REFLECT UPON

• What do we mean by severe intellectual disabilities? What is the definition of multiple disabilities? How are these conditions related?

• What are the significant characteristics of students with severe intellectual and/or multiple disabilities?

• How many students have severe intellectual disabilities and multiple disabilities, and what are the causes of these disabilities?

• What types of assessment and planning procedures are used with students with severe intellectual disabilities and multiple disabilities?

• What should we teach students with severe intellectual disabilities and multiple disabilities, and how should we teach them? What other types of supports should be provided?

• What are some of the major issues related to educating students with severe intellectual disabilities and multiple disabilities?
Pam Mims started out in one area, got into another, and then found her teaching home. Her first goal in college was to be a physical therapist, but that didn’t work out. Switching her major to special education seemed like a logical thing to do, but what she studied was how to teach students with learning disabilities. When she found out after graduation that the only available job was in “severe-profound,” she thought, “Why not? I was always interested in doing something different. And I thought, like, ‘this will be fun, we can do coloring and stuff like that.’ I really had no idea.”

What Pam came to find was that the middle school students she was assigned to teach had many medical needs; were often not very responsive; and sometimes exhibited unusual behavior, including stereotyped movements and self-injury. But the challenge didn’t scare her away. In fact, it drew her in and made her want to learn more about how to meet her students’ needs. Now in her 6th year, Pam says, “I love my job. I couldn’t be a traditional teacher, but working with these guys . . . it’s challenging; there’s always something. And the families really keep me going too.”

A typical day for Pam begins when she helps get her kids off the bus and into the classroom. She teaches seven students and has two full-time assistants helping her. The day begins with toileting and then breakfast. From that point there is a group activity where they discuss what they will be doing during the day. Some students use a picture or object communication system to express preferences for the day. They proceed to working individually or in small groups on their individual objectives during the morning and into the afternoon. During instruction, Pam will use systematic instruction and collect performance data in order to document students’ progress. This is important both for their individual objectives and for documenting progress for the state’s alternate assessment portfolio, which must be completed for each of her students.

Lunch begins at about 11:00 and takes about 2 hours to complete. In fact, toileting, hygiene, and eating require a lot of time in a typical day. Throughout the day the students receive services from a physical therapist and speech therapist who come into their classroom and work with them individually. They also leave their classroom to go to specials—art, music, PE—or to visit other classes. It’s a little frustrating to Pam that they are not more included, but that’s the reality.

Pam is also frustrated by some of the other conditions related to her work. Her classroom can be very busy with the comings and goings of assistants,
to Students to Students module on the DVD-ROM and click on clip 5: Severe & Sensory.

Reflective Exercise #1
Would you consider teaching students with severe disabilities? What do you think would be most interesting about such a teaching position? What would be most challenging?

Until the mid-1970s, many public schools in the United States did not admit some children. The problem was that these schools thought the children’s disabilities were too challenging and their potential for learning too limited. This changed in 1975 when IDEA was first passed because, as you know, IDEA requires U.S. public schools to accept all children with disabilities regardless of the extent of their disabilities.

In this chapter we will discuss two overlapping groups of students: those with severe intellectual disabilities and those with multiple disabilities. Students who have severe intellectual disabilities are at the lower end of the spectrum within the category of intellectual disabilities. (This category also includes students with mild intellectual disabilities, and they are discussed in Chapter 8.) Traditionally, students with more severe intellectual disabilities are referred to as having “moderate,” “severe,” or “profound” intellectual disabilities (or mental retardation). Students with multiple disabilities are students who have an intellectual disability—usually in the severe to profound range—who also have at least one additional disability such as blindness or a physical disability. There is a great deal of overlap between the groups because individuals who have more severe intellectual disabilities are also likely to have additional disabilities and those with multiple disabilities are likely to have significantly reduced intellectual abilities. Many professionals use the term students with severe disabilities in a generic sense when referring students in either group. For the purpose of this chapter, we will use that term unless additional clarification is necessary.

All students with disabilities present unique challenges to their teachers, and this is certainly true for students with severe disabilities. However, as we saw with Pam Mims, these students can be a strong magnet that draws teachers to them in a way that might not occur with other students. In this chapter we hope to give you some relevant information about these students. For some of you, this information may be an introduction that will attract you to these students as Pam Mims was attracted. For others, we hope that it will help you better understand and accept these students as individuals just as you do others with special needs. Most important, we want to let you know who these students are and what types of services and programs are most appropriate for them. For a quick introduction, you might wish to examine the critical information about students with severe disabilities in the “FAQ Sheet.”
# FAQ Sheet

## Students with Severe Intellectual Disabilities and Multiple Disabilities

**Who are they?**

Classifications may include
- Intellectual disabilities (moderate, severe, profound)
- Multiple disabilities
- Deaf-blindness
- Developmental delay

**What are typical characteristics?**

Significant weaknesses in
- General learning ability
- Personal and social skills
- Sensory and physical development

Some may
- Exhibit uncommon characteristics (self-stimulatory or self-injurious behavior)
- Have serious medical conditions

**What are the demographics?**

- 0.5 to 1% of all school-age children will have severe disabilities. This is about 10% of all students with disabilities.

**Where are students educated?**

- The majority of these students will be placed in self-contained special classes, and many will be in special schools. Sometimes they are included in regular classrooms.

**What are the outcomes?**

- Most live with their families or in community-based residential settings after high school.
- Some may work in supported employment settings or in sheltered workshop settings.

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### Definitions and Classification Criteria for Students with Severe Intellectual Disabilities and Multiple Disabilities

What do you think of when you hear the term *severe*? Do you think of someone getting a “severe reprimand” or having a “severe sunburn”? When we say *severe*, generally we think of a condition that is (1) generally not positive and (2) beyond *mild* in terms of its seriousness or harshness. Reviewing the history of the concept of severe disabilities, we find that different ideas have been expressed over time. The more common concepts reflected by the term severe disabilities include the following (Westling & Fox, 2004):

- A condition in which the development of typical abilities is in some way negatively affected, resulting in diminished self-care ability
• A generic concept that includes traditional disability categories such as those pertaining to persons who have moderate, severe, or profound intellectual disabilities; those who fall on the autism spectrum; and those who have multiple disabilities, including intellectual disabilities
• Persons who exhibit relatively high rates of uncommon behaviors, such as self-stimulation, while at the same time lacking typical age-appropriate skills
• Persons who require extensive services to achieve their maximum potential

TASH, an organization supporting “equity, opportunity and inclusion for people with disabilities” (formerly called The Association for Persons with Severe Handicaps), defined the condition of severe disabilities in terms of necessary support, as suggested by the last meaning in the previous list:

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

As you may expect, persons who are considered to have severe disabilities constitute a very heterogeneous group. Although many people might be considered to have a severe disability, each is quite different from the other. If there is a common characteristic of the group, it is that individuals’ ability to function on a day-to-day basis is very limited. As the TASH definition states, these individuals need a great deal of support to participate in various life activities. Here we outline some of the traditional categories of persons with severe disabilities.

INTELLECTUAL DISABILITIES CLASSIFICATIONS

As you may recall from Chapter 8, historically professional organizations and agencies have placed persons with intellectual disabilities in different subcategories based on IQ levels and functional abilities. These subcategories of intellectual disabilities and their approximate corresponding IQ levels included mild (55–70), moderate (40–55), severe (25–40), and profound (below 25).

