmer, 1996; Reid, Parsons, Green, & Browning, 2001; Sands & Wehmeyer, 1996). Table 2–2 summarizes some strategies recommended by Doll et al. (1996) that may be employed at different stages.

### Table 2–2 Strategies to Improve Self-Determination

<table>
<thead>
<tr>
<th>Life Stage</th>
<th>Self-Determination Strategies</th>
</tr>
</thead>
</table>
| Early Childhood (Ages 2 to 5) | • Teach the child to recognize personal preferences and be aware of alternative options; let him or her pick between two alternatives.  
• Teach the child that 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 to 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 to 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 so 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. |
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 to 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. Even though they could not talk, their preference was clearly expressed.

Doll et al. (1996) stressed that, although we cannot always know how well individuals with very severe intellectual disabilities can exercise self-determination, often the greater problem is with the opportunity and support for self-determination, more than the person’s ability. Likewise, Brown and Cohen (1996) suggested that often teachers develop instructional objectives that focus more on the student responding to the teacher than on responding to the situation based on a self-conducted analysis of the situation and the need to respond. When developing instructional goals and objectives, consideration should be given to this issue.

It is clear that individuals with the most significant disabilities will be less likely than other individuals to express their preferences, wants, or interests, at least in a traditional sense. There are two ways that this challenge can be addressed. In the first, individuals who are very close to the person with very severe intellectual disabilities, such as parents, siblings, and teachers, may determine their wishes through close, personal observation and an interpretation of their behavior (Brown, Gothelf, Guess, & Lehr, 1998). Those who make these determinations are in critical positions, because they may be more influenced by what they want for the person, than by what the person would determine for himself or herself. A primary way to undertake this approach is through the process of person-centered planning. Only by focusing on promoting self-determination to the extent appropriate

### Table 2–2

<table>
<thead>
<tr>
<th>Life Stage</th>
<th>Self-Determination Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Late Elementary</strong></td>
<td>• Encourage the child to set personal goals and to take actions to reach these goals, if possible; have them write down the goals and review them occasionally.</td>
</tr>
<tr>
<td>(Ages 9 to 11)</td>
<td>• Teach the child to change their opinions or behavior when they get new information.</td>
</tr>
<tr>
<td></td>
<td>• Help the child learn that sometimes extra effort will help him or her reach a goal.</td>
</tr>
<tr>
<td></td>
<td>• Show the child how others might react to his or her actions or activities; the use of visual displays like pictures may be helpful.</td>
</tr>
<tr>
<td></td>
<td>• 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.</td>
</tr>
<tr>
<td></td>
<td>• Support the child to undertake self-evaluation of completed tasks and what might be done to improve his or her performance.</td>
</tr>
<tr>
<td><strong>Secondary</strong></td>
<td>• Encourage the adolescent to think systematically and support his or her use of problem solving.</td>
</tr>
<tr>
<td>(Ages 12 to 18)</td>
<td>• Encourage students to be more rational and less emotional when dealing with challenging situations.</td>
</tr>
<tr>
<td></td>
<td>• Provide opportunities for students to make important decisions about their daily activities and about longer-term goals like diet, academics, and career possibilities.</td>
</tr>
<tr>
<td></td>
<td>• Encourage students to see the links between their daily decisions and their ability to achieve longer term goals.</td>
</tr>
<tr>
<td></td>
<td>• Help students to see how long-term goals can be broken down into smaller tasks that will ultimately lead to the goals.</td>
</tr>
<tr>
<td></td>
<td>• Help students to recognize their strengths and weaknesses and how to set and achieve goals in light of this information.</td>
</tr>
<tr>
<td></td>
<td>• Encourage students to recognize different sources of support and to seek it when necessary.</td>
</tr>
</tbody>
</table>
Chapter 2  Philosophies and Practices for Teaching Students with Severe Disabilities

within a context of interdependence might a person providing support also support self-determination (Brown et al., 1998).

A second approach to interpreting self-determination by persons with significant disabilities is through a preference assessment procedure. These procedures require closely observing the person’s positive and negative reactions as they are presented with different items and activities. These reactions allow the observer to determine items and events that are preferred and those that are not. Reid, Everson, and Green (1999) found that only some of the preferred leisure items that were identified in several person-centered planning processes were actually preferred by individuals with profound multiple disabilities when they were presented to them in a preference assessment procedure.

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. Below we consider some of the main tenets of this practice.

Why Participate in the General Curriculum?

For many years, some students with severe disabilities demonstrated the ability to learn basic academic 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. 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 why participation in the general curriculum became a dominant movement is because many special education professionals believed that students with severe disabilities would be better served if they were given the opportunity to engage in more traditional academic activities, such as literacy instruction and other areas of the general curriculum (Katims, 2000; Kliweer & Biklen, 2001; Kliweer & Linds, 1999; Ryndak, Morrison, & Sommerstein, 1999; Spooner & Browder, 2006; Spooner, Dymond et al., 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 (Agran, Alper, & Wehmeyer, 2002; Wehmeyer et al., 2001; Wehmeyer, 2006). Spooner, Dymond et al. (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)

What Is Taught in the General Curriculum?

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 most 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).

