chapter five

LEARNERS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Angela Hampton/Bubbles Photolibrary/Alamy Stock Photo

LEARNING OUTCOMES

Learning Outcome 5.1: Understand why the term *intellectual disabilities* is used rather than *mental retardation*, how professionals define intellectual disabilities, and the prevalence of intellectual disabilities.

Learning Outcome 5.2: Learn the causes of intellectual disabilities.

Learning Outcome 5.3: Learn about assessments used to identify intellectual disabilities and some of the psychological and behavioral characteristics of learners with intellectual disabilities.

Learning Outcome 5.4: Understand some of the educational considerations for people with intellectual disabilities and how professionals assess progress in academics and adaptive behavior.

Learning Outcome 5.5: Learn about issues that should be considered with respect to early intervention and transition to adulthood for learners with intellectual disabilities.

MISCONCEPTIONS ABOUT Learners with Intellectual and Developmental Disabilities

MYTH Professionals agree about the definition of intellectual disabilities.

FACT Considerable disagreement exists among professionals about definition, classification, and terminology.

MYTH Once diagnosed as having intellectual disabilities, a person retains this classification for life.

FACT A person's level of intellectual functioning doesn't necessarily remain stable; this is particularly true for those individuals who have mild intellectual disabilities. With intensive educational programming, some persons can improve to the point that they are no longer classified as having intellectual disabilities.

MYTH Intellectual disability is defined by how a person scores on an IQ test.

FACT The most commonly used definition specifies that an individual must meet two criteria in order to be considered as having intellectual disabilities: (1) low intellectual functioning and (2) low adaptive skills.

MYTH In most cases, it's easy to identify the cause of intellectual disability.

FACT Although the mapping of the human genome has increased our knowledge about causes of intellectual disabilities, it's still difficult to pinpoint the cause of intellectual disabilities in many people, especially those with mild intellectual disabilities.

MYTH Psychosocial factors are the cause of the vast majority of cases of mild intellectual disabilities.

FACT Exact percentages aren't available, but researchers are finding more and more genetic syndromes that result in mild intellectual disabilities; hereditary factors are also involved in some cases.

MYTH The teaching of vocational skills to students with intellectual disabilities is best reserved for secondary school and beyond.

FACT Many authorities now believe it appropriate to introduce vocational content in elementary school to students with intellectual disabilities.

MYTH People with intellectual disabilities should not be expected to work in the competitive job market.

FACT More and more people who have intellectual disabilities hold jobs in competitive employment. Many are helped through supportive employment situations, in which a job coach helps them and their employer adapt to the workplace.

GUIDING QUESTIONS

- Why are most professionals now using the term *intellectual disabilities* instead of *mental retardation?*
- How do professionals define *intellectual disabilities?*
- What is the prevalence of intellectual disabilities?
- What causes intellectual disabilities?
- What methods of assessment are used to identify individuals with intellectual disabilities?
- What are some of the psychological and behavioral characteristics of learners with intellectual disabilities?
- What are some educational considerations for learners with intellectual disabilities?
- What issues should educators and other professionals consider with respect to early intervention for learners with intellectual disabilities?
- What are some important considerations with respect to transition to adulthood for learners with intellectual disabilities?

The education of students with intellectual disabilities has undergone remarkable changes in the past several years, in terms of both the quantity and the quality of services. