

# chapter thirteen

## LEARNERS WITH LOW-INCIDENCE, MULTIPLE, AND SEVERE DISABILITIES



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### LEARNING OUTCOMES

**Learning Outcome 13.1:** Understand the most current definitions for and the prevalence of low-incidence, multiple, and severe disabilities.

**Learning Outcome 13.2:** Understand the definition, characteristics, prevalence, causes, and educational considerations associated with traumatic brain injury.

**Learning Outcome 13.3:** Understand the definition, prevalence, causes, psychological

and behavioral characteristics, and educational considerations associated with deaf-blindness.

**Learning Outcome 13.4:** Learn about educational considerations for many students with low-incidence, multiple, and severe disabilities (e.g., augmentative or alternative communication, dealing with behavior problems, early intervention, and transition to adulthood).

## MISCONCEPTIONS ABOUT

## Learners with Low-Incidence, Multiple, and Severe Disabilities

- MYTH** People with severe and multiple disabilities have problems so debilitating that the best they can hope for is employment in a sheltered workshop.
- FACT** With intensive and extensive instruction, many people with severe and multiple disabilities can now be employed in more integrated work settings.
- MYTH** People with severe and multiple disabilities have problems so debilitating that the best they can hope for is to live under close supervision in a large residential facility.
- FACT** With intensive and extensive instruction, many people with severe and multiple disabilities can now live independently or semi-independently by themselves or in a small community residential facility (CRF).
- MYTH** A person with traumatic brain injury (TBI) can be expected, with time, to recover completely and function without disabilities.
- FACT** Some people with TBI do recover completely, but many do not. Usually, a person with TBI has long-term disabilities that may be compensated for in many ways, but these disabilities don't ordinarily disappear completely, even with the best treatment and rehabilitation.
- MYTH** For students with Usher syndrome whose vision will deteriorate over time, it's best not to introduce braille and training with the long cane while their vision is still relatively good because to do so stigmatizes them.
- FACT** Braille and orientation and mobility training should not wait until the later stages of vision loss. Getting a head start on learning these complex skills almost always outweighs any stigmatization that might occur.
- MYTH** People who can't speak have extreme difficulty making themselves understood to others.
- FACT** With an appropriate augmentative or alternative communication (AAC) system, people who can't speak can carry on a normal conversation, sometimes very near the rate of speakers without disabilities. The flexibility, speed, and usefulness of communication with AAC systems are increasing rapidly with new technologies, and they now often allow a user to approximate typical verbal exchanges between speakers.
- MYTH** The only really effective way of controlling the undesirable behavior of people with severe and multiple disabilities is to use punishment.
- FACT** Functional behavioral assessment and positive behavioral supports are being used more frequently to replace undesirable behavior with desirable behavior—without the use of punishment. Often, the key is finding out what the person with severe and multiple disabilities is trying to communicate and helping him or her find a more effective, efficient way of communicating that to others.
- MYTH** Braille is only for people who are blind.
- FACT** It is helpful to teach braille to two groups of individuals who are not blind: (1) those who have visual impairments so severe that they can't read print reliably and (2) those whose condition will worsen with time to the point at which braille will be their only option.

## GUIDING QUESTIONS

- What is the definition of low-incidence, multiple, and severe disabilities, and what is the prevalence?
- What is traumatic brain injury, and how might it affect education?
- How is deaf-blindness defined, and what are the special educational problems it entails?
- What educational considerations apply to many students with low-incidence, multiple, and severe disabilities?

**T**he definition of low-incidence, severe, and multiple disabilities, like the definition of all other categories of disabilities, is controversial. Disabilities are particularly mystifying when they are seldom seen, multiple, or severe. The causes and meanings of such disabilities, and the life course of the people who have them, may be particularly difficult to understand.

## DEFINITION AND PREVALENCE

TASH (originally the Association for Persons with Severe Handicaps, then The Association for the Severely Handicapped, but now simply called TASH to avoid use of “handicapped” because some believe that the term is pejorative) is a major professional organization focused on individuals with severe disabilities. TASH defines a disability as “severe” if it results in the person needing ongoing support in more than one major life activity necessary to reside in the community and to enjoy a quality of life similar to that of members of the population without disabilities. Examples of life activities are such things as being able to communicate, engage in self-care, and learn skills to be employed and live in the community.

People with a severe disability in any area typically have more than one disability (Kauffman, Hallahan, Pullen, & Badar, 2018). Furthermore, a combination of mild disabilities may present severe educational problems (Kauffman, 2008). As noted in the Individuals with Disabilities Education Improvement Act of 2004 (IDEA): “Multiple disabilities means concomitant impairments . . . the combination of which causes such severe educational problems that they cannot be accommodated in special education programs solely for one of the impairments” (34 CFR, Sec. 300 (b)(6)). IDEA also states:

The term “children with severe disabilities” refers to children with disabilities who, because of the intensity of their physical, mental, or emotional problems, need highly specialized education, social, psychological, and medical services in order to maximize their full potential for useful and meaningful participation in society and for self-fulfillment. The term includes those children with severe emotional disturbance (including schizophrenia), autism, severe and profound mental retardation, and those who have two or more serious disabilities, such as deaf-blindness, mental retardation and blindness, and cerebral palsy and deafness.

Children with severe disabilities may experience severe speech, language, and/or perceptual-cognitive deprivations, and evidence abnormal behaviors, such as failure to respond to pronounced social stimuli, self-mutilation, self-stimulation, manifestation of intense and prolonged temper tantrums, and the absence of rudimentary forms of verbal control, and may also have intensely fragile physiological conditions. (34 CFR, Sec. 315.4(d))

Low-incidence, severe, and multiple disabilities are often linked conceptually. They occur in only a relatively small percentage of cases of disability (Bruce & Ivy, 2017). Furthermore, nearly any low-incidence, severe disability will involve extensive and ongoing

support in more than one major life activity. That is, low-incidence, severe, and multiple disabilities tend to go together. All of the low-incidence, severe, and multiple disabilities that we discuss in the chapter probably affect fewer than 1% of the population.

With these considerations in mind, in this chapter, we first discuss the categories and problems of traumatic brain injury and deaf-blindness. Then we discuss issues that apply to all categories of low-incidence, multiple, and severe disabilities: augmentative and alternative communication, behavior problems, early intervention, and transition to adulthood.

We mentioned severe and profound intellectual disability in Chapter 5 and discussed autism spectrum disorders in Chapter 9. However, much of what we present in this chapter applies to some individuals with autism and to those with severe or profound intellectual disability as well. Remember, though, that autism spectrum disorders can range from mild to severe, as is the case in all other categories of disability.

#### MyLab Education Self-Check 13.1

#### MyLab Education Application Exercise 13.1: Multiple Disabilities and Severe Disabilities

Review the definitions of *severe and profound intellectual disabilities* and *multiple disabilities* in your text, and then answer the questions in this exercise.

## TRAUMATIC BRAIN INJURY

Since 1990, when IDEA recognized the category of **traumatic brain injury (TBI)**, students with TBI have been eligible to be considered for special education and related services (Kauffman et al., 2018). Today, there is much greater understanding of the nature of TBI and the educational needs of students with TBI (e.g., <http://www.ninds.nih.gov/disorders/tbi/tbi.htm>). Unlike cerebral palsy, TBI is brain damage that is acquired by trauma after a period of normal neurological development. TBI is a life-altering experience that results in neurological, cognitive, and psychosocial consequences (Trenchard, Rust, & Bunton, 2013).

Historically, recognition and treatment of disabilities are often triggered by the return of injured soldiers to civilian life. Because TBI is one of the most common injuries of the wars in Iraq and Afghanistan, perhaps the public will become more aware of and demand better treatment of those with TBI. Additionally, the national media has highlighted the significance of TBI as it relates to athletes. The celebrity status of many NFL players who have developed TBI as a result of sports injuries is also increasing awareness of and demand for better efforts at prevention, as well as early diagnosis and treatment.

### Definition and Characteristics

Commonly accepted definitions of TBI specify the following:

1. There is injury to the brain caused by an external force.
2. The injury is not caused by a degenerative or congenital condition.
3. There is a diminished or altered state of consciousness.
4. Neurological or neurobehavioral dysfunction results from the injury.

Most definitions also specify that the injury be followed by impairments in abilities required for learning in school and everyday functioning.

TBI can result from two categories of injury: open or closed. **Open head injuries** involve a penetrating head wound from such causes as a fall, gunshot, assault, vehicular



#### MyLab Education Video Example 13.1

Meet Rebekah and listen to her story about her life after experiencing a traumatic brain injury.

accident, or surgery. Individuals with closed head injuries have no open head wound but may have brain damage caused by internal compression, stretching, or other shearing motion of neural tissues within the head. A common cause of closed head injuries is sporting and recreational accidents. For example, concussions in youth sports have received significant attention in recent years. For more information on such injuries read the Focus On Brain Injury in Athletics feature.

Soldiers have often acquired TBI as a result of improvised explosive devices (IEDs). They may experience either open head injuries, in which something penetrates the head or removes part of the brain, or closed head injuries, in which the concussive force of the explosion or the soldier's being thrown against an object damages the brain without creating an open wound. The effects of damage to the brain and the resulting symptoms can be severe with either type of injury.