Relatively recent research has resulted in the development of promising practices for teaching students with severe disabilities in several academic areas. These include teaching emergent literacy, literacy, and more complex reading skills (Baker, Spooner, Ahlgrim-Delzell, Flowers, & Browder, 2010; Browder, Courtade-Little, Wakeman, & Rickelman, 2006; Browder, Wakeman, Spooner, Ahlgrim-Delzell, & Algozzine, 2006; Downing, 2005, 2006; Erickson & Kopenhaver, 1995; Spooner, Rivera, Browder, Baker, & Salas, 2009); math skills (Browder et al., 2012; Collins, Kleinert, & Land, 2006); and science knowledge (Cooper-Duffy & Perlmutter, 2006; Courtade, Spooner, & Browder, 2007; Courtade, Browder, Spooner, & Di Biase, 2010; Dymond et al., 2006; Spooner, Di Biase, & Courtade-Little, 2006).

**How Do Students Participate in the General Curriculum?**

In some cases students with severe disabilities may be able to adequately participate 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. Additionally, more specialized instructional methods may be used to better assure successful learning (Copeland & Cosbey, 2008; 2009). A number of planning and instructional strategies have been developed and demonstrated to allow students with severe disabilities to participate in the general curriculum. These are described briefly in Table 2–3.

**TABLE 2–3** Strategies for Participation in the General Curriculum

<table>
<thead>
<tr>
<th>Strategies</th>
<th>Implementation Descriptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developing curriculum extensions</td>
<td>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.</td>
</tr>
<tr>
<td>Using UDL principles to design</td>
<td>Universal Design for Learning (UDL) is a planning process that is meant to allow academic content be made 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 may maintain their engagement in the learning process.</td>
</tr>
<tr>
<td>curriculum</td>
<td></td>
</tr>
<tr>
<td>Using assistive technology</td>
<td>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.</td>
</tr>
</tbody>
</table>
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 that students with disabilities participate in annual statewide assessments. If the student has a disability that inhibits him or her from 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), for students with severe intellectual disabilities the most common type of alternate assessment used 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, 2012).

An AA-AAS may take different forms including portfolios, rating scales, and item-based tests (NCEO, 2012). 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.

Several studies have been conducted to determine the value of alternate assessments for students with severe disabilities. Turner et al. (2000) studied the relationship between student outcomes as assessed by Kentucky’s alternate portfolio assessment system, the quality of the students’ IEPs, and the quality of the services offered to the students within the schools. Their results implied that better school programs for students with severe disabilities will result in better outcomes for the students as reflected in their portfolio assessment scores. Roach (2006) found that parents in Wisconsin were generally supportive of the Wisconsin Alternate Assessment (WAA), a checklist assessment form that was used by teachers to report performance on skills related to the general curriculum as well as IEP skills. Flowers, Ahlgrim-Delzell, Browder, and Spooner (2005) reported that teachers spent an inordinate amount of time to complete the alternate assessments.
and many felt that the alternate assessment requirement competed with individual student needs. A minority of those questioned believed that the alternate assessment was associated with other benefits such as promoting self-determination, increasing access to the general curriculum, promoting communication between teachers and parents, increasing progress on IEP objectives, increasing the quality of the student’s education, or better preparing students for transition. Towles-Reeves, Klienert, and Anderson (2008) questioned principals about the value of alternate assessments and found they generally held positive views of them. Most of the principals agreed that these assessments increased grade level instruction, increased expectations of student performance, and resulted in more shared responsibilities between general educators and special educators.

**Concerns about Participation in the General Curriculum**

Spooner, Dymond et al. (2006) noted that there were “obstacles” related to students with severe disabilities participating in the general curriculum. These included (1) the lack of a clear definition of what constituted the general curriculum; (2) newly developing approaches to accessing the general curriculum that have not yet been evaluated with regard to acquiring and generalizing new skills; (3) recognition of the context in which access to the general curriculum should occur (through inclusion in general education classrooms or in separate courses that parallel the general curriculum); and, (4) the impact of participation in the general curriculum on post-school outcomes.

More intense criticism has been directed at this last point by Brown and Ahlgren (2012). They maintained that, given the learning characteristics of students with severe disabilities, more focus should be placed on teaching skills that will allow them to function with more independence as adults. They proposed the development of educational standards focused on developing functional skills and stated, “Our primary concern is to generate educational standards and practices that result in meaningful integrated post school outcomes” (p. 16).

**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 the focus is 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 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 as soon as a delay is observed until the child turns three. When the child turns three, he or she should begin participation in a preschool program. Since 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**

The effectiveness of services for students with severe disabilities will be maximized if professionals collaborate with each other, as well as with parents, in order to offer quality services. Professionals and parents should work on 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.
### TABLE 2–4  Key Components of Early Intervention and Preschool Programs