Beginning in 1992, the American Association on Mental Retardation (AAMR, now the American Association on Intellectual and Developmental Disabilities) stopped using subcategories and instead developed a system in which it referred to individuals with intellectual disabilities based on support needs rather than disability levels (American Association on Mental Retardation, 2002). However, because classifications such as moderate, severe, and profound are still used by many organizations and agencies (such as public schools, human service agencies, and the American Psychiatric Association [1994]) when referring to people with intellectual disabilities, we think it is important that you have an accurate view of the ability of these individuals classified under these headings.

Persons with moderate intellectual disabilities score above 35 to 40 and below 50 to 55 on traditional intelligence tests. Generally, they are able to learn many basic skills in areas such as communication, self-help, functional academics, domestic skills, community functioning skills, and vocational skills. Many adults with a moderate intellectual disability are able to manage all of their own daily self-care needs, prepare food, participate in conversations, interact appropriately with others, use money correctly, and hold different kinds of jobs in the community (Westling & Fox, 2004).

If a person with severe intellectual disabilities has received a good education and has had adequate support, by adulthood he or she may have learned several useful skills. These could include being able to eat with a fork or spoon, dressing and bathing with some supervision, using the toilet independently, and washing hands and face without help (although he or she may have to be told or reminded to do so). The individual’s physical ability will probably be fair to good, and he or she will probably be able to attend school or work in a supported employment setting.

Reflective Exercise #2

Based on certain concepts of severe disabilities, some persons who have a moderate intellectual disability would not be considered to have a severe disability. What’s your opinion?
able to walk, run, hop, skip, dance, and maybe skate, sled, or jump rope. The person with a severe intellectual disability probably will not learn many academic skills, such as reading, but may be able to recognize some words and common signs and enjoy books read aloud. The person may know that money is of value but may not be able to state the specific value of coins. Most adults with severe intellectual disability will be able to communicate using signs, symbols, or words (McLean, Brady, & McLean, 1996).

Often individuals with **profound intellectual disabilities** are referred to as having “the most severe” or “significant” disabilities. Their developmental levels will often be comparable to that of a child under 12 months of age. It is difficult to provide a typical profile of an individual at this functioning level because there is such an extreme degree of variability among them. Some are capable of near independent functioning in common self-care activities, such as eating and toileting, and may also possess functional skills in other domains such as vocational and domestic skills. Others may not speak, may have very limited sensory and motor abilities, might be nonambulatory, and may only minimally attend or respond to environmental stimuli. Still, many of these persons demonstrate the ability to learn and are capable of at least “partial participation” in normal daily activities (Westling & Fox, 2004).

**INTELLECTUAL DISABILITIES SYNDROMES**

Another way professionals categorize persons with severe disabilities is according to specific syndromes. A **syndrome** is a condition signified by a cluster of similar physical and behavioral characteristics having a common etiology or origin. Table 12.1 lists a few syndromes that might result in a “severe disability” classification. For additional information about these and other syndromes, you should refer to more complete references such as Batshaw (2002) or Dykens, Hodapp, and Finucane (2000).

**MULTIPLE DISABILITIES**

As we have said, the category of multiple disabilities usually includes a combination of some degree of intellectual disability as well as concomitant physical or sensory disabilities. The level of the intellectual disability is usually in the severe to profound range, but the individual’s intellect may actually be higher than what is estimated. Because of how the person’s physical condition limits his or her interaction with others, precisely determining how intelligent the person is may be very difficult.

People with multiple disabilities usually have various health problems that complicate and worsen their disabilities. They often develop diseases such as high blood pressure, obesity, brittle bones, depression, and general tiredness. Other conditions include cardiovascular (heart) diseases, respiratory diseases, eating disorders, and growth impairments (Heller, 2004; Thuppal & Sobsey, 2004).

**CHARACTERISTICS OF STUDENTS WITH SEVERE INTELLIGENCE DISABILITIES AND MULTIPLE DISABILITIES**

Considering the pool of students who can be classified as having severe disabilities, you will certainly agree that there are many differences among them. You might also agree that to speak in general about their characteristics is almost impossible. If you teach or work with any of these students, or if you do in the future, the best advice we can offer is to take your time to get to know each one. Having said that, though, we think it’s fair to help you understand the very diverse population of these students by discussing in a limited way some things about them that seem to be generally true.

**INTELLIGENCE**

Quantitative measures of intellectual ability of persons with severe disabilities (i.e., IQ scores) as well as qualitative indicators (e.g., ability to demonstrate independent adaptive behavior) suggest that they function significantly below average. Individuals...
TABLE 12.1
SYNDROMES ASSOCIATED WITH SEVERE INTELLECTUAL DISABILITIES

<table>
<thead>
<tr>
<th>Name</th>
<th>Etiology</th>
<th>Key Features</th>
<th>Sources of Information</th>
</tr>
</thead>
</table>
| Down syndrome         | Chromosomal anomaly (trisomy 21) | Mild to severe intellectual disabilities  
Physical characteristics: a flattening of the back of the head; slanting eyelids; small folds of skin at the inner corners of the eyes; depressed nasal bridge; small ears, mouth, hands, and feet; decreased muscle tone  
60 to 80% have hearing impairments  
40 to 45% have congenital heart disease  
A tendency toward obesity  
Hypothyroidism affects 15 to 20%  
Frequent skeletal problems, immunological concerns, leukemia, Alzheimer’s disease, seizures, sleep disorders | National Down Syndrome Society (http://www.ndss.org/)  
National Association for Down Syndrome (http://www.nads.org/)  
Roizen (2001) |
| Fragile-X syndrome    | X-linked transmission             | Physical characteristics: a long, narrow face; large ears, jaw, and forehead  
Common characteristics: an unusual style of social interaction; may avoid direct eye contact; sometimes hand flapping or hand biting; may speak fast and repetitiously; can have short attention span and hyperactivity | National Fragile-X Foundation (http://www.fragilex.org/)  
Fragile X Research Foundation (http://www.fraxa.org/)  
Meyer & Batshaw (2001) |
| Fetal alcohol syndrome| Consumption of alcohol during pregnancy | General developmental delay, growth problems, and other physical problems  
Intellectual disabilities may range from mild to severe  
May have a small head, narrow eye slits, a flat midface, and a low nasal bridge  
Babies may have sleeping problems, be restless and irritable, and have sucking problems | FASlink (http://www.acbr.com/fas/)  
Wunsch, Conlon, & Scheidt (2001) |
| Prader-Willi syndrome | Chromosomal anomaly on chromosome 15 | Often results in a moderate mental disability, but measured IQs have ranged from 40 to more than 100  
Between ages 1 and 3, will develop insatiable appetites, become very preoccupied with food, want to eat continuously, and develop life-threatening obesity. Begin to show delayed psycho-motor activity, intellectual delay, and emotional/behavioral problems | Prader-Willi Syndrome Association (http://www.pwsausa.org/)  
Scott, Smith, Hendricks, & Polloway (1999) |
| Angelman syndrome     | Chromosomal anomaly (a portion of chromosome 15 is missing) | Usually severe to profound intellectual disabilities  
Tend to have jerky body movements and stiff-legged walking  
Common facial features such as a wide smiling mouth, a thin upper lip, and deep-set eyes  
Often have fair hair and skin and light blue eyes  
About 80% of the time they will have epilepsy | Angelman Syndrome Foundation (http://www.angelman.org/angel/) |

who are classified as having severe disabilities will generally have an IQ below 35 or 40, sometimes going so low that it cannot be reliably measured. From a developmental perspective, this means that these individuals, when they reach maturity, at best may have a mental age that ranges from below 1 year of age up to 3 or 4 years of age. This limited degree of development means that these persons will continue to need regular support from family, friends, and professionals throughout their lives.

www.prenhall.com/roenberg
LEARNING

From an instructional point of view, teachers and others can expect that the learning abilities of students with severe disabilities will be very weak. In what is now considered a classic paper, Lou Brown and his colleagues (1983) made a strong case for providing the most functional education possible to students with severe disabilities based on the students’ learning weaknesses. Brown et al. pointed out that, with regard to learning new skills, these students

- Require a greater amount of time to learn
- Have much difficulty in learning more complex skills
- Overall, learn fewer skills as compared to other students

While it is possible for these students to learn many skills, the number and type of skills will not be comparable to those learned by most individuals. So those skills that we attempt to teach should be very functional and applicable to the individual’s current and future needs.