The educational definition of TBI focuses on impairments in one or more areas important for learning. The federal (IDEA) definition of TBI states that it is

an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not apply to injuries that are congenital or degenerative, or brain injuries induced by birth trauma. (34 CFR, Sec. 300.7(6)(12))

The effects of TBI range from very mild to profound, and TBI is often a part of or accompanied by other medical issues (Best, Heller, & Bigge, 2010). Often, the effects are immediate, and these immediate effects set TBI apart from most other disabilities—the child or youth is literally changed overnight. The sudden change presents particular difficulties to families and teachers, not to mention the individual sustaining the injury (Ashley, 2004; McDonald, 2013). However, sometimes the effects of TBI are not seen immediately after the injury but appear months or even years afterward. The possible effects of TBI include a long list of learning and psychosocial problems, such as:

- Problems remembering things
- Problems learning new information
- Speech and/or language problems
- Difficulty sequencing things
- Difficulty in processing information (making sense of things)
- Extremely uneven abilities or performance (able to do some things but not others)
- Extremely uneven progress (quick gains sometimes, no gains other times)
- Inappropriate manners or mannerisms
- Failure to understand humor or social situations
- Becoming easily tired, frustrated, or angered
- Unreasonable fear or anxiety
- Irritability
- Sudden, exaggerated swings of mood
- Depression
- Aggression
- Perseveration (persistent repetition of one thought or behavior)

From the length and variety of this list, it's not begging the question to state that narrowing down the definition of TBI is virtually impossible. In fact, perhaps the distinguishing feature of TBI is that it defies a narrow definition, reinforcing the basic principle of special education individualization and the importance of individualized education programs (IEPs). Just a few examples from research document problems in working memory (Raghubar, Barnes, Prasad, Johnson, Ewing-Cobbs, 2013), social skills (Anderson et al., 2013; Yeates et al., 2013), and depression (Ewing-Cobbs, Prasad, Mendez, Barnes, & Swank, 2013).

## FOCUS ON

### Brain Injury in Athletics

Sports-related concussions have occurred in all levels of athletics, including youth sports, since their inception. So why are we hearing about it in the media now? Is it simply a sense of greater awareness, or are concussions happening with greater frequency? The fact is, both are true. Sports-related concussions occur frequently in contact sports such as football, wrestling, boxing, and hockey, but they are also common in bicycling, playground accidents, and less combative sports like basketball and soccer (Centers for Disease Control and Prevention, 2011; McCrea et al., 2012). The incidence of concussions in organized sports resulting in emergency room visits has doubled in recent years for children ages 8 to 13, and more than doubled for children ages 14 to 19 (Bakhos, Lockhart, Myers, & Linakis, 2010).

Fortunately, new rules in organized athletics designed to help prevent serious TBI are a result of medical advances in the diagnosis and treatment of concussion, along with media attention and organized awareness efforts (e.g., *Heads Up—Concussion in Youth Sports*, Centers for Disease Control, <https://www.cdc.gov/headsup/youthsports/index.html>). The National Federation of State High School Associations has instituted new regulations for football that focus on concussion. Most states have passed laws that prevent players who have sustained a concussion in a sporting event from returning to play in the same game. (Visit the website for Law Atlas, click on Interactive Law Maps, and select Youth Sports TBI Laws to find out if your state has laws about youth sports and head injuries.)

Despite new awareness and medical advances in the prevention and treatment of concussion, problems still exist in athletics. An article in the *Chronicle of Higher Education* (Wolverton, 2013) cites concerns that athletic trainers in the National Collegiate Athletic Association (NCAA) answer directly to football coaches. Therefore, if players are injured (e.g., suffer a concussion), the trainers' job is to keep the player safe, but coaches want them back on the field.

Another challenge is that if a player is exhibiting symptoms, he or she may not disclose this to the coach for fear of losing playing time. However, the NCAA now provides guidelines for the evaluation of concussive symptoms on the sideline of sporting events and states that a player may not return to play until concussive symptoms have subsided completely. Enforcing these guidelines remains a critical issue in college athletics.

Repeated concussions put a person at risk for chronic traumatic encephalopathy (CTE). **Chronic traumatic encephalopathy (CTE)** is a degenerative brain disease caused by repetitive trauma to the brain. This trauma may include unsymptomatic subconcussive blows that are never even diagnosed, as well as more severe concussions and brain injuries (Lakhan & Kirchgessner, 2012). The first signs of CTE to appear are behavioral (e.g., impulsivity and physical and verbal abuse) and mood changes (e.g., depression and anxiety), followed by neurocognitive decline (e.g., problems with memory, executive functioning, and attention) (Stern et al., 2013).

Although the concept of a "punch-drunk syndrome" in boxers has been around since the early part of the 20th century (Martland, 1928), the recognition of concussions in many other sports causing long-term neurological symptoms did not come about until the early 2000s. The emergence of CTE as a medical condition in the scientific community originated with the case study of an autopsy performed on a deceased NFL football player reported by Dr. Bennet Omalu and his research team. Public awareness of CTE was sparked by the 2015 movie, *Concussion* (<http://www.imdb.com/title/tt3322364/>), which focused on Omalu (portrayed by Will Smith) and his struggles to convince the National Football League of the existence of CTE (Asken et al., 2016).

The tragic suicides of NFL players Junior Seau and Dave Duerson further publicized the debilitating effects of CTE. Both athletes' brains were donated to the National Institutes of Health to help researchers learn more about how to prevent and/or treat CTE. As they suspected, CTE in both athletes was confirmed. Research at Boston University's CTE center has found that 99 percent of the former NFL players studied had some level of CTE (Moran, 2017).

Unfortunately, as mentioned earlier, symptoms of CTE often do not appear at the time of the injury; instead, the repetition of this brain trauma shows up years later. Many athletes begin in youth sports and continue through high school and college. A selected few go on to play in professional leagues. The media has brought attention to the celebrities, but how many of our own children may one day feel the effects of the trauma their brains have experienced over years of participating in contact sports? Just as we need to attend more to the seriousness of diagnosed concussions, we must consider the danger of participating in contact sports and learn how to better protect the most important organ in the body, the brain.

One of the great difficulties with TBI is that it's often "invisible." True, in some cases, a person with TBI has paralysis, slurred speech, or some other indicator of brain damage that is quickly apparent. But in many cases, the person with TBI looks just like everyone else. The casual observer doesn't see anything obvious, as is true in some cases of physical disability. Recurrent concussions, for example, can affect a person's life in dramatic ways, but the individual may not manifest any visible evidence that a brain injury has taken place.

## Prevalence

The exact prevalence of TBI is difficult to determine, but we do know that it occurs at an alarming rate among children and youths. We also know that 0.04% of the 6- to 21-year-old population are identified as needing special education services (U.S. Department of Education, 2016). Estimates suggest that 16% of those with TBI are considered to have moderate to severe impairment, with some cases leading to death (Trenchard et al., 2013). Males are more prone to TBI than females are, and the age range in which TBI is most likely to occur for both males and females is late adolescence and early adulthood. The Council for Exceptional Children (2001) refers to TBI as a “silent epidemic.” TBI is considered an epidemic because of its increasing prevalence (Grandinette & Best, 2009; Stichter, Conroy, & Kauffman, 2008); and it’s “silent” because many serious head injuries are unreported, and many cases of TBI go undetected or are mistaken for other disabilities. Some of the upsurge in TBI prevalence is due to increased survival rates because of medical advances. The prevalence of TBI is disconcerting because so many of the causes of TBI are entirely preventable or avoidable by following ordinary safety precautions.



### MyLab Education Video Example 13.2

Car accidents are a leading cause of TBI. Rebekah discusses the importance of wearing seatbelts. She was not wearing a seatbelt when she had an accident that led to a life-altering TBI.

## Causes

Among children younger than 5 years old, accidental falls are the dominant cause of TBI, with vehicular accidents and child abuse causing substantial injuries as well. After age 5, and increasingly through adolescence, vehicular accidents (including accidents involving pedestrians, bicycles, motorcycles, and cars) account for the majority of TBI; assaults and gunshot wounds are increasingly prevalent among youths at older ages. Closed head injuries may be caused by a variety of events besides vehicular accidents, including a fall or abuse such as violent shaking of a child by an adult (see Lajiness-O’Neill & Erdodi, 2017).