<table>
<thead>
<tr>
<th>Components</th>
<th>Descriptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early start</td>
<td>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.</td>
</tr>
<tr>
<td>Family centered</td>
<td>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.</td>
</tr>
<tr>
<td>Extended support system</td>
<td>In addition to family involvement, the extended family and other members of the family’s social network should be considered a part of the support system for the child.</td>
</tr>
<tr>
<td>Professional–Family relations</td>
<td>Professional assistance should be provided to buttress the natural system of family support, not to supplant it.</td>
</tr>
<tr>
<td>Developmentally appropriate</td>
<td>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 effectively influence what happens in their environment.</td>
</tr>
<tr>
<td>Progress assessments</td>
<td>Frequent assessment should occur, and learning activities should be planned as a result of these assessments.</td>
</tr>
<tr>
<td>Transition planning</td>
<td>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.</td>
</tr>
<tr>
<td>Program evaluation</td>
<td>Program evaluation should occur on a regular basis, with input from parents, teachers, and administrators on the satisfactory outcome of the program.</td>
</tr>
</tbody>
</table>

### TABLE 2–5  Key Components of Collaboration and Planning

<table>
<thead>
<tr>
<th>Components</th>
<th>Key Practices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Team representation</td>
<td>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.</td>
</tr>
<tr>
<td>Team awareness</td>
<td>Team members should be aware of the knowledge and expertise of each other. All disciplines should share knowledge and skills with all others to meet different needs and in different situations.</td>
</tr>
<tr>
<td>Decision making</td>
<td>Decisions are made through a consensus of the group based on the best information available to them.</td>
</tr>
<tr>
<td>Student focused</td>
<td>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.</td>
</tr>
</tbody>
</table>
TABLE 2–5  Continued

<table>
<thead>
<tr>
<th>Components</th>
<th>Key Practices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental involvement</td>
<td>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.</td>
</tr>
<tr>
<td>Communication</td>
<td>Parent–school communication is critical. Parents and professionals are a primary source of information for each other. Parents will often need information about school and community services that are available.</td>
</tr>
<tr>
<td>Holistic planning</td>
<td>When planning, consideration should be given to functioning in all life domains, including participating in the general curriculum and being involved in home, community, recreational, and work activities. Consideration should be given to planning for the future as well as the present.</td>
</tr>
<tr>
<td>Targeting specific skills</td>
<td>The student's needs and current skill level in different areas should prescribe specific skills that will be listed as objectives on the IEP.</td>
</tr>
<tr>
<td>Planning for transitions</td>
<td>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.</td>
</tr>
<tr>
<td>Planning for inclusion</td>
<td>Special focus should be on planning to move the student to an inclusive classroom or setting if he or she is not already there.</td>
</tr>
</tbody>
</table>

**Related Services**

Related services are those that students receive, in addition to instruction, that allow them to fully benefit 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 supplemental to those listed in Table 2–5.

**TABLE 2–6  Best Practices for Providing Related Services**

<table>
<thead>
<tr>
<th>Components</th>
<th>Best Practices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location of services</td>
<td>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 difficult tasks.</td>
</tr>
<tr>
<td>Therapy in the natural environment</td>
<td>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.</td>
</tr>
<tr>
<td>Integrating therapy</td>
<td>Therapy goals should be integrated into the student's other objectives, and vice versa. The more opportunity to practice a skill, the better is the chance for it to be learned sooner.</td>
</tr>
<tr>
<td>Sharing knowledge</td>
<td>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.</td>
</tr>
</tbody>
</table>
Best Practices for Teaching Individuals with ASD

Most of the practices 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 the unique characteristics of individuals with ASD, they have often been studied as a separate population and unique best practices for addressing their needs have been enumerated by various authors (Machalicek et al., 2008; National Autism Center, 2009; National Research Council, 2001; Odom, Boyd, Hall & Hume, 2010; Reichow, 2012). The following sections present programs, practices, and interventions that have been shown to be especially effective for students with ASD.

Programs Specifically for Persons with ASD

There are a number of educational or therapeutic programs, referred to as “Comprehensive Treatment Models” (CTMs) (Odom et al., 2010), that 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 impacted 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.

Focusing on the specific characteristics of effective programs, such as those listed above or others, reveals several important factors. Based on its review of 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....
- ...children should receive specialized instruction in settings in which ongoing interactions occur with typically developing children. (pp. 220–221)

Instructional Practices and Interventions

Besides looking at the effects of comprehensive programs, some researchers have examined instructional practices or interventions to determine their effectiveness for students with ASD. The National Autism Center (NAC, 2009) analyzed 775 studies in which various instructional practices or interventions were used to teach appropriate skills (academic skills, communication skills, self-regulation, etc.) or decrease challenging behaviors exhibited by individuals with ASDs (problem
behaviors, repetitive non-functional behaviors, etc.). In their analysis, the NAC included the scientific merit of each study (how well the study was conducted with regard to scientific rigor) and the effect of the study on the individual(s) in the study (how effectively the practice or intervention resulted in the development of new skills or decreased inappropriate behavior). Clustering together similar studies, the NAC rated each practice or intervention as “established,” “emerging,” “unestablished,” or “ineffective/harmful.” These “strength of evidence” categories were defined in this way:

- **Established.** Sufficient evidence is available to confidently determine that a treatment produces beneficial treatment effects for individuals on the autism spectrum. That is, these treatments are established as effective.
- **Emerging.** Although one or more studies suggest that a treatment produces beneficial treatment effects for individuals with ASD, additional high quality studies must consistently show this outcome before we can draw firm conclusions about treatment effectiveness.
- **Unestablished.** There is little or no evidence to allow us to draw firm conclusions about treatment effectiveness with individuals with ASD. Additional research may show the treatment to be effective, ineffective, or harmful.
- **Ineffective/Harmful.** Sufficient evidence is available to determine that a treatment is ineffective or harmful for individuals on the autism spectrum. (NAC, 2009, p. 32)

Table 2–7 lists classes of interventions found by the NAC to be “established,” the number of studies found to be in support of the intervention, and a brief description of the intervention. To review treatments falling into other categories, readers are encouraged to study the original report.