You can see evidence of the limited learning abilities of students with severe disabilities in various ways. Psychological research on specific aspects of learning can help us understand some of the specific learning weaknesses of these students. Westling and Fox (2004) summarized some of the most significant learning difficulties of students with severe disabilities:

- **Attending to relevant environmental stimuli, dimensions of stimuli, and cues within the dimensions.** This means students may have difficulty learning what feature of an item or situation gives the information necessary for correct action.
- **Observational and incidental learning.** Observational learning is learning through watching and imitating a model (i.e., another person). Incidental learning is learning something that was not taught directly but that might be learned if attended to. Students with severe disabilities benefit from these forms of learning less well than do students who do not have disabilities.
- **Memory:** Major problems in this area are related to not being adequately exposed to the learning condition initially, having insufficient opportunity to practice or use the information or skill after it is initially learned, and then not using strategies adequately to pull the information from long-term memory for use when needed.
- **Skill synthesis.** Students with severe disabilities often fail to see the relation of different pieces of information to other information or to see how one area of knowledge or skill can be combined with another to produce a new skill set. Therefore, you usually cannot teach several separate skills and expect the student to organize them for application.
- **Generalization and discrimination.** With weak generalization skills, students have difficulty applying what was learned in one situation to other places, times, people, activities, and materials. Conversely, with weak discrimination skills, a student doesn’t know when to do something and when not to do it. For example, a young man might know it is okay to hug his mom but not realize it is inappropriate to hug another woman.
- **Self-regulation.** In order to self-regulate, an individual must monitor her own behavior, evaluate it as being correct or incorrect, and then self-reinforce or withhold reinforcement. This is a sophisticated task, one that students with severe disabilities often have difficulty with. However, some research shows instructional methods might help students learn skills in this area (e.g., Agran, Fodor-Davis, Moore, & Martella, 1992; Hughes & Agran, 1993; Hughes, Hugo, & Blatt, 1996).
SOCIAL BEHAVIOR

Many people with severe disabilities have full lives. They have friends, enjoy various leisure and recreational activities, and, as teenagers or adults, may have jobs in the community. However, these outcomes do not occur as easily as they do for persons without disabilities, and usually some intentional planning is necessary.

The learning weaknesses we have described can have an effect on the challenges that people with severe disabilities face when attempting to learn appropriate social skills. For example, they may not easily learn social skills simply by observing someone else and picking up the skills incidentally; they may not generalize skills that have been learned, or they may use social skills that are inappropriate for the time and place. As a result, it’s common to see inappropriate social behaviors among persons with severe disabilities, especially when they have not received adequate instruction or had enough learning experiences.

On the other hand, persons with severe disabilities may develop positive relations with others when they have the opportunity to do so, when they are taught appropriate social behaviors, and when others have a little understanding about the nature of the person and how he is affected by his disabilities (Westling & Fox, 2004). Certainly this should be an important goal of instruction for these students.

Sometimes persons with severe disabilities have very challenging behavior. They may exhibit unusual, repetitive behaviors that are called stereotyped behaviors, or stereotypies. Or sometimes we may see episodes of aggression, self-injury, or noncompliance. The cause of these behaviors is often difficult to understand, but several theories have been developed in an attempt to explain them. Today, as we discussed...
• Steve indicated two desires very reliably: He wanted something to drink, and he wanted to get out of his chair and lie on his mat. When he did so and Pam responded, his screaming and self-hitting went way down. In fact, this behavior went from an average of more than 300 minutes a day to near zero!

As Steve’s behavior began to improve, Pam was assisted by faculty members from Western Carolina University and its teacher support program. Through their efforts she located an electric wheelchair equipped with some special sensing-vibrating devices to let Steve try to propel himself.

• When Steve was placed in the wheelchair, Pam taught him how to press the joystick to go forward, backward, right, or left. The sensing devices were attached to vibrators in the seat of the chair to let Steve know when he was going to run into something.

• Pam used systematic instruction and was successful at teaching her student to go forward and to stop the chair. It was reported that Steve was always upright, smiling, and attentive in his electric wheelchair and never screamed or hit himself while using it!

The challenges Steve presented were certainly difficult but are not unlike those of many students who have severe or profound intellectual disabilities and multiple disabilities. Teachers of these students must be inquisitive and creative in order to seek and find answers that will lead to effective instructional approaches. There are many other students like Steve, and many more teachers like Pam Mims, who are needed to provide them with the most effective instruction. Perhaps you would be interested in engaging in this very meaningful work.

For more information on intervening with students who exhibit challenging behaviors, you may find the following references useful:


EXTEND AND APPLY

• What was Pam’s greatest challenge? Was it Steve’s lack of skills? His challenging behavior? Or his mother’s expectations?
• What personal characteristics do you have that might help you be an effective teacher of students like Steve?
• What particular strategy did Pam use that you would like to learn more about?

Activity: Go to the Student and Teacher Artifacts section of the Teacher Prep website, click on Special Education and then module 16: Severe Disabilities. Read Artifact 1 and answer the accompanying questions. Think about what kind of assistive technology could be beneficial for Steve.

In Chapter 5, professionals often use functional behavior assessment and positive behavior support programs in an effort to improve challenging behaviors. A great deal of research has shown these procedures to generally be very effective (Carr et al., 1999; Hanley, Iwata, & McCord, 2003). In the “Can You Help Me with This Student?” feature we describe how a functional assessment and positive behavior support were used to address Steve’s very serious behavioral problem. (He is a student with deaf-blindness and profound intellectual disabilities.)

PHYSICAL CHARACTERISTICS

As we have stated in this chapter, individuals with severe intellectual disabilities and multiple disabilities often have serious medical or physical conditions. Cerebral palsy and epilepsy are two conditions that are often present (see Chapter 14). Other conditions can also limit normal physical development and activities. Common medical conditions include gastrointestinal disorders, inadequate ventilation of lungs, kidney and heart problems, sensory problems, and frequent infections (Thuppal & Sobsey, 2004).

In the classroom, teachers of students with severe disabilities will typically work with school nurses as well as physical and occupational therapists to address students’ physical and medical needs. On a regular basis, students may have nutritional problems, anemia, dehydration, skin irritation and pressure sores, respiratory infections, asthma, ear infections, and contractures (Heller, 2004). These kinds of conditions led Pam Mims to think that part of Steve’s problems might have been related to his discomfort (see the “Can You Help Me with This Student?” feature).

Reflective Exercise #4

How do you think students’ physical and medical characteristics might affect their learning abilities? Do you think this would be a challenge to you as a teacher? How do you think a successful teacher would approach these students?
PREVALENCE AND TRENDS

It is difficult to pin down the exact number of public school-age students with severe disabilities. One problem is that there are no universal definition or accepted criteria. In our “FAQ Sheet,” we reported an estimate of students with severe disabilities to be about 0.5 to 1% of all school-age children. This works out to roughly 10% of all students with disabilities. These figures are based on numbers reported by the U.S. Department of Education (2005) in certain disability categories, with a few adjustments to subtract students with milder disabilities.