## Educational Considerations

The educational implications of TBI are varied and depend on the nature and severity of the injury and the age and abilities of the individual at the time of injury. A significant issue in educating someone who has experienced TBI is helping family members, teachers, and peers to respond appropriately to the sudden and sometimes dramatic changes that may occur in the student’s academic abilities, appearance, behavior, and emotional state (Lajiness-O’Neill & Erdodi, 2017). Both general and special education teachers need training about TBI and its ramifications if students are to be reintegrated successfully into the schools and classrooms they attended before the injury (DePompei & Tyler, 2004; Grandinette & Best, 2009; Kauffman et al., 2018; Stichter et al., 2008). The following characteristics are essential features of appropriate education for students with TBI:

1. Well planned transition from a hospital or rehabilitation center to the school
2. A team approach involving regular and special educators, other specialized teachers, a guidance counselor, administrators, and the student’s family
3. An individualized education program (IEP) concerned with cognitive, social/behavioral, and sensorimotor domains
4. Educational procedures to help students solve problems in focusing and sustaining attention for long periods, remembering previously learned facts and skills, learning new things, dealing with fatigue, and engaging in appropriate social behavior
5. Emphasis on the cognitive processes through which academic skills are learned, not just curriculum content
6. Plans for addressing long-term needs in addition to immediate and annual IEP goals

It’s critical that educators understand the implications of the brain injury for structuring the student’s psychological and social environments in school (Best et al., 2010).

The teacher must focus on helping the student with TBI to recover cognitive abilities because these are most critical to academic and social progress. The abilities to remember and to make sense of academic information and social circumstances are key



### MyLab Education Video Example 13.3

The Clubhouse is a program for individuals with Traumatic Brain Injury. Consider the benefits of such a program, including the individualization of the services for the participants.

to the student's long-term success. The teacher must help the student learn to use coping mechanisms and alternative strategies, such as using a tape recorder, smartphone, planner, or other organizational devices and memory aids for whatever abilities cannot be recovered.

A major problem in reentry to school after TBI—at least if the consequences are serious—is that students with TBI tend to see themselves as not having changed, whereas peers and teachers are likely to notice that they are not the same. Dell Orto and Power (2000) note that our societal emphasis on productiveness, organization, independence, and achievement can contribute to negative attitudes toward a student with TBI. “Academic deficits displayed by survivors of TBI conflict with achievement values, not only causing discomfort in teachers, but frustration and perhaps a sense of rejection in the young person” (p. 22). Many teachers apparently don't want students with TBI in their classrooms, probably because these students exhibit characteristics that teachers find troublesome (just consider the bulleted list of learning and psychosocial problems presented earlier). Thus, a student's returning to school after TBI is a major issue that typically requires a team approach involving a variety of professionals, as we mentioned in our list of essential features of appropriate educational programs. Collaboration and problem solving by this team are essential to the success of the student's reentry.

The assessment of a student's academic and social skills following TBI is tricky because it's often difficult or impossible to separate physiological causes or reasons for difficulty with a task from other causes. More important than knowing precisely what difficulties have a physiological cause is pinpointing just what the student's academic and social learning difficulties are. Here again, a team approach is essential. Neurologists can often provide information about the consequences of TBI that helps teachers to set reasonable expectations and teach coping skills that help the student to compensate for abilities that will not return.

**LANGUAGE DISORDERS** A student with TBI might acquire a language disorder after a period of normal development, or acquire a more severe language disorder than existed before the injury (see Chapter 10). Individuals with TBI comprise a very diverse population, although a disproportionate number of students with TBI have a pre-trauma history of learning problems or delayed speech and language.

Language or speech disorders are the greatest complicating factor in most students' return to school following TBI. A loss of ability to understand and formulate language due to brain injury is sometimes referred to as a **motor-speech disorder**, which we discussed in Chapter 10. The student may have trouble finding or saying words or constructing sentences that are appropriate for the topic of conversation or social context. Problems like these can be a source of frustration, anger, and confusion for students with TBI.

The language problems associated with TBI are primarily related to the cognitive and social demands of communication. The student might have problems with tasks that demand responding quickly, organizing, dealing with abstractions, sustaining attention (especially if there are distractions), learning new skills, responding appropriately in social situations, and showing appropriate affect. In fact, TBI can potentially disrupt all aspects of the give-and-take of social interaction that are required for effective communication.

The effects of TBI on language are extremely variable, and careful assessment of the given individual's abilities and disabilities is critically important. Interventions may range from making special accommodations, such as allowing more response time or keeping distractions to a minimum, to focusing on instruction in the social uses of language.

Depending on the site and degree of brain damage, a person with TBI may have motor control problems that interfere with communication, including the cognitive and social aspects of communication. Some students with TBI cannot communicate orally using the muscles of speech and must rely on alternative or augmentative communication systems, which we describe later in the chapter.



**MyLab Education**  
Video Example 13.4

This video shows an example of the importance of interdisciplinary teamwork in implementing a successful educational program for a child with TBI.



**MyLab Education**  
Video Example 13.5

Chris sustained a head injury from a car accident. He discusses his difficulty with language, as well as the importance of art to allow him to have fulfillment in life.

**SOCIAL AND EMOTIONAL PROBLEMS** Brain injury may be accompanied by a variety of serious social and emotional effects. We know that TBI can cause violent aggression, hyperactivity, impulsivity, inattention, and a wide range of other emotional or behavioral problems, depending on just what parts of the brain are damaged. The possible effects of TBI include a long list of other psychosocial problems, some of which we listed previously as general characteristics.

The emotional and behavioral effects of TBI are determined by more than the physical damage; they also depend on the student's age at the time of injury and the social environment before and after the injury. Home, community, or school environments that foster misbehavior of any child or youth are known to be associated with increased risk for acquiring TBI. Such environments are extremely likely to worsen any emotional or behavioral problem resulting from TBI. Creating an environment that is conducive to and supportive of appropriate behavior is one of the great challenges of dealing effectively with the results of brain injury.

Many of the typical **behavior modification** or **behavior management** strategies that are used with other students who have emotional or behavioral difficulties are appropriate for use with students who have TBI. Consistency, predictability, and reinforcement (praise, encouragement, and other rewards) are particularly important (Persel & Persel, 2004), as is developing rapport with the student. Developing a good personal relationship with a student with TBI can be particularly challenging, as such students can be unpredictable, irritable, and angry with those who are trying to help (see ; Kauffman & Badar, 2018; Kauffman, Pullen, Mostert, & Trent, 2011).

TBI often shatters an individual's sense of self. Recovering one's identity can require a long period of rehabilitation and can be a painstaking process requiring multidisciplinary efforts (Best et al., 2010; Grandinette & Best, 2009). Effective education and treatment often require not only classroom behavior management but also family therapy, medication, cognitive training, and communication training.

#### MyLab Education Self-Check 13.2

#### MyLab Education Application Exercise 13.2: Traumatic Brain Injury

Watch a video of Matt and his two teachers discussing his behaviors in the classroom. Then, answer a follow-up question.



## DEAF-BLINDNESS

In Chapters 11 and 12, we noted that, depending on the level of severity, blindness or deafness can have a substantial impact on a person's ability to function independently. For those who are both deaf and blind, the impact can be even more profound than simply adding the effects of each disability. Because the primary avenues for receiving information—sight and sound—are limited, those who are deaf-blind are at risk for having extensive problems in communicating and in navigating their environments.

Although being cut off from the sights and sounds of daily life makes deaf-blindness one of the most challenging of all multiple disabilities, this doesn't mean that a person with deaf-blindness is doomed to a poor-quality life. In general, outcomes for individuals with deaf-blindness depend on at least three factors:

1. *The quality and intensity of instruction the person receives are critical.* Teachers of students with deaf-blindness “must make the most of every opportunity for learning. All interactions with adults and all aspects of the environment will be harnessed to help the child overcome the restrictions imposed by sensory impairments” (Hodges, 2000, p. 167).

2. *The degree and type of auditory impairment and visual impairment can vary dramatically in individuals with deaf-blindness.* The term *deaf-blindness* covers those with hearing impairments ranging from mild to profound. Likewise, the term covers those with visual impairments ranging from low vision (20/70 to 20/200 in the better eye with correction) to those who are totally blind. Despite some very notable exceptions, in general, the more severe the impairments, the greater is the impact on a person's ability to adapt.
3. *The vast majority of students who are deaf-blind have other disabilities and medical conditions.* For example, they may have intellectual disabilities, autism, and/or physical disabilities.

## Definition

As we discussed in Chapters 11 and 12, considerable controversy exists over the definitions of deafness and blindness. As one might expect, this means that defining deaf-blindness is even more controversial than defining deafness or blindness separately. The Individuals with Disabilities Education Improvement Act (2004) describes deaf-blindness as an individual

(1)(i) Who has a central visual acuity of 20/200 or less in the better eye with corrective lenses, or a field defect such that the peripheral diameter of visual field subtends an angular distance no greater than 20 degrees, or a progressive visual loss having a prognosis leading to one or both of these conditions:

(ii) Who has a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, or a progressive hearing loss having a prognosis leading to this condition; and

(iii) For whom the combination of impairments described in paragraphs (1)(i) and (ii) of this definition causes extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation;

(2) Who, despite the inability to be measured accurately for hearing and vision loss due to cognitive or behavioral constraints, or both, can be determined through functional and performance assessment to have severe hearing and visual disabilities that cause extreme difficulty in attaining independence in daily life activities, or obtaining vocational objectives; or

(3) Who meets any other requirements that the Secretary may prescribe. (34 CFR, Sec. 396.4 (c)(2))

## Prevalence

Deaf-blindness is very rare—much more rare, for example, than either deafness or blindness alone. The best estimate available is that only about 1 in 1,000 persons from birth to 21 years has deaf-blindness (National Center on Deaf-Blindness, 2015).