**TABLE 2–7 Effective Practices and Interventions for Individuals with ASDs**

<table>
<thead>
<tr>
<th>Practice or Intervention</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Antecedent Package</strong> (99 studies)</td>
<td>These interventions involve the modification of situational events that typically precede the occurrence of a target behavior. These alterations are made to increase the likelihood of success or reduce the likelihood of problems occurring. Treatments falling into this category reflect research representing the fields of applied behavior analysis (ABA), behavioral psychology, and positive behavior supports.</td>
</tr>
<tr>
<td><strong>Behavioral Package</strong> (231 studies)</td>
<td>These interventions are designed to reduce problem behavior and teach functional alternative behaviors or skills through the application of basic principles of behavior change. Treatments falling into this category reflect research representing the fields of applied behavior analysis, behavioral psychology, and positive behavior supports.</td>
</tr>
<tr>
<td><strong>Comprehensive Behavioral Treatment for Young Children</strong> (22 studies)</td>
<td>This treatment reflects research from comprehensive treatment programs that involve a combination of applied behavior analytic procedures (e.g., discrete trial, incidental teaching, etc.) that are delivered to young children (generally under the age of 8). These treatments may be delivered in a variety of settings (home, self-contained classroom, inclusive classroom, community) and involve a low student-to-teacher ratio (1:1).</td>
</tr>
<tr>
<td><strong>Joint Attention Intervention</strong> (6 studies)</td>
<td>These interventions involve building foundational skills involved in regulating the behaviors of others. Joint attention often involves teaching a child to respond to the nonverbal social bids of others or to initiate joint attention interactions. Examples include pointing to objects, showing items/activities to another person, and following eye gaze.</td>
</tr>
<tr>
<td><strong>Modeling</strong> (50 studies)</td>
<td>These interventions rely on an adult or peer providing a demonstration of the target behavior that should result in an imitation of the target behavior by the individual with ASD. Modeling can include simple and complex behaviors. This intervention is often combined with other strategies such as prompting and reinforcement. Examples include live modeling and video modeling.</td>
</tr>
<tr>
<td>Practice or Intervention</td>
<td>Description</td>
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<tr>
<td>Naturalistic Teaching Strategies (32 studies)</td>
<td>These interventions involve using primarily child-directed interactions to teach functional skills in the natural environment. These interventions often involve providing a stimulating environment, modeling how to play, encouraging conversation, providing choices and direct/natural reinforcers, and rewarding reasonable attempts. Examples of this type of approach include but are not limited to focused stimulation, incidental teaching, milieu teaching, embedded teaching, and responsive education and prelinguistic milieu teaching.</td>
</tr>
<tr>
<td>Peer Training Package (33 studies)</td>
<td>These interventions involve teaching children without disabilities strategies for facilitating play and social interactions with children on the autism spectrum. Peers may often include classmates or siblings. When both initiation training and peer training were components of treatment in a study, the study was coded as “peer training package.” These interventions may include components of other treatment packages (self-management for peers, prompting, reinforcement, etc.). Common names for intervention strategies include peer networks, circle of friends, buddy skills package, Integrated Play Groups™, peer initiation training, and peer-mediated social interactions.</td>
</tr>
<tr>
<td>Pivotal Response Treatment (14 studies)</td>
<td>This treatment is also referred to as PRT, Pivotal Response Teaching, and Pivotal Response Training. PRT focuses on targeting “pivotal” behavioral areas — such as motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues, with the development of these areas having the goal of very widespread and fluently integrated collateral improvements. Key aspects of PRT intervention delivery also focus on parent involvement in the intervention delivery, and on intervention in the natural environment such as homes and schools with the goal of producing naturalized behavioral improvements. This treatment is an expansion of the Natural Language Paradigm, which is also included in this category.</td>
</tr>
<tr>
<td>Schedules (12 studies)</td>
<td>These interventions involve the presentation of a task list that communicates a series of activities or steps required to complete a specific activity. Schedules are often supplemented by other interventions such as reinforcement. Schedules can take several forms including written words, pictures or photographs, or work stations.</td>
</tr>
<tr>
<td>Self-management (21 studies)</td>
<td>These interventions involve promoting independence by teaching individuals with ASD to regulate their behavior by recording the occurrence/non-occurrence of the target behavior, and securing reinforcement for doing so. Initial skills development may involve other strategies and may include the task of setting one’s own goals. In addition, reinforcement is a component of this intervention with the individual with ASD independently seeking and/or delivering reinforcers. Examples include the use of checklists (using checks, smiley/frowning faces), wrist counters, visual prompts, and tokens.</td>
</tr>
<tr>
<td>Story-based Intervention Package (21 studies)</td>
<td>These treatments involve a written description of the situations under which specific behaviors are expected to occur. Stories may be supplemented with additional components (prompting, reinforcement, discussion, etc.). Social Stories™ are the best-known story-based interventions and they seek to answer the “who,” “what,” “when,” “where,” and “why” in order to improve perspective-taking.</td>
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Philosophies and Practices for Teaching Students with Severe Disabilities: Where Do They Come From?