What the numbers mean to you is based on what role you might play. Let’s consider an elementary school with 400 students where inclusion is the norm. Of the 400, the school may provide special education services to 45 to 50 students. If they are proportionally represented, there may only be four or five students in the whole school with more severe disabilities. So if you are a special education teacher working with students with more severe disabilities in this school, you will have relatively few students. If you are a classroom teacher working in this school, you should not see more than two or three students with disabilities in your classroom and probably no more than one student with severe disabilities.

It is very hard to track the occurrence of disabilities and changes in occurrence across different times and places. Epidemiologists undertake this type of research. From their work, some conditions or syndromes have been recognized as occurring more often or being identified more often—for example, autism, Fragile-X, and Angelman syndrome. To better understand how such conditions appear within our society, the Centers for Disease Control (2004) have conducted an epidemiological study of birth anomalies and developmental disabilities in the Atlanta, Georgia, metropolitan area.

CAUSAL FACTORS

Severe disabilities can result from numerous etiological conditions. It is common to classify causes as occurring before birth (prenatal), around the time of birth (perinatal), or after birth (postnatal). The major causes, most of which are prenatal, are briefly explained in this section. For more detailed information, see Batshaw (2002); Dykens et al. (2000); Beirne-Smith, Patton, and Kim (2006); or Taylor, Richards, and Brady (2005).

PRENATAL CAUSES

Common prenatal causes of severe disabilities include genetic conditions, chromosomal anomalies, maternal infections, the ingestion of harmful substances, and radiation.

Genetic Conditions

Rare genetic conditions can lead to children being born with certain syndromes that are characterized by severe intellectual or multiple disabilities. These genetic conditions may be recessive or dominant. If they are recessive, both parents of the child must be carriers of the condition, and each of their offspring will have a 25% chance of inheriting the condition. If the condition is due to a dominant genetic condition, only one parent must have the genetic information, and each child will have a 50% chance of inheriting the condition. Recessive conditions cause severe disabilities more often than dominant conditions do. Syndromes that occur due to recessive genetic conditions include Tay-Sachs disease.

Some syndromes result from genetic material located on the chromosomes that determine the sex of an individual—that is, the 23rd pair of chromosomes in a human cell. These are called X-linked conditions, and in these cases the mother is the carrier of the genetic material but does not have the condition herself. The most common

Reflective Exercise #5

If you are currently working in a school, can you describe the prevalence of students with severe intellectual disabilities and multiple disabilities? Do you see these students in inclusive schools? How many are in a classroom?
X-linked condition is Fragile-X (see Table 12.1). Another is Lesch-Nyhan syndrome, a condition characterized by a high frequency of self-injurious behavior.

**Chromosomal Anomalies**

The genetic conditions just described occur because of specific genetic information that one or two parents pass on to the child. The genes are situated on specific strands of chromosomes. There are 23 chromosome pairs, including 22 autosomes and the 23rd pair of sex chromosomes that determine the sex of a person.

Sometimes a strand of chromosome may not join another during conception or a strand may break off and/or attach itself to another strand in an uncommon way. These chromosomal anomalies are not genetic inherited disorders in the sense that the parents transmit them to their children. However, they do affect the development of the offspring in an adverse way because of the change in the chromosomal patterns.

Several syndromes due to chromosomal anomalies are listed in Table 12.1, including Down syndrome, Prader-Willi syndrome, and Angelman syndrome. Websites with additional information about these syndromes are included in Table 12.1 and also on our Companion Website.

**Maternal Infections**

Various viral or bacterial infections can occur during pregnancy that have little effect on the mother but may have more serious consequences for the developing fetus and result in severe disabilities. Rubella, cytomegalovirus, herpes, syphilis, and toxoplasmosis are common types of infections.

Most infections cause the greatest damage to the developing fetus during the first trimester of the pregnancy. At this time, the central nervous system is developing rapidly, and the infection can cause inflammation and damage brain tissue. The result is often severe intellectual disabilities and also physical and/or sensory disabilities.

**Harmful Substances**

If a mother consumes alcohol or takes drugs or ingests other chemicals during pregnancy, sometimes severe intellectual and multiple disabilities will occur. These substances can affect the development of the fetus by damaging the structure and functioning of cells. Physical growth, the developing brain, or both might be affected. For example, thalidomide, a drug developed in the 1950s to reduce morning sickness during pregnancy, results in impaired limb development; and alcohol can lead to brain damage. Anticonvulsant drugs and anticancer drugs are other agents that can lead to adverse development.

**Radiation**

If a woman is exposed to radiation during pregnancy (e.g., has an X ray for medical purposes), it is possible that the radiation may damage the baby’s developing brain. This could result in severe intellectual disabilities. For the most part, the risk is small unless the X ray is directly targeted at the woman’s stomach area.

Some have raised questions about the effects of being exposed to radiation before conception due to the possibility that the woman’s ova or the man’s sperm could be adversely affected by the radiation. Radioiodine therapy is often considered to create the greatest risk for this type of condition. A good discussion on this topic,
including answers to commonly asked questions, is available from the Health Physics Society (2005; http://hps.org/).

PERINATAL AND POSTNATAL CAUSES

Most of the conditions that lead a child to have severe intellectual and multiple disabilities occur during the prenatal period. However, there are perinatal and postnatal conditions that can affect the child’s development as well.

Conditions that can have an effect around the time of birth are often related to the health of the mother during pregnancy and when she is ready to deliver. If the mother has a chronic health condition, such as diabetes, toxemia, high blood pressure, or another ongoing illness, it may bear on the child’s later intellectual development. If the mother has an acute illness at the time of birth, such as a viral infection, it may be transmitted to the infant. An active case of genital herpes is an example. If the baby is delivered vaginally, he or she will contract the infection when coming into contact with the lesions. For this reason, the baby will be delivered through a caesarian section.

After the child has been born, other conditions can affect development and lead to severe disabilities. One is meningitis. This condition is a bacterial or viral infection of the spinal cord and the fluid that surrounds the brain. The bacterial form is treatable through antibiotics, but there is no effective treatment for the viral form. If the condition is not effectively treated, it can result in brain damage, hearing loss, or learning disabilities (Centers for Disease Control, 2003). Other conditions that can result in severe intellectual disabilities include nearly anything that can lead to sufficiently severe damage to the brain such as a near drowning, physical abuse, stroke, electric shock, or poisonous gas.

ASSESSMENT AND PLANNING

In Chapter 4 we discussed how students with disabilities are identified, the classification criteria for different disabilities, and how the IEP and other plans (such as individual family service plans and transition plans) are developed. We also explained the different types of tests and how they are used in special education to determine eligibility and to plan for students’ needs.

There are no specific tests used to classify a student as having a severe disability. School personnel will use intelligence tests and adaptive behavior assessments to determine if a child meets the eligibility criteria for intellectual disabilities, and individuals with severe disabilities will not perform well on these assessments and may not be able to acquire any meaningful score at all. But for these students, more important than assessing to determine eligibility is assessing to plan what to teach. This is what we discuss in this section: tools and procedures to help determine what to teach.

ADAPTIVE BEHAVIOR ASSESSMENT

When the teacher is ready to gather data about the student’s abilities and needs, a good place to start is with an adaptive behavior assessment. We described the content of adaptive behavior scales in Chapter 4. As you will recall, these scales assess skills that are especially useful for daily functioning. Usual items include daily living skills, some community skills, and functioning in key areas such as demonstrating appropriate social behaviors, communicating, motor abilities, and applying basic academic skills. We mentioned some of the commercially available scales in Chapter 4. The scales are completed by someone who knows the student very well, such as a teacher, a parent, or a caregiver, or through an interview, such as a teacher’s interview of a parent.