## Causes

Causes of deaf-blindness can be grouped into three broad categories: (1) genetic/chromosomal syndromes, (2) prenatal conditions, and (3) postnatal conditions.

**GENETIC/CHROMOSOMAL SYNDROMES** Researchers are making enormous strides in discovering genetic/chromosomal syndromes involved in deaf-blindness. Some of these syndromes are inherited, and some result from damaged genetic and/or chromosomal material. Dozens of genetic/chromosomal syndromes are now known to be associated with deaf-blindness. The most common are CHARGE syndrome, Usher syndrome, and Down syndrome.

**CHARGE Syndrome** Caused by a gene mutation (Zentner, Layman, Martin, & Scacheri, 2010), **CHARGE syndrome** is characterized by a number of physical anomalies present at birth. These anomalies include such things as structural defects resulting in difficulties swallowing and breathing. Of the features of CHARGE syndrome, the most important for vision is coloboma. **Coloboma** refers to a condition in which the child is born with an

abnormally shaped pupil and/or abnormalities of the retina or optic nerve. Coloboma can result in a variety of visual problems, including deficits in visual acuity and extreme sensitivity to light.

**USHER Syndrome** An inherited condition, *Usher syndrome* is characterized by hearing impairment and *retinitis pigmentosa*. As mentioned in Chapter 12, *retinitis pigmentosa* can result in vision problems starting in infancy, early childhood, or the teenage years, with the condition becoming progressively worse. It results in problems with seeing in low light, referred to as *night blindness*, and as it progresses, it results in a narrowing of the field of vision, referred to as *tunnel vision*.

Thus far, researchers have found that a mutation in any one of about 11 genes can result in Usher syndrome (National Institute on Deafness and Other Communication Disorders, 2010). Although Usher syndrome is one of the most common hereditary conditions causing deaf-blindness, its overall prevalence is very low. Estimates suggest that about 16,000 people in the United States have Usher syndrome (Wrong Diagnosis, 2010). The genetics of Usher syndrome show an interesting demographic pattern.

**DOWN Syndrome** Most often noted as a cause of intellectual disability (see Chapter 5), *Down syndrome* is also sometimes associated with deaf-blindness. Unlike Usher syndrome, which is inherited, Down syndrome results from damaged chromosomal material.

**PRENATAL CONDITIONS** Like Down syndrome, two of the most common types of prenatal conditions—*rubella*, sometimes referred to as *German measles*, and *congenital cytomegalovirus (CMV)*—can cause intellectual disability and/or deaf-blindness. When rubella occurs in a pregnant woman, especially in the first trimester, it can lead to a variety of disabilities, including deaf-blindness. Children born with CMV, a herpes virus, are also at risk for a variety of disabilities, including deaf-blindness.

**POSTNATAL CONDITIONS** Among the most common postnatal conditions that can cause deaf-blindness are *meningitis* and *TBI*. As we learned in Chapter 5, *meningitis*, which is an infection of the covering of the brain, can also cause intellectual disability. *TBI*, as we discussed earlier in this chapter, can result in a variety of other disabilities, as well as deaf-blindness.

## FOCUS ON

### The Genetics of Usher Syndrome and Its Geographic Distribution

About 1 in 75 people carries an Usher gene, but most don't realize they have it. *Usher syndrome* is an *autosomal-recessive disorder*, meaning that for a child to have the condition, both parents must be carriers of the gene. And with each such pregnancy, there is a one-in-four chance of the child having Usher syndrome. Thus, the chance of having a child with Usher syndrome is relatively rare even among those who carry the gene, and that is why the prevalence of Usher syndrome is so low. However, the odds of producing an offspring with Usher syndrome rise dramatically among people who are related.

Unfortunately, social forces have operated historically to make the likelihood of intermarriage higher among a certain cultural group: the Acadian French of south Louisiana. This has

resulted in a relatively higher number of people with Usher syndrome in this area of the country. The high prevalence of Usher syndrome in south Louisiana is also the subject of a video narrated by the well-known neurologist Oliver Sacks, *The Ragin' Cajun Usher Syndrome*, produced by the British Broadcasting Company.

Ironically, events of the early 21st century may serve to reverse some of the social forces that led to a high incidence of Usher syndrome among Acadians. It's too early to tell, but Hurricane Katrina in 2005 and the British Petroleum oil spill in 2006 have resulted in a population displacement along the Louisiana Gulf Coast. It's possible that such dispersion will result in a decrease in intermarriage, which in turn would result in fewer offspring with Usher syndrome.

## Psychological and Behavioral Characteristics

People who are deaf-blind can have significant problems in at least four areas: (1) accessing information, (2) communicating, (3) navigating the environment, and (4) achieving successful social emotional development (Hartshorne & Schmittl, 2016).

**PROBLEMS ACCESSING INFORMATION** For people who are deaf-blind, access to the usual sources of information (e.g., Internet, television, newspapers) is more difficult than for those who are sighted. And because communication depends largely on the availability of information, restricted access to information can have a negative impact on the ability to communicate. For one thing, without this store of world knowledge, there's much less to communicate about (Aitken, 2000).

**PROBLEMS COMMUNICATING** Most authorities agree that the biggest obstacle faced by people with deaf-blindness is communication. Without a strong commitment by teachers and other professionals and parents to providing a variety of opportunities for communication, the child who is deaf-blind can easily become socially isolated. The pattern for this isolation can begin at birth. The baby who is deaf and blind has limited ability to interact with his or her parents and the environment, presenting the context for an unpredictable world. For example, consider how the simple act of being picked up by an adult might be startling and be perceived as threatening (Pease, 2000). In the face of such experiences in infancy and early childhood, the child who is deaf-blind is a candidate for social isolation.

Once this pattern of isolation has been established, it's difficult to reverse. Therefore, it's not surprising that individuals who are deaf-blind are at risk for developing behavior disorders such as anxiety, depression, and even psychosis (Bodsworth, Clare, & Simblett, 2011; Dammeyer, 2011). It's critical that professionals and parents work together to provide an environment that's as supportive and rich in communication opportunities as possible.

No better example of the importance of providing a language-rich environment exists than the classic case of Helen Keller (1880–1968) and her teacher Anne Sullivan (1866–1936). Popularized by the classic movie *The Miracle Worker* (Green & Penn, 1962), Helen Keller's accomplishments are now familiar to most of us. Having lost her sight and hearing at the age of 19 months, Keller went on to extraordinary achievements, including graduating cum laude from Radcliffe College in 1904; publishing essays and books (including the much acclaimed *The Story of My Life*, 1905, written while she was in college and available in over 50 languages); touring the country lecturing on blindness; being a spokesperson for women's right to vote; and receiving the Presidential Medal of Freedom, the nation's highest civilian award. To see rare video footage of Helen Keller when she was younger and older, go to: <http://www.youtube.com/watch?v=GzlrQv16gg> and [http://www.youtube.com/watch?v=8ch\\_H8pt9M8](http://www.youtube.com/watch?v=8ch_H8pt9M8).

Helen Keller is testimony to the power of the human spirit to overcome overwhelming odds. However, just as important, she is testimony to the power of intensive and extensive special education instruction. As remarkable as she was, it's doubtful that Keller would have conquered her condition without the prolonged instruction from Annie Sullivan, herself born blind, who devoted nearly 50 years to being Keller's teacher and constant companion. Through persistence and intensive instruction, Sullivan was able to set Helen's mind free to learn language and higher concepts.

**PROBLEMS NAVIGATING THE ENVIRONMENT** As we discussed in Chapter 12, people who are blind or who have low vision can have significant difficulties with orientation and mobility (O & M). For people who are deaf-blind, these problems are often even more pronounced. Individuals who are blind and hearing can pick up auditory cues that help them in navigation. For example, being able to hear approaching traffic can be very helpful when crossing an intersection, and being able to hear such things as buses, trains, and construction noises can help a person who is blind to identify her location. However, people who are both deaf and blind are restricted in their ability to make use of auditory signals for navigating the environment.



MyLab Education  
Video Example 13.6

This video shows a group lesson with deaf-blind students focused on increasing communication skills—oral and sign language.

## FOCUS ON

### Laura Bridgman (1829–1889), The First Documented Case of a Deaf-Blind Person to Learn Language

Sullivan and Keller are not the only famous teacher–student team to demonstrate the importance of intensive instruction for persons who are deaf-blind. Actually, predating the Keller-Sullivan relationship was the one of Laura Bridgman and Samuel Gridley Howe. Although most people are familiar with the story of Helen Keller, Laura Bridgman (1829–1889) was actually the first documented case of a deaf-blind person to learn language. Laura became ill with scarlet fever at the age of 2, and it left her deaf and blind.

Samuel Gridley Howe (1801–1876) was one of the 19th century's most daring social activists, reforming schools, prisons, and mental institutions as well as being a member of the "Secret Six," who lent financial support to John Brown's campaign to end slavery in the United States with his ill-fated launching of the raid at Harper's Ferry in 1859. Howe received his medical degree from Harvard University in 1824. After serving a 7-year stint as a surgeon in the Greek civil conflict, he returned to Boston. In 1832, he was named head of the Perkins Institution and Massachusetts School for the Blind (now named the Perkins School for the Blind).