How does a particular philosophy or practice come to be considered appropriate, or desirable, whereas others do not? Why would professionals espouse one approach over another? And why are some educational approaches, even though accepted in the past, not supported by many people today? To answer these questions, this section examines four important influences: social values, legal requirements, professional consensus, and research-based evidence.

Social Values

The values of any society change with the passing of time. A major change that began to flourish in the last half of the 20th century is the value that our society places on the rights of the individual. Beginning in the 1950s and 1960s, significant positive changes in the course of U.S. society appeared. Civil rights legislation was passed, “separate but equal” schools for different races were ruled unconstitutional by the U.S. Supreme Court, and racial integration in society began to occur. Such changes as these, and many more, began and continued because the values of the society changed.

It is important to recognize this, because values related to the education and treatment of people with disabilities do not exist in a social vacuum. If the rights of minorities were not valued, the quality of education for persons with severe disabilities would not be where it is today. Although research has led to many important “evidenced-based” practices, Peck (1991) discussed the need for linking values and science in social policy decisions. Stated another way, the traditional reliance on research data should be supplemented by consideration for values. This is particularly promoted by organizations such as TASH (www.tash.org), which calls for “equity, opportunity and inclusion for people with disabilities.” Peck suggested that “knowledge gained through scientific research should affect and be affected by knowledge from other sources, including personal and cultural values” (p. 2).

To the extent that certain practices are in accord with the general values of society, they are likely to be considered best practices for educating persons with severe disabilities. Social values affect ideas such as students with disabilities having the right to attend public school and to do so in the least restrictive environment. If society did not hold such values, practices would likely be different, as they are in other parts of the world where such values are not held.

Legal Requirements

When a society strongly endorses certain values, those values often become the laws of that society. The laws of a democratic society, written by its legislative representatives, express the values of that society, and once values are placed into law, they are less likely to be affected by temporary whims of select individuals in that society. Since the 1970s a series of U.S. federal laws were passed that support many current practices affecting students with severe disabilities. Several of these laws and their requirements are highlighted in Table 2–8.

From time to time, the judiciary must interpret the laws so they can be carried out as intended, and these rulings, too, can affect educational and related practices. For example, in the recent case of H.H. v. Moffett and Chesterfield School Board, a federal circuit court ruled that the malicious restraint of a child with severe disabilities violated her freedom from undue restraint under the Fourteenth Amendment (Wrightslaw, 2012). This ruling will subsequently be considered in the future practices regarding restraints of students with severe disabilities. Other key rulings by the U.S. Supreme Court that have affected practices in special education include these:

- **Brown v. Bd of Education, 347 U. S. 483 (1954).** In this landmark decision, the Supreme Court found that segregated public schools are inherently unequal; this decision is relevant to children in segregated special education placements.
- **Irving Independent Sch. Dist. v. Amber Tatro, 468 U.S. 883 (1984).** The Supreme Court found that a medical treatment such as clean intermittent catheterization (CIC) is a related service under the Education for All Handicapped Children Act, and that the school is required to provide it.
## Table 2–8 Federal Laws Affecting the Education and Treatment of People with Severe Disabilities