Adaptive behavior scales provide an important way to understand a student with severe disabilities (Browder, 2001). What the teacher can see from them is a profile of the “hills and valleys” showing a student’s strengths and weaknesses. This might give the teacher an idea about areas in which the student needs instruction or areas in which the student already has strengths to build on.
One problem with adaptive behavior scales is that they are too “high” for some students with very severe disabilities. By this we mean that, for students with the most severe intellectual disabilities or multiple disabilities, the items on the adaptive behavior scales are far beyond their skill level. When they can’t do anything on the scale, this information is not very useful for the purpose of planning instruction.

CURRICULUM/ACTIVITY GUIDES

In Chapter 4 we discussed curriculum-based assessment, which evaluates the student within the context of the curriculum he or she is working on. Similar to that, teachers can use existing curricula, primarily designed for students with severe disabilities, to help determine what might be important for a student to learn. Some states, school districts, or individual schools produce their own curriculum guides; but there are also commercially available curriculum or activity guides that can be useful. Examples are COACH (Giangreco, Cloninger, & Iverson, 1998), The Syracuse Community-Referenced Curriculum Guide for Students with Moderate and Severe Disabilities (Ford et al., 1989); Community Living Skills: A Taxonomy (Dever, 1988); and The Activities Catalog: An Alternative Curriculum for Youth and Adults with Severe Disabilities (Wilcox & Bellamy, 1987). Like adaptive behaviors scales, curriculum and activity guides can be very useful as a basis for conducting parent interviews to determine a student’s goals and objectives. Items in the guides can be rated to note whether or not the student can already do them. For example, the Syracuse curriculum guide allows each skill to be rated using one of the following:

• Needs assistance on most steps
• Needs assistance on some steps
• Performs all steps independently

COACH uses a similar procedure. Each skill is rated on the following scale:

• R—Resistant to assistance from others
• E—Early/emerging skill (1–25%)
• P—Partial skill (25–80%)
• S—Skillful (80–100%)

Once the various skills and activities within the guides have been rated, they may be prioritized by parents and teachers for instruction.

ECOLOGICAL INVENTORIES

An ecological inventory approaches the question of what to teach a student with severe disabilities from the perspective of what skills the student needs to learn to live more fully in his or her current or future environments (Brown et al., 1979). Ecological inventories can provide a wealth of information about what students need to learn, what they can already do, and what might be done to help them learn certain skills.

An ecological inventory first looks at key environments such as the home, the school, and maybe different places in the community. Then it looks at sub-environments, such as the kitchen at home or the cafeteria at school. Then we ask, “What does a person normally need to do to function in here?” In the kitchen, someone might prepare a meal; in the cafeteria, someone might walk through a line to get a meal.

As you can see, many different skills might be identified for different environments. So the next step is to work with the parents or caregivers to identify skills that would be most useful for the student to learn. For example, maybe preparing a meal isn’t the most appropriate thing for an 8-year-old to do, but helping to set or clear the table would be. These skills then become the key learning objectives for the student.

Once the teacher identifies objectives, she will need to determine what the student can and cannot do.
Once the teacher identifies specific possible objectives, she will need to determine what the student can and cannot do. The teacher will do this by writing a task analysis that includes the specific steps of the activity. The teacher then observes the student over several sessions as he is attempting to complete the task (this is usually referred to as baseline data). This allows the teacher to determine what the student can and cannot do, which provides the basis for what to teach the student.

PERSON-CENTERED PLANNING

Person-centered planning is not so much an assessment procedure as it is a process to help caring people develop a consensus about how to improve the quality of life for an individual with severe disabilities. There are different approaches to person-centered planning, and some have become fairly well recognized over the years. We will look briefly at two.

Personal Futures Planning

Personal futures planning (Mount & Zwernik, 1988) is meant to provide a positive approach for life planning for persons with severe disabilities. Its purpose is to help friends and family members plan ways in which the individual can have a better life that includes personal relationships, an active life in the community, and more personal control. Personal futures planning doesn’t focus on a person’s deficits but on developing more positive opportunities for the person. It also isn’t limited by current conditions and services but by what would be necessary to allow fuller participation in society. The process has five important characteristics:

1. It describes capacities and opportunities in people and environments.
2. It seeks ideals.
3. It involves people who interact on a daily basis with the person with a severe disability.
4. It encourages experimentation with new courses of action.
5. It prompts people to act and to accept commitments to be involved in improving the quality of life for the person with the disability.

The most significant outcome of personal futures planning is finding desirable images of the future. During the planning session, participants are asked to imagine ways for the person to have more positive life experiences. The process is concluded when an action plan is developed that will help the person to enjoy a better quality of life. This plan includes a “circle of support” of family members, friends, neighbors, and others who are close to the person with disabilities and who will help see that the action plan is undertaken and the person’s life is improved.

Making Action Plans (MAPs)

MAPs (Forest & Lusthaus, 1987; Vandercook, York, & Forest, 1989) is another person-centered planning process; but unlike personal futures planning, it focuses specifically on providing information for developing full inclusion placements for students with severe disabilities.

During a MAPs session, the individual with disabilities, family members, friends without disabilities, and teachers and other professional personnel gather to discuss the educational and life needs of the target individual. An important feature of MAPs is the inclusion of the targeted individual’s chronological-age peers on the planning team.

As the session proceeds, a facilitator asks participants to respond to the following key questions:

• What is the individual’s history?
• What is your dream for the individual?
• What is your nightmare?
• Who is the individual?
• What are the individual’s strengths, gifts, and abilities?
• What are the individual’s needs?
• What would the individual’s ideal day at school look like, and what must be done to make it happen?

Answers to the questions are intended to help determine the learning goals for the student and how instruction should be provided in an inclusive environment throughout the school day.

**EFFECTIVE INSTRUCTIONAL PRACTICES**

Students with severe disabilities will benefit from effective instruction that should begin when they are very young and continue throughout life. Even though they may not achieve the level of learning and development reached by individuals without disabilities, there is overwhelming evidence that good instruction can promote skill development and a better quality of life (Snell & Brown, 2005; Westling & Fox, 2004).

**PRESCHOOL PROGRAMS**

In Chapter 4 we described how states may offer programs for infants and toddlers with disabilities and how, at age 3, children with identified disabilities have the right to services through public schools. Children who have severe intellectual and multiple disabilities will almost always participate in these programs. Because their disabilities are often apparent early in life, their parents usually seek services very actively. Although early programs for children with severe disabilities will not eliminate the need for later services, they can maximize the child’s development, prevent secondary disabilities from occurring, and be a tremendous source of support to the child’s family.

Programs for infants, toddlers, and preschoolers with severe disabilities have many different features, but two are most important: They must be family-centered, and teaching and learning must be based on developmentally appropriate practices.

**Family-Centered Programs**

The younger a child is, the more related his or her learning and development are to the family’s well-being. Early interventionists will therefore work hard to support the family so that the family can support the child. A family-centered approach means that the services provided to a child will be directed by family needs and what will enhance the family’s ability to support the child (Bailey et al., 1998). This means that the professional who works with young children is more than a teacher of the child. He must also be a consultant, a resource, and an enabler for the family. Support of the family is an integral component of early intervention, and this is why the family’s strengths and needs must be identified on the individual family services plan (see Chapter 4).

**Developmentally Appropriate Practices**

In addition to being family-centered, the most effective early intervention programs for children with severe disabilities use developmentally appropriate practices. Use of such practices means that instructional activities are individually appropriate, age-appropriate, and reflective of the social and cultural conditions of the child’s life. Early interventionists must understand both typical child development and how cultural settings and practices influence how the child will develop. This professional must also understand how the child’s disability may affect learning and development.