After reading a newspaper account of Laura, Howe visited her parents and convinced them to send the 8-year-old to Perkins in 1837. There, he and his teachers worked painstakingly with Laura for several years. Although her achievements were not as spectacular as Keller's, Bridgman's accomplishments were extraordinary for the time, because many authorities believed that to be deaf-blind was to be mentally retarded. Furthermore, had it not been for Bridgman, Keller might never have received the instruction that unlocked her intellect. Helen's parents were alerted to the potential of teaching their own daughter after reading about Bridgman's accomplishments. Furthermore, Helen's teacher, Annie Sullivan, herself a former student at Perkins, consulted Howe's reports on Laura before embarking on her journey to tutor Helen.

The most important "lesson" of the Howe-Bridgman story might have been its sparking public interest in not only people who are deaf-blind but also those with other disabilities (Freeberg, 2001). Pioneers such as Samuel Gridley Howe began to open the eyes of society to the fact that people with disabilities were teachable.

**SOCIAL-EMOTIONAL DEVELOPMENT** Given the likelihood of being relatively isolated from interactions with their peers, it shouldn't be surprising that students who are deaf-blind are at risk for social-emotional difficulties (Hartshorne & Schmittl, 2016; Laugen, Jacobsen, Rieffe, & Wichstrøm, 2016). Typical developmental milestones such as attachment, the development of empathy, and friendships are more difficult due to these children's dual sensory impairments (Hartshorne & Schmittl, 2016).

#### MyLab Education Self-Check 13.3

#### MyLab Education Application Exercise 13.3: Teaching Students with Deaf-Blindness

Watch a video in which the teacher is previewing the day's activities with the students, and then answer the question that follows.



### Educational Considerations

The importance of early identification of deaf-blindness can't be overstated. As we have stressed in other chapters, early identification of any disability is important. But the fact that two senses—hearing and sight—are involved in deaf-blindness makes the need to intervene as early as possible of paramount importance (Anthony, 2016). In addition to educational intervention, early medical intervention, such as cochlear implants, is best provided as early as possible (Anthony, 2016).

From an educational perspective, the major needs of infants and preschoolers as well as of older students who are deaf-blind fall generally under the categories of

communication and orientation and mobility. Both abilities, but especially communication, are required for social interaction. If these skills are taught effectively, then the social interaction of deaf-blind individuals is enhanced considerably (Janssen, Riksen-Walraven, & van Dijk, 2004).

In addressing needs for communication, orientation, and mobility, practitioners and parents should keep in mind at least two important principles: direct teaching and structured and predictable routines.

**THE IMPORTANCE OF DIRECT TEACHING** Many students with disabilities (e.g., intellectual disability, learning disabilities, blindness, deafness) are more reliant than those without disabilities on having teachers instruct them directly. Whereas students without disabilities can learn a great deal incidentally (e.g., from seeing or hearing things that happen around them), students with disabilities are often in greater need of having material taught to them directly (see Kauffman et al., 2018; Pullen & Hallahan, 2015). Because of their restricted sensory input, this need for direct teaching of information is even more pronounced for students who are deaf-blind than it is for children with other disabilities.

**THE IMPORTANCE OF STRUCTURED AND PREDICTABLE ROUTINES** To create a successful environment for learning, it's also critical that teachers and other professionals and parents provide a sense of security for students who are deaf-blind. One of the best ways to create this sense of security is through the use of predictable, structured routines (Chen, Alsop, & Minor, 2000; Miles, 1998; Smith, Smith, & Blake, 2010), discussed in detail in the Responsive Instruction feature.

**COMMUNICATION** The hands play a critical role in communication for most students who are deaf-blind. In effect, the hands become the "voice, or the primary means of expression" (Miles, 1999, p. 1). Professionals use a number of modes of communication that involve touch with people who are deaf-blind. Braille is the most obvious one along with touch cues, which often entails the special educator providing information by touching the hands or face of the student (Chen, Downing, & Rodriguez-Gil, 2000/2001). Also, adapted signs are often invaluable. Signs used by the Deaf community, such as American Sign Language and signed English, are visually based, which makes them difficult or impossible for people who are deaf-blind to use, depending on the severity of their visual impairment. A variety of tactual versions of signing (adapted signs) therefore have been created (Chen et al., 2000/2001). For example, for the reception of signs, the person who is deaf-blind can place his or her hands on the hands of the signer. For a demonstration, using rap, of deaf-blind tactile signing, go to: <http://www.youtube.com/watch?v=LarnqAGeH6c&feature=relmfu>. For the expression of signs, the teacher or parent can hold the hands of the person who is deaf-blind and guide him or her to produce signs.

**ORIENTATION AND MOBILITY** For people who have both visual impairment and hearing impairment, the need for orientation and mobility (O & M) training is even more important than for those who are only blind because they are at even greater risk of being unable to navigate their environment.

O & M training for people who have both visual and hearing impairments differs in at least two ways from O & M training for those with only visual impairment. First, adaptations are needed to communicate with people with deaf-blindness (Gense & Gense, 2004). The O & M instructor might need to use adaptations such as an interpreter, adapted signs, and/or touch cues to communicate with the student who is deaf-blind.

Second, it's sometimes necessary to alert the public that a traveler is deaf-blind. Even the best travelers with deaf-blindness occasionally become temporarily disoriented and need assistance. People with visual impairment who can hear can ask for assistance relatively easily. However, people who have both hearing and visual impairments may have a more difficult time communicating their needs to the public, and it won't always be obvious to the public that the person has both a visual and a hearing impairment. A

## RESPONSIVE INSTRUCTION

### Meeting the Needs of Students with Low-Incidence, Multiple, and Severe Disabilities

#### THE IMPORTANCE OF ESTABLISHING PREDICTABLE, STRUCTURED ROUTINES

##### What the Research Says

Researchers and practitioners from Project PLAI (Promoting Learning Through Active Interaction) have developed several modules for working with infants who have multiple disabilities and their families (Chen et al., 2000; Klein, Chen, & Haney, 2000). One of the modules focuses on establishing predictable routines. Specifically, for infants who are deaf-blind, they have recommended the following objectives:

- Create a predictable routine by identifying at least five daily activities that can be scheduled in the same sequence each day.
- Identify predictable sequences within specific activities (i.e., "subroutines").
- Identify and use specific auditory, visual, tactile, olfactory, and kinesthetic cues to help the infant anticipate familiar activities (Chen et al., 2000, p. 6).

The following describes how they implemented these objectives with 14-month-old Michael, his mother, Cecelia, and older sister, Kate. Michael was born prematurely and only weighed 1 pound, 8 ounces at birth. He was diagnosed with severe ROP (retinopathy of prematurity), cerebral palsy, and a hearing loss of undetermined severity.

An early interventionist helped Cecelia realize that Michael could better understand what was going on around him if his daily events were more predictable. In addition to the early morning and evening routines, Cecelia decided to try to increase the predictability of Michael's routines in several ways. After he finished his morning bottle, he would always get a bath. After the bath, Cecelia would put lotion on him and give him a shoulder and back massage. At bedtime, she would give him his bottle and then Kate would rock him while watching TV. Cecelia also realized that she and Michael had developed "subroutines." For example, after removing Michael's diaper and cleaning him, she would blow on his tummy and say, "Okay, all dry. All dry." Then she would sprinkle powder and put a new

diaper on him, say "All done," and give him a kiss while picking him up.

Other predictable routines and subroutines followed. Before going into Michael's room, Cecelia would always announce loudly, "Here comes Mommy." She would touch his shoulders before picking him up. Before putting him in the bath, she would put his foot in the water a couple of times, which helped him to stop screaming when he was placed in the tub. Before Cecelia gave Michael his back massage, she would rub some lotion on her fingers and let him smell it. (Chen et al., 2000, pp. 6–7)

##### Applying the Research to Teaching

Although the preceding example pertains to infants, predictable, structured routines are no less important for school-age children who have multiple disabilities, including deaf-blindness. School routines are particularly important for students who are deaf-blind because the only way for these children to learn is by doing. The students will be unable to learn through visually observing or hearing stimuli that will assist them in making sense of the world. Therefore, they will depend on the creation of a safe learning environment and trust with the primary instructor (Moss & Hagood, 1995). School routines that would benefit students who are deaf-blind follow:

1. *Turn-taking routines.* By keeping interactions balanced ("me, then you"), students will consistently know when to respond and be more active in their learning.
2. *Travel or movement routines.* If students do not feel comfortable moving around the classroom or school, they may choose to not move. Lack of mobility decreases opportunities for exploration, social interaction, and independence.
3. *Communication routines.* Students who are deaf-blind will rely on tactile communication. Students will be unable to make connections among input without direct interaction with others. Therefore, it is important to establish routines for communication as these students move from objects to gestures for communication.