<table>
<thead>
<tr>
<th>Federal Law</th>
<th>Major Components</th>
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<tbody>
<tr>
<td>P.L. 94-142: The Education for All Handicapped Children Act (1975)</td>
<td>• First law to give students with severe disabilities the right to a free, appropriate public education (FAPE)</td>
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<td>• The law required an Individual Education Program (IEP), related services, and education in the “least restrictive environment.”</td>
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<td>• It allowed parents the right to “due process” procedures if they disagreed with the school system about placement or other educational issues.</td>
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<td>P.L. 99-457: The Education of the Handicapped Act Amendments (1986)</td>
<td>• Extended the right to FAPE for children between 3 and 5 years</td>
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<td>• Created a discretionary <em>Handicapped Infants and Toddlers Program</em> that allowed states to provide service to children between birth and 2 years.</td>
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<td>• Key components of this service included an Individual Family Service Plan (IFSP), a multidisciplinary assessment of the child, a multidisciplinary early intervention program, and the use of case managers.</td>
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<tr>
<td>P.L. 101-336: Americans with Disabilities Act (ADA) of 1990 (1990)</td>
<td>• Persons with disabilities cannot be discriminated against in hiring practices and employers must make “reasonable accommodations” to help the person perform the job.</td>
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<td>• All new vehicles used for public transportation must be accessible.</td>
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<td></td>
<td>• Public buildings and public accommodations, such as hotels, restaurants, grocery stores, schools, and parks, must be accessible.</td>
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<tr>
<td>P.L. 101-476: The Individuals with Disabilities Education Act (IDEA) (1990)</td>
<td>• It changed the name of the law to “Individuals with Disabilities Education Act.”</td>
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<td>• Placed more emphasis on inclusion of students with severe disabilities.</td>
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<td>• Required that transition planning and services be included in the student’s IEP no later than age 16.</td>
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<tr>
<td>P.L. 105-17: Individuals with Disabilities Education Act Amendments of 1997 (1997)</td>
<td>• Required that students with disabilities participate in state-mandated assessments, including alternate assessments for students with severe disabilities.</td>
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<td>• Allowed parents to provide input about their child during the evaluation procedure.</td>
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<td>• Required greater participation in the general curriculum and in extracurricular and nonacademic activities for all students with disabilities.</td>
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<tr>
<td></td>
<td>• Required the use of positive behavior interventions and supports to improve any challenging behavior.</td>
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<td></td>
<td>• Required that transition planning begin at age 14 and that before age 21, students with disabilities must be informed of their rights as adults.</td>
</tr>
<tr>
<td>P.L. 108-446: Individuals with Disabilities Education Improvement Act of 2004 (2004)</td>
<td>• The major purpose of the revised law was to align it with the requirements of <em>No Child Left Behind</em>.</td>
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<td></td>
<td>• Required that alternate assessments test students with severe disabilities on academic content standards.</td>
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<td></td>
<td>• The IEP must include accommodations so the student can participate in the general curriculum.</td>
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<tr>
<td></td>
<td>• If a student exhibits challenging behavior that is a function of a disability, before a change in placement can be made a functional behavior assessment must be conducted and a positive behavior support plan must be implemented.</td>
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</table>
• *Florence Co. Sch Dist Four v. Shannon Carter*, 510 U.S. 7, (1993). In a unanimous 9–0 decision, the Supreme Court found that if the public school fails to provide an appropriate education and the child receives an appropriate education in a private placement, the parents are entitled to be reimbursed for the child’s education, even if the private school does not comply with state standards.

• *Winkelman v. Parma City School District* (2007). The Supreme Court ruled that parents may represent their children’s interests in special education cases, and are not required to hire a lawyer before going to court. The Court held that parents have legal rights under IDEA and can pursue IDEA claims on their own behalf, although they are not licensed attorneys (Wrightslaw, 2011).

**Opinions of Professionals and Others**

Beyond social values and legal requirements, many of the practices used for teaching students with severe disabilities are based on opinions expressed in survey research. Researchers have sought the opinions of teachers, teacher educators, individuals with disabilities, and parents of individuals with disabilities to guide the development of certain practices or to validate them. Over the years, survey research has been used to determine opinions about:

- Components of the inclusion/functional instruction model (B. Ayres et al., 1994; Meyer et al., 1987; Williams et al., 1990)
- Self-determination as a learning outcome (Wehmeyer, Agran, & Hughes, 2000)
- Participation in the general curriculum (Agran, Alper & Wehmeyer, 2002)
- Literacy instruction (Copeland, Keefe, Calhoon, Tanner, & Park, 2011; Ruppar, Dymond, & Gaffney, 2011)
- Participation in alternate assessments (Flowers et al., 2005; Roach, 2006)

Examining these studies leads to different conclusions about the practices discussed here and how well they are supported. For the most part, these practices have been favored by survey participants, but not in all cases. A few examples of the latter are worth noting.

Ayres et al. (1994) asked a sample of special education teachers who taught students with severe disabilities in regular schools to rate the importance of 79 “best practices” that largely reflected the inclusion/functional instruction model. The teachers who participated in the study were considered by their administrators to be excellent teachers. On separate 5-point scales, they were asked to indicate (1) their own knowledge or skill related to each best practice, (2) the degree of presence of the indicator within their program, and (3) the difficulty of implementing the practice. Ayres et al. reported that the teachers considered the best practice indicators to be largely within their skill repertoire, but the degree of their presence within a program was related to the degree of difficulty in implementing them. The two major factors that the teachers cited as hindering the implementation of best practices were insufficient time and inadequate administrative support.

In a survey of special education teachers conducted shortly after access to the general curriculum was mandated, Agran et al. (2002) found that most teachers were not supportive of their students participating in the general curriculum. Even though 81% of the teachers reported that their students were included in general education classrooms, 63% thought participation in the general curriculum was more important for students with mild disabilities, rather than those with severe disabilities. However, the reason for this finding by Agran et al. may have been that teachers were not adequately prepared to teach the content of the general curriculum. As noted in a later paper by Delano, Keefe, and Perner (2008–2009), “The current philosophy for educating students with extensive support needs is to provide meaningful access to both general curriculum and functional curriculum. When all teacher preparation programs reflect this, opportunities for best practices to occur will be present” (p. 233).

Besides the timing of a survey, we should note that other variables also may affect the opinions of survey participants. In a recent study, Ruppar et al. (2011) found that most teachers who participated in their survey supported literacy instruction for students with severe disabilities, but the level of their support varied with their employment setting. Teachers in integrated
schools were more supportive of literacy instruction than were those in segregated schools, and teachers working in inclusive classrooms were more supportive than those in special education classrooms.

In summary, some survey studies have supported some practices, others have not. The opportunity to engage in the practice, the preparation to do so, and the current teaching context may all affect how respondents feel about certain practices and how they value them.