Programs based on developmentally appropriate practices use relevant concrete materials, stimulate exploration, help the child make age-appropriate choices, and include a great deal of interaction with adults and peers. Adults prompt the child to communicate and socialize with other children as often as possible and respond to children immediately and directly when they see any effort made by the child. They also provide an array of interesting toys and activities to stimulate children’s interest. Even though teaching and learning are occurring in a natural context using relevant materials, systematic instructional methods are used to better ensure the child’s participation and success.
SCHOOL PROGRAMS AND RELATED SERVICES

If you teach school-age students with severe disabilities, you are likely to face some challenges and dilemmas that are unique even within the broader field of special education.

To begin, there is the issue of where you will teach your students. Most students with severe disabilities are served primarily in separate special classes, either in general education schools or in special schools, just as Pam Mims’s students were. You will recall, however, that this fact was a little disconcerting to Pam, and she hoped to achieve more inclusion for her students, a position taken by many authorities for more than 20 years (e.g., Bricker, 1978; Gaylord-Ross & Peck, 1985; McDonnell & Hardman, 1989; Snell & Eichner, 1989; Stainback & Stainback, 1989) and one supported by IDEA as well.

Another issue for teachers of students with severe disabilities is what to teach. For many years, the focus of instruction has been on areas such as functional skills and participation in meaningful activities. However, under IDEA, in contrast to being taught a functional curriculum, all students with disabilities—including those with severe disabilities—are expected to participate in the general education curriculum as much as possible. Some authorities believe that this is a good idea for students with severe disabilities (e.g., Jorgensen, 1998; Kliewer & Biklen, 2001; Tashie, Jorgensen, Shapiro-Barnard, Martin, & Schuh, 1996), but many teachers seem doubtful (Agran, Alper, & Wehmeyer, 2002).

Teachers of students with severe disabilities also have to know how to teach their students. Because their learners are very challenged, teachers cannot rely solely on traditional methods such as verbal instructions, role playing, or modeling. Instead, they must use a process often referred to as systematic instruction, which provides the learner with different types of support and structure to learn specific skills.

Finally, like Pam Mims, you may have additional responsibilities related to providing physical care and supporting students’ hygiene needs. This type of support clearly goes beyond what other teachers must provide, even most other special educators. However, providing such assistance is necessary if students are to participate in learning activities.

Inclusion versus Special Class Settings

Research evidence supports the idea that some, if not all, students with severe disabilities are able to learn and be successful in the general education classroom (e.g., Fisher & Meyer, 2002; Foreman, Arthur-Kelly, Pascoe, & King, 2004; Hunt & Goetz, 1997). In order for this to work, however, teachers must use different strategies. Key to them all is collaboration between the general education teacher and the special educator. The teachers must work together to plan activities for the general class and then modify those activities, to the extent necessary, for the student with severe disabilities. The idea is to include the student in all class activities. After all, the true meaning of inclusion is that the student is a real part of the class and is as much engaged in learning and participating as is any other student (Villa & Thousand, 2000).

As the teachers work together, they often develop classroom structures and routines that will help the student with severe disabilities be a full member of class activities. Typically, there are modified or adapted curricular goals and learning activities, perhaps some physical changes in the environment to support the student’s needs, and the involvement of peers to help the student with disabilities maintain a high level of engagement. Teachers commonly use peer tutor-
ing or interaction and cooperative learning groups to better allow the involvement of students with severe disabilities. Also, a paraprofessional usually works in the general classroom to assist students with disabilities as well as other students (Giangreco & Doyle, 2002).

In contrast to placement in inclusive classrooms, students with severe disabilities who attend full-time special classes are there mostly with other students who have similar disabilities. In these classrooms, teachers develop activities specifically for the intellectual and physical characteristics of their students. Although students without disabilities do not attend the special class per se, many special educators use “reverse mainstreaming” to invite them into the special class to tutor or socially interact with the students with disabilities. Also in the special class, there are typically two or more paraprofessionals who assist the teacher.

Functional Curriculum versus the General Curriculum

Since the 1970s, teaching functional skills has been the primary curricular philosophy guiding the education of students with severe disabilities (Brown, Nietupski, & Hamre-Nietupski, 1976; Brown et al., 1979). Such a curriculum includes skills that are necessary for living day to day and for participating in daily life as much as possible. Whether students are in the general education classroom or a special classroom, the functional curriculum model is supposed to prepare them for living, playing, and working in the same world that everyone else lives in.

A functional curriculum includes a broad group of skills that range from learning to feed oneself and use the toilet to learning to cross the street and shop for groceries. Westling and Fox (2004) suggest several preferred practices for teaching functional skills:

- Teachers should not teach skills in isolation but as integrated clusters that build on each other.
- All objectives should focus on increasing the independence, participation, or self-determination of the individual or on making the individual less dependent and less isolated.
- Students should not be excluded from instructional activities because they cannot learn a complete skill independently. Instead, meaningful partial participation should be a target.
- The teacher should identify the most important skills as instructional objectives and develop instructional programs and data collection systems to better ensure learning.
- Objectives should be written so that they describe specific observable behaviors and include criteria so that the student’s skill level on a particular objective can be readily determined.
- The teacher should teach important skills that contribute to all life domains (such as language, ambulation and mobility, motor skills, and social skills) within functional routines and contexts.

In addition to other functional skills, teachers often teach students with severe disabilities functional academic skills. Functional academics include areas such as sight word reading, basic arithmetic operations, counting money, and telling time. Since 1997, however, IDEA requires even students with severe disabilities to have access to the general curriculum as much as possible and to be assessed on end-of-grade tests using alternate assessment systems. The intent is for their progress to be evaluated like that of other students in public schools.

One strategy to increasing participation in the general curriculum is to design a universal curriculum from which all students can learn. Wehmeyer, Lance, and Bashinski (2002) say there are three essential aspects of a universal curriculum:

1. **Multiple means of representation.** This means presenting the curriculum material in a variety of ways so that each student is able to grasp something relevant from it.
2. **Multiple means of expression.** This means that students can respond in their preferred way. For example, instead of giving a written or oral response, they might respond through the use of an alternative or augmentative communication (AAC) device.

3. **Multiple means of engagement.** All students do not need to participate in the learning activity in the same way. Involvement may mean, for example, working with a peer instead of working alone.

**Systematic Instruction**

Over the past 30 years, we have learned quite a bit about how to teach students with very severe disabilities. The most significant lesson is that the more precise and systematic we are with our instruction, the more likely the student is to learn. We use the term **systematic instruction** for the way we approach teaching specific objectives to students with severe disabilities. In the “Highly Effective Instructional Strategies” feature, we describe how systematic instruction is used with students with severe disabilities.

Teachers have used systematic instruction to teach a variety of skills to students with severe disabilities in areas such as personal care, leisure and recreation, community participation, vocational performance, and academic skills. They have used this
**TASK ANALYSIS/FUNCTIONAL ROUTINE**

1. Gather all towels, bathmats, and washcloths and place them in the laundry cart in the hallway.
2. Gather old soap and trash basket and empty into the container in the hallway.
3. Turn on the cold water and wet the inner portion of the bathtub.
4. Sprinkle cleanser in the bathtub.
5. Use sponge to wipe the bathtub thoroughly.
6. Rinse tub and dry.
7. Sprinkle cleanser in toilet bowl and on the outside of the toilet.
8. Wipe inside and outside of the toilet.
9. Use second damp cloth to wipe cleanser off toilet.
10. Sprinkle cleanser on sink.
11. Wipe sink clean.
12. Rinse sink.
13. Clean mirror with glass cleaner and cloth.
15. Put clean towels, bathmats, and washcloths in bathroom.