BY KRISTIN L. SAYESKI

long cane can signal vision loss, but it does not indicate hearing impairment. Therefore, some professionals advocate the use of assistance cards. Assistance cards are usually relatively small (e.g., 3 × 6 inches) and can be held up by the person who is deaf-blind at a busy or unfamiliar intersection. The words on the card indicate that the person is asking for assistance—for example, "Please help me to CROSS STREET. I am both DEAF and VISUALLY IMPAIRED, so TAP ME if you can help. Thank you" (Franklin & Bourquin, 2000, p. 175).

**SPECIAL CONSIDERATIONS FOR STUDENTS WITH USHER SYNDROME** Students with Usher syndrome present some special educational challenges because most have progressive visual impairment. They might start out having relatively good vision, but their vision inevitably declines to the point at which they are legally, if not totally, blind. The effects of retinitis pigmentosa, which accompanies Usher syndrome, can sometimes be erratic and change rapidly, thus catching these students and their family off guard (Miner & Cioffi, 1999). Even when the deterioration occurs slowly over the course of several years, parents and teachers of children with Usher syndrome might neglect the importance of preparing them for the fact that they will one day have substantial visual impairment. Sometimes, they fear that the early introduction of braille and O & M training will stigmatize the children and damage their self-concept. However, most authorities now agree that braille instruction and O & M training should not be delayed until these students can no longer function as seeing individuals.

## EDUCATIONAL CONSIDERATIONS FOR MANY STUDENTS WITH LOW-INCIDENCE, MULTIPLE, AND SEVERE DISABILITIES

Some of the devices and methods that we describe here might apply to any of the disabilities we discuss in this chapter. Communication, behavior management, early intervention, transition, employment, family involvement, and normalization are all frequent concerns with any of these disabilities.

### Augmentative or Alternative Communication

For some individuals with severe and multiple disabilities, oral language is out of the question; they have physical or cognitive disabilities, usually as a result of neurological damage, that preclude their learning to communicate through normal speech. Educators and professionals must design a system of **augmentative and alternative communication (AAC)** for them. AAC includes any manual or electronic means by which such a person expresses wants and needs, shares information, engages in social closeness, or manages social etiquette (Beukelman, Yorkston, & Reichle, 2000; Gerenser & Forman, 2007; Heller & Bigge, 2010). Students for whom AAC must be designed range in intelligence from highly gifted to having profoundly intellectual disabilities, but they all have one characteristic in common: the inability to communicate effectively through speech because of a physical impairment. Some of these individuals cannot make any speech sounds at all; others need a system to augment their speech when they cannot make themselves understood because of environmental noise, difficulty in producing certain words or sounds, or unfamiliarity with the person with whom they want to communicate.

Manual signs or gestures are useful for some individuals. But many individuals with severe physical limitations cannot use their hands to communicate through the usual sign language; they must use another means of communication, usually involving special equipment. Dr. Nikki Kissane, now a surgeon, developed a simplified sign language system while a University of Virginia undergraduate student. (Search Nikki Kissane UVA to learn more.) Children and adults with limited speech capabilities can learn and use her simplified signs more easily than traditional signs.

The problems to be solved in helping individuals communicate in ways other than signing include selecting a vocabulary and giving them an effective, efficient means of indicating elements in their vocabularies. Although the basic ideas behind AAC are quite simple, selecting the best vocabulary and devising an efficient means of communication for many individuals with severe disabilities are extraordinarily challenging. As one AAC user put it, "The AAC evaluation should be done with the AAC user involved in the process from step one. It is the augmented speaker who will be using the device every day, both personally and professionally, not the AAC specialist" (Cardona, 2000, p. 237).

A variety of approaches to AAC have been developed, some involving relatively simple or so-called low-technology solutions and some requiring complex or

high-technology solutions. Many different direct-selection and scanning methods have been devised for AAC, depending on individual capabilities. The system that is used may involve pointing with the hand or a head-stick, eye movements, or operation of a microswitch by foot, tongue, or head movement or breath control. Sometimes, the individual can use a typewriter or computer terminal that is fitted with a key guard so that keys are not likely to be pressed accidentally or use an alternative means for selecting keystrokes. Other students use communication boards, which offer an array of pictures, words, or other symbols and can be operated with either a direct-selection or scanning strategy. The content and arrangement of the board will vary, depending on the person's capabilities, preferences, and communication needs.

Today, researchers are finding increasingly innovative and creative technological solutions to the problem of nonvocal communication. At the same time, they are recognizing the importance of making decisions that are highly individualized and evidence-based. No one is well served by AAC that is not highly reliable from a scientific point of view. Researchers are attempting to make it possible for young AAC users to talk about the same kinds of things that other youngsters do. Other efforts are directed at training AAC users to tell those with whom they communicate how to interact with them more effectively—that is, to train AAC users in pragmatics. The important thing is that some people have physical limitations that preclude their efficient use of oral language and need an augmented or alternative means of communicating.

Users of AAC encounter three particular challenges that are not faced by natural communicators:

1. AAC is often much slower than natural communication—perhaps 1/20th the typical rate of speech. This can result in great frustration for both AAC users and natural communicators.
2. Users of AAC who are not literate must rely on a vocabulary and symbols that are selected by others. If the vocabulary and symbols, as well as other features of the system, are not well chosen, AAC will be quite limited in the learning and personal relationships it allows.
3. AAC must be constructed to be useful in a variety of social contexts, allow accurate and efficient communication without undue fatigue, and support the individual's learning of language and academic skills.

Progress in the field of AAC requires that all of these challenges be addressed simultaneously. AAC is increasingly focused on literacy and the right to use print, including writing, for communication. In many ways the emphasis on basic literacy skills parallels the emphasis on literacy for all students, regardless of disabilities (Yoder, 2001).

The remarkable increase in the power and availability of microcomputers (including small devices such as tablets and smartphones) is radically changing the ability to provide AAC and make sure that the user's words are communicated. New ways of using computer-based devices and new apps for such devices may lead to breakthroughs that will allow people with severe disabilities to communicate more effectively, even if they have extremely limited muscle control. Furthermore, existing software suggests ways of encouraging children to use their existing language skills.

Much information about AAC is now available on various websites. The International Society for Augmentative and Alternative Communication (ISAAC) publishes the professional journal *Augmentative and Alternative Communication* and maintains a website. Parents need to be aware of the availability of AAC and demand equipment and training that are effective for their child.

### Behavior Problems

Some individuals who have certain severe or multiple disabilities engage in problematic behaviors such as self-stimulation, self-injury, tantrums, aggression toward others, or some combination of these. We caution that not all people with low-incidence, severe, or multiple disabilities exhibit the behavior problems we discuss here. Many people who are deaf-blind and many who have TBI, autism, or other severe or multiple disabilities do not

engage in these behaviors. Nevertheless, most of the people who do exhibit these problems to a significant extent have severe and multiple disabilities. Moreover, behaviors of the type that we discuss here add a level of complexity and seriousness to any disability. Thus, finding solutions to these behavior problems is critical to treating the individual with respect and helping the person to participate in typical school and community activities (see Best et al., 2010; Heller, Forney, Alberto, Best, & Schwartzman, 2009).

Much controversy exists regarding the behavior problems of people with severe disabilities. Some educators and professionals assume that such problems simply will not occur if appropriate programs of instruction are provided. Others suggest that functional behavioral assessment (FBA), positive behavioral support (PBS), and nonaversive treatments (i.e., treatments in which punishment has no place) will be sufficient in all cases. However, others claim that positive behavioral supports and nonaversive treatments are insufficient in some cases to overcome behavior problems (e.g., Foxx, 2016; Mudford & Cullen, C., 2016; Mulick & Butter, 2016; Newsom & Kroeger, 2016).

**SELF-STIMULATION** Self-stimulation can be defined as any repetitive, stereotyped behavior that seems to have no immediately apparent purpose other than providing sensory stimulation. Self-stimulation (a form of stereotyped movement) may take a wide variety of forms, such as swishing saliva, twirling objects, hand-flapping, fixed staring, and the like. Repetitive, stereotyped behavior (sometimes called *stereotypy*) may have multiple causes, including social consequences, in addition to sensory stimulation (Bodfish, 2007).

Nearly everyone sometimes engages in some form of self-stimulation, such as lip-biting, hair-stroking, and nail-biting, but not at the high rate that characterizes a disability. Infants without disabilities engage in self-stimulation, and so do adults without disabilities, particularly when they are tired or bored. Only the high rate, lack of subtlety, and social inappropriateness of such self-stimulation differentiate it from the norm.

Self-stimulation becomes problematic when it occurs at such a high rate that it interferes with learning or social acceptability or when it occurs with such intensity that it does injury. Some individuals with autism or other pervasive developmental disabilities engage in self-stimulation to the exclusion of academic and social learning. In most of these cases, it appears that only intrusive, directive intervention will be successful in helping the individual learn academic and social skills (Kauffman & Landrum, 2018).