**Evidence-Based Practices**

The final basis for arguing that a particular practice is valued is if evidence has been generated through research to demonstrate its effectiveness. Earlier, this chapter described the evaluation undertaken by the National Autism Center (2009) to determine effective treatment approaches for students with ASD. Although such an evaluation may sound like a straightforward process, it is complicated by several factors.

1. First, persons with severe disabilities are not a homogenous group in terms of their characteristics or abilities. Therefore, research that might demonstrate a practice is effective for one group of students might not be generalizable to another group.

2. Not all research is the same; purposes, methods, outcomes, and possible conclusions vary. To say that a practice is supported by research is insufficient; the assertion regarding level of support needs to be qualified with information on the type of research conducted and the context in which it was done.

3. There are some practices for which research is not ethically or practically possible. For example, it is not possible to test whether IEPs are of value because the law requires all students in special education to have IEPs.

4. A single research study, even one that is well designed, cannot lead to a definitive conclusion. Greater credence can be given to a practice if several different studies lead to the same conclusion.

5. To be of value it must be possible for the essence of the research treatment or intervention to be carried out in real-world settings. Practices that cannot or will not be implemented within schools by teachers will be of little value (Odom, Brantlinger, Gersten, Horner, Thompson, & Harris, 2005). Still, if the most effective practices for educating students with severe disabilities are to be identified, high-quality research must be conducted, interpreted, and applied.

Four types of research are commonly conducted in the field of special education for the development of evidence-based practices for students with severe disabilities. These are (1) group experimental and quasi-experimental studies, (2) correlational studies, (3) single-subject studies, and (4) qualitative studies (Odom et al., 2005). Each of these research methods is briefly described below.

Group experimental or quasi-experimental designs provide large groups of students (usually around 20 to 30 students per group) with different treatments or interventions (such as placement in regular classes or in special classes) for an extended period of time (such as 1 or 2 years), and then analyze quantifiable changes in the participants’ skills or abilities using valid and reliable pre-test and post-test assessments (Leary, 2008). In a true experimental design, randomized assignment of the participants to the different treatments, or randomized clinical trials, is employed so that any observed outcomes can be attributed to the treatment as opposed to various characteristics or incidental influences on the participants. This is considered to be the “gold standard” in scientific research. On the other hand, when randomized placements or assignments to conditions cannot occur, a quasi-experimental design will be used in which existing different placements or treatments are used. Although this is a less desirable design, the results will still have a degree of validity. Criteria for the use and evaluation of experimental and quasi-experimental research to create evidence-based practices have been discussed by Gersten, Fuchs, Compton, Coyne, Greenwood, and Innocenti (2005).

Correlational studies also use large numbers of individuals but are not considered experimental studies because the individuals are not separated into equivalent groups (randomly or non-randomly) and then treated differently. Instead, there is an examination of the relationship of two or more variables that exist within the group of individuals (Cohen, Cohen, West, & Aiken, 2002). For example, researchers might study the relationship between the (1) amount of time a group of
students with ASD receive physical exercise and (2) the amount of time they stay engaged in the classroom. Or a study might examine how two or more variables predict a third variable. The use of correlational studies as a basis for evidence-based practices in special education has been discussed by Thompson, Diamond, McWilliam, Snyder & Snyder (2005).

Single-subject researchers use experimental designs in which one or a few individuals are sequentially treated under systematically varied experimental conditions. Their behavior during these conditions is continuously and directly measured (Alberto & Troutman, 2009; Cooper, Heron, & Heward, 2007). For example, a researcher might study three individuals who engage in challenging behavior by looking at the number of times the behavior occurs within a 1-hour period each day. After teaching the students to sign when they want a break, the researcher would continue to measure the challenging behavior to see if it decreases. If a change in the participants occurs in a systematic manner that corresponds with the change in the treatment, the researcher could conclude that the treatment caused the change in the behavior. Horner, Carr, Halle, McGee, Odom, and Wolery (2005) provided guidelines for deciding if single-subject research can be used as a basis for evidence-based practice.

Finally, qualitative research (also called naturalistic or ethnographic research) may be used to identify practices that have value. As opposed to the previous types of research that analyze quantitative measures, a qualitative researcher or ethnographer examines naturally existing conditions and contexts in order to study a particular phenomenon. Typically the researcher spends a great deal of time observing and taking notes about what is seen, interviewing significant individuals, examining documents, and participating in daily activities as a participant–observer (Denzin & Lincoln, 2011). For example, if a researcher wanted to find ways by which special education teachers and general education teachers could collaborate effectively, then he or she might conduct a qualitative study to identify effective practices. Examples of qualitative studies that have produced important practices in special education and criteria for evaluating qualitative research have been reported by Brantlinger, Jimenez, Klingner, Pugach, and Richardson (2005).