**INSTRUCTIONAL PROCEDURE**

(*INCLUDING PROMPTING SEQUENCE*)

Use the system of least prompts for each step in the task analysis, beginning when Josh enters the bathroom. Wait 5 seconds between prompts to see if Josh responds to the least prompt.

1. No prompt.
2. Gesture by pointing to the materials of the activity to occur. (Point to the tub and the cleanser and the cloth.)
3. Verbally suggest the step in the task analysis that is to be completed, using an indirect statement. (“What are you supposed to do with the sink now?”)
4. Tell Josh what step in the task analysis he is to do. (“Throw away the old soap and the trash.”)

**REINFORCEMENT**

During the first 3 days of training, reinforce Josh after each step in the task analysis is completed correctly by saying “Looks good” or something similar. On the next 3 days, reinforce only after every other step. Continue reducing comments until a point is reached where Josh is congratulated for a good job after he has finished the entire task. If the amount of time required for task completion is greater than called for in the objective, reinforce more often for faster performance (adapted from Westling & Fox, 2004, p. 177).

To help arrange instructional opportunities, when teachers are teaching students with severe disabilities in general education classrooms, they will use an instructional matrix as an aid to plan instruction throughout the day. To do this, they create a matrix and along one axis list the times and activities of the typical daily routine. Along another, they list the students’ primary objectives. Then they note the intersections of the times or activities during the day and when the students’ objectives can be taught. For example, if a student has an objective related to putting on or removing clothing, we can look across the day and see that the objective might be addressed on arrival, when preparing to go out to lunch and free play, and when preparing to go home at the end of the day. During these times, the teacher works on helping the student meet the objective by using systematic instruction.

Approach in special classes, general education classes, and out-of-school settings. It has been used with both individual students and groups of students. Teachers such as Pam Mims consider systematic instruction to be an essential tool for providing effective instruction to students with severe disabilities.

Now the “Can You Help Me with This Student?” feature presents a challenge for you. See if you can develop a systematic instructional plan to teach the student the desired objective. Use the description given in the “Highly Effective Instructional Strategies” feature as a template. Be creative but be systematic!

**Providing Physical Care and Supporting Hygiene Needs**

As you have learned, students with severe disabilities, especially those with multiple disabilities, often have physical or medical conditions that require additional supports. Some, such as lacking toileting skills, are primarily due to the developmental level of the individual. Others are due to medical causes. For example, seizure disorders or cerebral palsy are caused by neurological causes; not being able to swallow food and thus needing to be tube-fed may be related to congenital abnormalities or other conditions. Still other conditions are secondary aspects of a primary disability. For example, respiratory infections often occur because a weak cough or a malformed chest or spine inhibits the student’s ability to expel mucus (Heller, 2004; Thuppal & Sobsey, 2004).

Activity: Go to the Video Classroom section of the Teacher Prep website, click on Special Education and then module 9: Intellectual Disabilities. Watch video 4 and answer the accompanying questions. How would you provide systematic instruction for Rachel on the tasks she completes as part of her job?
Consider the following objective for Jesus, a student with a profound intellectual disability:

Jesus will shake his head up and down to indicate when he wants an offered item or activity 90% of the time that something is offered. He will do this throughout the school day in different locations with different people for 5 consecutive days.

How would you teach Jesus to accomplish this objective? Here are some things to keep in mind:

- Since the skill needs to be taught and learned in different locations, you will need to think of the locations that are most appropriate. Where are the natural places where a student would need to say whether or not he wants something? If the skill is taught in only one location, by one person, at a certain time, then Jesus will not generalize it. This means that he may learn to do the skill but only in a very limited way.
- You will need to find out the kinds of things Jesus might like to have. To do this, you need to do a preference assessment. Basically a preference assessment is a systematic way to learn what a person with a severe disability likes or desires. Because individuals such as Jesus cannot tell us what they like or dislike, we must present them with items that may be of interest and then carefully monitor their interactions with these items. As they choose which they prefer to engage with, we need to make records so we will remember what is liked and disliked.
- Systematic instruction will need to be used. Look at the featured “Highly Effective Instructional Strategies” just presented. You see that two instructional approaches were described: time delay and least-to-most prompting. If you look in the following reference list, you will find other systematic instructional approaches. Can you see how such an approach may be used to teach Jesus? Can you describe other approaches? See if you can develop a prompting system that will help you to teach Jesus to respond.
- Peers might be used to help Jesus learn this skill. For many reasons, peers without disabilities can be very effective instructors for students such as Jesus. Why do you think this is true? Do you think students without disabilities who are about the same age as Jesus could help him learn to shake his head up and down to let them know what he wants? How would you use them in an instructional lesson? Would you have any concerns about having peers involved in instructing or prompting Jesus? If so, what would they be?
- Students like Jesus who have significant disabilities often make progress very slowly. For this reason, special education teachers who teach these students often record their progress quite frequently, even daily. What type of data do you think they collect? What kind of data would you collect to see if Jesus is making progress toward achieving his objective? How often would you take a measure of his performance? What kind of information do you think you could glean from the data?

If instruction of students such as Jesus is to be successful, we need to use very precise and systematic instructional methods. Research suggests that, if we do, many students can learn skills that will allow them to participate more meaningfully in their personal environments.

For more information on how you might teach students like Jesus, see the following sources:


EXTEND AND APPLY

- What do you think about the process of systematic instruction? Is this something you might want to apply sometime? You may find it very effective!
- There are different ways in which someone might react to teaching a student like Jesus. One might be “This is a real challenge, and I think it would be exciting to try to achieve it.” Another could be “Is it really worth the time and effort to teach such a basic skill?” What is your thought on this matter?

Activity: Go to the Video Classroom section of the Teacher Prep website, click on Special Education and then module 9: Intellectual Disabilities. Watch video 3 and answer the accompanying questions. Think about how important peer interaction can be when teaching skills and content to students with severe disabilities.

Regardless of the condition or the cause, school personnel must provide a student with severe disabilities additional physical assistance and adequate supports. While such tasks may initially seem daunting to a nonmedical professional, there are several strategies that make accepting such challenges less threatening.

You Are Not Alone. First, you must remember that no one expects you to become a health care expert overnight. Parents, school nurses, and physical and occupational
therapists are all important sources of information about how to provide specific types of care and treatment. You will be able to rely on these individuals as long as necessary for your personal development before you are expected to take on any challenges without assistance. And then these persons will be able to continue to support you as necessary.

**Individual Health Care Plans.** Each student who requires special medical care or consideration will have his or her own individual health care plan. You do not need to become an expert on all medical issues; you need only to be able to provide care or a response based on the unique needs of the student.

**Time Is an Ally:** The biggest challenge you may face is lack of understanding and familiarity with certain procedures. As time goes by and you become more accustomed to managing certain matters, they will become more commonplace to you. These unique challenges will then become part of your day-to-day routine.

**TRANSITION, ADOLESCENCE, AND ADULT NEEDS AND SERVICES**

Sometimes, as teachers, we forget that life continues after the school years. But we need to realize that it is often the postschool years that are most challenging for individuals with severe disabilities and their families. Personal challenges continue, but there is no longer an entitlement to services as there is during the school years. This is why transition planning, beginning in the adolescent years, is required as part of IDEA.

As you saw in Chapter 4, a transition plan must be a part of the IEP when the student becomes a teenager. The plan needs to consider the kinds of services the student will need after the school years, the agencies and organizations that might provide the services, and what preparations are most important for the student and the family to get ready for young adulthood.