**SELF-INJURY** Self-injurious behavior (SIB) is repeated physical self-abuse, such as biting, scratching, or poking oneself, head-banging, and so on (see Foxx, 2016). Unchecked, SIB often results in self-mutilation. Self-stimulation can be so frequent and intense that it becomes SIB. Hand-mouthing is self-stimulation of the kind that all infants do; even some adults without disabilities can be seen occasionally mouthing their hands. However, hand-mouthing becomes self-injurious for some people with severe developmental disabilities, resulting in serious skin lesions.

**TANTRUMS** Severe tantrums can include a variety of behaviors, including self-injury, screaming, crying, throwing or destroying objects, and aggression toward others. Sometimes, the event that sets off a tantrum is unknown, at least to the casual observer. Often, however, a tantrum is precipitated by a request or demand that the individual do something (perhaps a self-care task or some academic work), and the consequence of the tantrum is that the demand is withdrawn, thus reinforcing the tantrum behavior.

Tantrums impose a handicap on the individual who uses them to avoid learning or doing important things. They stymie socialization, as most people want to avoid interacting with someone who is likely to have a tantrum. Teachers and others who work most successfully with individuals who have tantrums do not withdraw reasonable demands for performance. They modify their demand or circumstances in some way or alternate their demands for performance in ways that are less likely to set off a tantrum.

**AGGRESSION TOWARD OTHERS** Not all aggression toward others is associated with tantrums. Some individuals with severe or multiple disabilities engage in calculated

physical attacks that threaten or injure others (Gardner, 2007). Sometimes these attacks come without warning or only after subtle indications of imminent assault that only someone who knows the individual well is likely to perceive.

**LACK OF DAILY LIVING SKILLS** Lack of daily living skills refers to the absence or significant impairment of the ability to take care of one's basic needs, such as dressing, feeding, or toileting. Many people with severe and multiple disabilities must be taught the adaptive behavior that is expected of older children and adults. These adaptive behaviors include a wide variety of tasks involving clothing selection and dressing, food preparation and eating, grooming, socializing, using money, using public transportation, playing games or other recreation, and so on (Snell & Brown, 2006).

**FUNCTIONAL BEHAVIORAL ASSESSMENT AND POSITIVE BEHAVIORAL INTERVENTION AND SUPPORT** Problem behaviors are often related to a brain disorder or brain injury, even if the disorder is not understood. An example is severe autism, which often includes self-stimulation, self-injury, tantrums, or all of these. However, professionals and educators are increasing their emphasis on analyzing and changing the environments in which problem behavior is exhibited; that is, focusing on the immediate and alterable influences on behavior rather than on immutable or historical reasons for behavior (Best et al., 2010; Bodfish, 2007; Foxx, 2016).

In earlier chapters, we introduced the ideas of **functional behavioral assessment (FBA)** and **positive behavioral intervention and support (PBIS)**, primarily as they apply to students with less severe disabilities (see Chapters 7 to 9). However, these procedures may be particularly important for students with severe and multiple disabilities. FBA entails finding out why or under what circumstances problem behavior is exhibited, and PBIS involves creating an environment that supports appropriate behavior.

FBA often reveals how a student uses self-stimulation, SIB, tantrums, or aggression against others. A student might behave inappropriately to escape or avoid unpleasant or nonpreferred activities or tasks (see Kauffman & Landrum, 2018). In many instances, researchers and practitioners find that the student has no other effective and efficient means of communication. The task, therefore, is to figure out how the student is using unacceptable communication and teach the student a more effective, efficient, and acceptable means of letting others know what he or she wants or is feeling. FBA has led to the discovery that sometimes people with severe and multiple disabilities use inappropriate behavior to communicate a variety of their wants or needs (e.g., "Pay attention to me," "Let me out of here," "There's nothing to do," "There's too much to do," or "I don't want to do that now").

PBIS is the vehicle for teaching students how to behave more appropriately, making appropriate behavior "work" for their communication. In the case of students with severe and multiple disabilities, making PBIS a part of managing behavior across school, home, neighborhood, and community is particularly important. The accompanying Responsive Instruction box provides a more detailed discussion of PBIS for students with multiple or severe disabilities.

## Early Intervention

Most children with multiple and severe disabilities are identified at birth or soon thereafter because their disabilities are very noticeable to parents, physicians, and/or nurses. Some newborns with severe and multiple disabilities require extensive medical treatment and therefore are immediately placed in **neonatal intensive care units (NICUs)**. NICUs are the equivalent of intensive care units (ICUs) for older children and adults, providing around-the-clock monitoring of bodily functions. The NICU staff consists of several specialists, often including specially trained nurses, physicians, respiratory care practitioners, occupational therapists, and social workers. Because NICUs are expensive to staff and administer, not all hospitals have them; therefore, newborns are sometimes transported from one hospital to another that has an NICU. Even though the infant is under constant medical supervision, most authorities agree that parents should be allowed to

spend as much time as possible with their newborns to promote parent–infant bonding. Some NICUs allow parents to “room in” with their babies.

Other children with severe and multiple disabilities might seem typical at birth but are recognized as having pervasive developmental disabilities within the first couple years. In the case of very serious TBI, an individual might actually be developing normally until the event that causes severe brain damage. Early intervention therefore should be seen as having two meanings: (1) early in the child’s life and (2) as soon as possible after the disability is detected.

The Division for Early Childhood (DEC) of the Council for Exceptional Children (CEC) recommends practices based on six criteria that are considered essential to early intervention programs in special education: (1) research- or value-based practices, (2) family-centered practices, (3) a multicultural perspective, (4) cross-disciplinary collaboration, (5) developmentally and chronologically age-appropriate practices, and (6) adherence to the principle of normalization (see Dunst & Espe-Sherwindt, 2017; Noonan & McCormick, 2006; see also discussion of normalization in Chapter 1).

**RESEARCH- OR VALUE-BASED PRACTICES** Early intervention programs should be based as much as possible on techniques that research has shown to be effective (Dunst & Espe-Sherwindt, 2017; Morris & Mather, 2008). Unfortunately, it is not always possible to conduct all the necessary research before an approach or technique is adopted. The CEC task force recommends that when research has not provided definitive evidence of an approach’s effectiveness, the approach should be based on values held by the early childhood special education community. Some of these value-based practices are providing individualized practices for each child and family, communicating with family members in a nonpaternalistic manner and with mutual respect and caring, making center environments safe and clean, and providing opportunities for families to have access to medical decision making.

**FAMILY-CENTERED PRACTICES** At one time, the prevailing philosophy in early childhood special education programming ignored parents and families at best or viewed them primarily as potential negative influences on the child with disabilities. When early intervention programs did involve parents, the assumption often was that the parents had little to offer and were in need of training to improve their parenting skills. Although it’s true that some parents do need to be educated about how to be better parents, to assume that this is always the case is paternalistic and off-putting to the majority of parents, who are very capable. For this reason, authorities now recommend that one not assume that parents have little or nothing to offer with respect to how to work with their children. Instead, they emphasize that parents, siblings, and extended family can be a valuable and integral part of the educational process for young children with disabilities.

As we discussed in Chapters 1, 2, and 4, IDEA also recognizes that parents and families should be central to the educational process for infants and toddlers. The requirement for individualized family service plans (IFSPs), in fact, dictates that the family be central in the decision-making process for the child. A family-centered philosophy means taking into account the particular priorities and needs of the family when developing an educational intervention plan for the child (see Section XI of Kauffman, Hallahan, & Pullen, 2017).

**MULTICULTURAL PERSPECTIVE** Given the changing ethnic demographics in the United States, it is critical that all special education programming be culturally sensitive. It’s particularly important that early intervention professionals adopt a multicultural perspective because parents are often still coping with the stress of having had their child diagnosed with a disability (Dunst & Espe-Sherwindt, 2017; Noonan & McCormick, 2006). Having at least someone in the program who can speak the family’s language is important. So is communicating respect, caring, and sensitivity. And it’s important to provide services that are unbiased and nondiscriminatory with regard to disability, gender, race, religion, and ethnic and cultural orientation. Perhaps the most important multicultural factor, however, is providing services that are effective (Kauffman, Conroy, Gardner, & Oswald, 2008).

## RESPONSIVE INSTRUCTION

### Meeting the Needs of Students with Low-Incidence, Multiple, and Severe Disabilities

#### POSITIVE BEHAVIORAL INTERVENTION AND SUPPORT

##### *What Is Positive Behavioral Intervention and Support?*

Reauthorizations of the Individuals with Disabilities Education Act require teachers, school systems, and those involved with students who exhibit challenging behaviors to approach problematic behavior through a mechanism called positive behavioral intervention and support (PBIS). PBIS refers to the process of identifying alternative, acceptable ways to communicate through teaching more appropriate behaviors and/or changing the environment to reduce the likelihood of prompting the undesirable behavior (Kauffman, Nelson, Simpson, & Ward, 2017; Kogel, Kogel, & Dunlap, 1996). This approach to behavior management differs fundamentally from traditional behavior modification plans that focus on the elimination of target behaviors, yet do not take into account possible environmental or personal triggers when doing so. For example, a student's undesirable behavior of banging his head on his desk might be eliminated by placing a baseball cap on his head. Although this might appear to be an acceptable solution, if the student's banging was a sign of boredom or an anxiety-producing peer in the vicinity, the baseball cap solution does not address the function of the behavior, and it is likely that another behavior will manifest in response to the original source of the behavior.