Definition and Characteristics of Special Education for Students with Severe Disabilities

Special education for persons with severe disabilities consists of an instructional process by which students with intellectual, social, and sometimes physical limitations are able to maximize their potential in such a way that they can enjoy a quality of life and a level of self-determination similar to that enjoyed by persons who do not have disabilities. As a result of this process, these persons should be able to experience a life in their home and community very much like that experienced by others of the same chronological age. Special education is not made “special” by the nature of the instructional materials used or by being provided in special settings where the only other students also have severe disabilities. It is made special by the nature of the skills that are taught and the methods used to teach them. Special education should consist of the supportive educational programs necessary to best ensure that a student with severe disabilities lives a normal life and learns normal behaviors to the degree he or she is most capable.

Program Characteristics

A high-quality special education program should be characterized by the following 12 features:

1. Students should be treated with dignity. The language and the attitudes of the teachers and others should reflect the value of the students as human beings. The professionals and paraprofessionals providing services should respect the humanity of the individual students whom they are teaching. They should also believe in the value of teaching them.

2. Students should be allowed to determine for themselves as much as possible in accordance with their chronological age and life circumstance. They should be encouraged to make choices, self-regulate, and solve their own problems to the extent that they can.
3. There should be a pervasive attitude that all students are capable of learning meaningful skills that will move them away from dependence and toward independence, away from isolation and toward involvement.

4. All students should be involved in the normal routines and schedules of the school along with the students who do not have disabilities. Interactions with students who do not have disabilities should occur in normal patterns throughout the school day.

5. Meaningful learning activities should be planned, and each student should be working toward individually prescribed objectives within these activities. Effective accommodation should be used to allow the student to participate in the general curriculum, and real progress in the curriculum should be monitored. General curriculum and functional objectives should be taught that allow the student to participate as well as possible in all current environments and to be prepared for operating in future environments. Instruction directed toward the achievement of specific objectives should be distributed throughout the day in a natural fashion, not presented in an artificial, massed array.

6. Instruction should occur in the most natural and least restrictive settings, including regular classes to the extent possible, and in different settings within the school, community, and home. Placement in special classes should be avoided as much as possible.

7. Materials used and instructional activities should be natural. They should be items and activities used in everyday life and not materials especially designed for special education, with the exception of technologically sophisticated devices designed to assist in areas such as communication or mobility.

8. Instructional procedures should be as precise as necessary, yet as natural as possible. The procedures should be those that best ensure that learning will occur, but that show respect for the dignity of the individual and thus are not overly intrusive.

9. Student performance data on key, specific objectives should be collected on a regular basis in order to assess the student’s progress. End of year, end of grade, or other summative assessments required by state or local school districts should be valid and reliable, and should evaluate important skills that contribute to life quality.

10. Instruction should focus on skill acquisition, maintenance, and generalization. Targeted skills should not be checked off a checklist when completed, but should become a part of the repertoire of functional or academic skills possessed by the student. Whenever possible, evidence-based practices should be used in the instructional process.

11. Specific efforts to improve the knowledge and attitudes of other students and school employees toward people with severe disabilities should be made. Teachers should encourage students and other professionals, paraprofessionals, and nonprofessionals in the school to interact appropriately with students who have disabilities. Friendships between students with and without disabilities should be encouraged.

12. Parents should be acknowledged as the student’s primary teachers and should be included in the educational program to the degree that they wish. Most important, parents should be involved in the educational planning process.

Conclusion

During the past 20 to 25 years, research evidence has accumulated to support many of the practices discussed in this chapter. What has been learned from these areas of research has provided much of the information that will be presented throughout the rest of this text. Although there is apparently a substantial amount of research to support many of the practices that have been recommended, not all best practices are fully supported by research, nor would we expect them to be. Not all questions of social practice should be subjected to research. (Does allowing women to vote make the country a better place? Should minority individuals be free to live and work where they want?) The role of social science is probably better for the evaluation of social policy than for its invention (Peck, 1991). Thus, some practices included on our list and elsewhere may
not have evolved from research and, in fact, need not be subjected to research in order to provide a defense for them. Instead, the more appropriate role of research is to improve practices that are socially valued.

Our society has advanced to a point where there is relatively clear direction about what, when, where, and how to provide the best, most humane services to persons who have severe disabilities. Because this is an evolving field, additional practices need to be developed, given consideration, and perhaps added to those discussed here. The responsibility of current and future professionals, administrators, parents, and citizens is to work to improve the status quo and move forward to the implementation of the most appropriate instructional and related practices, not only for students with severe disabilities, but for all public school students. If this is achieved, the benefits will be realized not only by persons with severe disabilities, but by society as a whole. The remaining chapters of this text are devoted toward achieving this end.

**Questions for Reflection**

1. Of the instructional practices listed, which would you consider to be the most important? Why?
2. Why has self-determination come to be considered an important focus area for students with intellectual disabilities in recent years?
3. What are your views regarding participation by students with severe disabilities in the general curriculum? What are some effective ways to promote meaningful participation?
4. Do you disagree with any of the best practices discussed here? If so, which ones, and why do you disagree with them?
5. Could you suggest other important practices that should be included when providing services to people with severe disabilities?
6. What are the reactions of some professional educators to the practices discussed in this chapter? How about nonprofessionals?
7. Of the various ways by which we conclude that certain practices are preferred, which do you think is most important? Why?
8. From the point of view of a student with a severe disability, which of the practices described in this chapter would be considered most important?
9. What do you believe is the teacher’s role in implementing best practices?