Let us mention three areas that are going to be most crucial and challenging: acquiring a personal residence, finding employment or purposeful adult activities, and assuring a desirable quality of life. These will be important in adulthood, so it is critical that teachers, parents, and administrators address them when developing a transition plan.

**Residential Options**

Many young people leave their parents’ home when they enter adulthood, and this is also important for many young adults with severe disabilities. In reality, many of these individuals continue to live at home, often not by choice but by necessity or because of lack of planning. Planning for a place to live for a young adult with severe disabilities should be guided by several values that have developed in the post-institutionalization era. These values are based on the principles of normalization, which call for lifestyles and routines to be as normal as possible.

The most desired form of residence is a supported living arrangement based on a person-centered plan. Even for individuals with very severe disabilities, the model program is individually determined with necessary supports brought to the individual instead of placing the person in a restrictive setting simply because the supports are available in that setting (Racino, 1995). In addition to professional supports, natural supports are used as much as possible, and the person enjoys choices of location and type of home and roommates and, to the extent possible, has input on decisions about both services and living arrangements.

Chapter 12: Severe Intellectual Disabilities and Multiple Disabilities
Employment and Adult Routines

Employment, or engaging in a meaningful adult routine, is a second concern for adults. Although too many adults with severe and multiple disabilities are still served in sheltered workshops or activities centers (Rusch & Braddock, 2004), many are employed in community-based jobs and given supports that help them to do those jobs. These supports include job coaches and natural supports often available in the job setting.

An important part of transition is to offer adolescents vocational training in real-world settings where they can learn essential job skills. Working in the community offers a chance to do meaningful work in exchange for fair wages in a natural context. Of course, it is more than work that is important; it is the chance to have a life that includes co-workers and friends and the social connections that come with them. Persons with severe disabilities have been able to learn a variety of jobs from groundskeeping and housecleaning to photocopying and data entry.

Quality of Life

Most important for any adult with severe disabilities, just as it is for you, is something that is hard to define: quality of life. The things we have talked about already—having a nice place to live and being employed or participating in a supportive environment—will contribute to this. Overall, though, quality of life for any adult is defined by being able to decide within reason what you want and then having a reasonable chance of getting it. Like everyone else, most adults with severe disabilities want to have some choices in daily routine, friends, social, and leisure activities, and a self-determined degree of participation in their community.

When school personnel develop transition plans, they tend to focus on supported employment or residential placements. But this isn’t enough. Planning should also take into consideration the personal future of the person as well as the concerns of the family and look at ways to support a quality of life so that it can occur as it might for persons without disabilities (Kim & Turnbull, 2004).

PREVAILING ISSUES, CONTROVERSIES, AND IMPLICATIONS FOR THE TEACHER

From a historical perspective, students with severe intellectual and multiple disabilities were the last group to receive services under the special education umbrella. Until the mid-1970s they were excluded from most public schools. It took a federal law to give them the right to be taught in public schools. Even today, many issues continue to be discussed and debated:

- Should we spend so much on teaching students with severe disabilities when our educational budgets are always stretched?
- Can students with severe disabilities really be included in general education classrooms? How much can they learn? How will they affect the other students?
- Should students with severe disabilities be included in the general education curriculum? Is there any way they can participate meaningfully in the general education curriculum? Or should the focus be more on teaching functional skills and functional academics?
- Should these students be assessed at the end of the school year like students without disabilities and those with mild disabilities? Are the alternate assessment systems valid and reliable enough to get an accurate picture of their abilities? Should students’ test scores be considered in evaluating schools and holding them accountable?

If you are employed as a special educator to teach students with severe disabilities or if they are a part of your general education classroom, these questions will probably always be on your mind. You will encounter people, including friends and colleagues, who will question the value of what you are doing with these students and
whether or not they should really have the right to be in the public schools. There are many ways that you could respond to these challenges, but here is what we would say:

In a society as rich in resources and human acceptance as ours, the greater error would be to reject someone from participation because they may not benefit as much as someone else. If we are to make an error, let’s make it on the side of inclusion and acceptance rather than on the side of exclusion and rejection.

Of course, the answer that you give will have to be the one that makes most sense to you.

**SUMMARY**

Public schools in the United States have only served individuals with severe intellectual and multiple disabilities for about 30 years. In this chapter we have touched on some of the key points about this very heterogeneous population and how it is taught in public schools.

**Definitions of Students with Severe Intellectual Disabilities and Multiple Disabilities and How They Are Related**

- Persons with severe intellectual disabilities have been defined in different ways. Some people have defined them by their degree of intellectual disability (moderate, severe, or profound), by the syndromes they have, or by their limited abilities. Perhaps the most valid definition states that these individuals are likely to need some amount of support through life in order to have an adequate quality of life.
- Persons with multiple disabilities are those who, in addition to their intellectual disabilities, have physical or sensory disabilities.
- Many persons with severe to profound intellectual disabilities also have physical or sensory disabilities. Therefore, in reality these groups overlap a great deal. Persons in one or both groups are often referred to as having severe disabilities.

**Significant Characteristics of Students with Severe Intellectual and/or Multiple Disabilities**

- These individuals usually have reduced intellectual development; general learning weaknesses; and sometimes inappropriate, challenging behaviors.
- They often have medical problems associated with their intellectual and physical disabilities.

**Prevalence of Students with Severe Disabilities and Causes of Severe Disabilities**

- It is difficult to accurately state how many public school students are considered to have a severe disability, but a safe estimate is about 0.5 to 1% of all students or about 10% of the students served in special education.
- The causes of severe disabilities are varied. Most are due to prenatal factors including genetic conditions, chromosomal anomalies, maternal infections, and the mother’s ingestion of harmful substances. Different conditions that can occur at the time of birth or after birth can also lead to having severe disabilities.

**Assessment and Planning Procedures Used with Students with Severe Intellectual Disabilities and Multiple Disabilities**

- Different assessment and planning procedures can be very helpful in determining the instructional needs of students with severe disabilities. These can include adaptive behavior assessments, curriculum or activity guides, and ecological inventories.
- Person-centered planning may also be used. This procedure provides a very viable approach to developing meaningful instruction, daily activities, and other life conditions for students with severe disabilities.

**Instructional Content, Instructional Methods, and Related Supports for Students with Severe Disabilities**

- Traditionally, we have taught students with severe disabilities very functional skills, including functional academic skills.
- IDEA has directed schools to include these students in the general curriculum to the extent possible and to assess them at the end of the year using alternate assessment systems.
- Systematic instructional methods that involve identifying specific objectives, using prompting procedures such as the system of least prompts or constant time delay, and carefully measuring and monitoring student progress have been very
successful in helping students with severe disabilities learn new skills.

- Students with severe intellectual and multiple disabilities often have related physical and health care needs. Teachers can best address these needs by working collaboratively with parents and other school personnel such as the school nurse.

**Major Issues and Controversies Related to Educating Students with Severe Intellectual Disabilities and Multiple Disabilities**

- Controversies related to teaching students with severe disabilities revolve around cost-benefit issues, inclusion in general education, and participation in the general curriculum.

**ADDRESSING THE PROFESSIONAL STANDARDS**

Council for Exceptional Children (CEC) Knowledge Standards addressed in the chapter:

- CC1K: 1, 2, 4, 5, 7; IC1K: 1–8; CC2K: 2, 4, 5; IC2K: 1–4; CC3K: 1, 4; IC3K: 1, 3; IC4K: 2, 3, 4; IC5K: 5; CC7K: 1; IC7K: 1; CC8K: 1, 4; IC8K: 1; IC9K: 1, 2; CC10K: 1, 3

Appendix B: CEC Knowledge and Skill Standards Common Core has a full listing of the standards referenced here.