PBIS, by contrast, is guided by two fundamental assumptions: (1) Each behavior carries a communicative intent, and (2) typically, multiple factors influence the presence of specific behavior. Interventions based on these assumptions, therefore, include a functional behavioral assessment (FBA) (Horner, Vaughn, Day, & Ard, 1996; Kauffman et al., 2017).

FBA seeks to identify the purpose of the behavior and supporting environmental conditions. The results of such assessment lead to the development of multifaceted plans that can include changing situational events, altering events that immediately precede the behavior, teaching alternative responses to the situation, and providing meaningful reinforcers to promote acceptable responses.

##### *Applying the Research to Teaching*

The following support strategies are all involved in implementing PBIS:

- Remove high-frustration activities (e.g., difficult assignments, undesirable directives).
- Select functional and meaningful (from the student's perspective) curricula.
- Reduce fear or anxiety about a situation through pre-correction (e.g., a teacher might suggest what to do when feeling frustrated).
- Teach more appropriate ways to make requests or express oneself.
- Use behavior modification to reinforce desired behaviors and communicate nonacceptability.
- Create activities that build on student interest and strength.

One important component of implementing PBIS is to select functional and meaningful curricula for students. Typically, as students with multiple or severe disabilities progress through school, their curriculum becomes increasingly functional.

BY KRISTIN L. SAYESKI

**CROSS-DISCIPLINARY COLLABORATION** Because infants and young children with multiple and severe disabilities by definition have needs in multiple areas, best practice dictates the involvement of professionals from several disciplines. It's critical that these professionals collaborate in a coordinated way to provide high-quality services. Cross-disciplinary models vary, but the most essential feature for success is that the professionals in each of the disciplines work collaboratively, not independently. Some authorities also recommend that professionals should be willing to share roles.

**DEVELOPMENTALLY AND CHRONOLOGICALLY AGE-APPROPRIATE PRACTICES** The term *developmentally appropriate practice (DAP)* was first used by the National Association for the Education of Young Children, an organization that focuses on early childhood education for children without disabilities. DAP refers to the practice of using educational methods that are at the developmental levels of the child and that meet the child's individual needs. Many early childhood special educators agree with the notion of DAP, but they believe that it should be balanced with the need for using educational methods that are also chronologically age appropriate. They believe that young children

with disabilities should be educated as much as possible alongside their same-age peers without disabilities rather than with much younger peers who do not have disabilities.

## Transition to Adulthood

Transition to adulthood is a critical time for most people with severe and multiple disabilities. Special education has made great strides in developing transition services for people with disabilities. Much of this progress has been made because of a change in philosophy about how people with disabilities are treated, and this change is nowhere more evident than in the treatment of people with severe and multiple disabilities. For example, not long ago, the best employment that individuals with severe and multiple disabilities could hope for was in a **sheltered workshop**. Now, however, a much wider range of options is available, including, for some people, **competitive employment** alongside workers who do not have disabilities.

**CHANGING PHILOSOPHY** We can point to at least two principles of transition programming that reflect the change in philosophy toward treating people with severe disabilities with more dignity (Avellone & Taylor, 2017; Inge, 2017; Inge, Wehman, & Seward, 2017). First, as we noted in Chapter 5, is the emphasis on **self-determination**. As part of this emphasis on self-determination, professionals have developed a number of **person-centered plans**, which focus on the student's preferences and those of the family in planning for the future (Snell & Brown, 2006). Although person-centered planning is now part of most programs for people with severe disabilities, some have suggested that such plans are not a panacea (e.g., Osborne, 2005).

Second, authorities now recommend that natural supports be an integral part of transition planning. Rather than always creating new services for a person's particular needs, using **natural supports**, professionals first try to find the available resources already existing in the workplace or the community. With respect to work, the use of natural supports might mean training co-workers to provide assistance rather than immediately assuming that a **job coach** is required. With respect to community living, the use of natural supports might mean the person with a disability could live in an apartment, with assistance in **daily living skills** from a neighbor, family member, or paid attendant, rather than living in a residential facility with attendants.

**VOCATIONAL PROGRAMMING** A student's IEP must contain a transition plan, beginning no later than age 16 (and by age 14 when appropriate). The transition plan should contain recommendations for how to ready the student for the world of work and/or for postsecondary education or training.

For many students with severe and multiple disabilities, vocational training should begin in elementary school, because it might take several years for them to acquire all the skills needed to hold down a job successfully. In elementary school, the training might consist of learning to keep on schedule, building social skills, performing work-like tasks (e.g., helping to take attendance, collecting lunch money), and beginning to learn about different types of jobs.

In secondary school, the focus shifts to involving students in actual work situations in the community with the help of a job coach. The students should be involved in selecting these placements, which should vary sufficiently so that the students experience a good sample of the kinds of jobs available and can discover what they are good at and enjoy. In the early stages, this might involve the students' volunteering in several different types of placements. Later, it's preferable for students to engage in paid work placements. Being paid adds to the reality of the experience and provides an opportunity for students to learn how to handle finances.

**COMMUNITY AND DOMESTIC LIVING SKILLS** As we noted in Chapter 5, community living skills involve using transportation, shopping, using telephones, managing money, and using the Internet. Domestic living skills include preparing meals, doing laundry, doing housekeeping, performing yard maintenance, and so forth. Because students

aren't that far away from the time when they will move out of their parents' home and because teaching domestic skills is often done in small groups, there are some advantages to using a setting other than their own home. Thus, domestic living skills are often taught in a school setting, such as the school cafeteria.

Another reason for using the school as the instructional setting some of the time is to ensure that the student with disabilities has a chance to interact with peers who do not have disabilities. Inclusion in regular school programs provides social opportunities for students, and social skills are critical for successful integration into the community and workplace (see Avellone & Taylor, 2017; Inge et al., 2017).

The last 30 to 40 years have brought enormous strides in preparing people with multiple and severe disabilities to lead productive lives as adults. It wasn't that long ago that people with multiple and severe disabilities were housed in large residential institutions and had minimal contact with the public. Today, with intensive and extensive instruction and the support of professionals and the community, many people with multiple and severe disabilities can aspire to work alongside persons without disabilities and live independently or semi-independently by themselves or in a small community residential facility (CRF).

#### MyLab Education Self-Check 13.4

#### MyLab Education Application Exercise 13.4: Small Group Instruction for Students with Deaf-Blindness

Watch a video in which a teacher is working on a language lesson with the students. Answer the questions that follow.



## ▼ chapter thirteen SUMMARY

### What is the definition of low-incidence, multiple, and severe disabilities, and what is the prevalence?

- Low-incidence, multiple, and severe disabilities are those that occur relatively infrequently and require extensive support in more than one major life activity, such as mobility, communication, self-care, independent living, employment, and self-sufficiency. Probably 1% or fewer of all learners have such low-incidence, multiple, or severe disabilities.

### What is traumatic brain injury, and how might it affect education?

- Traumatic brain injury (TBI) is injury to the brain resulting in total or partial disability or psychosocial maladjustment that affects educational performance.
  - It may be the result of closed head injuries or open head injuries.
  - It may affect cognition, language, memory, attention, reasoning, abstract thinking, judgment, problem solving, sensory or perceptual and motor disabilities, psychosocial behavior, physical functions, information processing, or speech—all of which are important in school.

### How is deaf-blindness defined, and what are the special educational problems it entails?

- Deaf-blindness is defined by significant impairments in both hearing and seeing, although the individual may have some residual hearing or sight.
  - Deaf-blindness may be caused by a variety of genetic and chromosomal syndromes, prenatal conditions, and postnatal conditions.
  - The person who is deaf-blind has difficulty accessing information, communicating, and navigating the environment.
  - Deaf-blindness requires direct teaching; predictable, structured routines; and emphasis on communication and mobility.



martin bowra/istockphoto

### What educational considerations apply to many students with low-incidence, multiple, and severe disabilities?

- Communication, behavior management, early intervention, and transition to adulthood are concerns that apply to many learners with these disabilities.
- Augmentative and alternative communication (AAC) is important for those who can't communicate effectively through speech.
- Common behavior problems requiring special management include self-stimulation, self-injury, tantrums, aggression toward others, and lack of daily living skills, all of which may require functional behavioral assessment and positive behavioral support.
- Early intervention should be based on both research and values and be family centered, multicultural, cross disciplinary, and age appropriate, and feature normalization.
- Transition to adulthood should honor the concepts of person-centered planning and natural supports, feature vocational programming, and include community and domestic living skills.

## ▼ INTERNET RESOURCES

### Pertinent Organizations

- The United Cerebral Palsy Association ([www.ucp.org](http://www.ucp.org)) provides information and resources for people with CP and their families.
- Two websites ([www.deafblind.com](http://www.deafblind.com) and <http://nationaldb.org>) provide a variety of information about learners with low-incidence, multiple, and severe disabilities.
- More information about traumatic brain injury may be found at the Brain Injury Association of America ([www.biausa.org](http://www.biausa.org)).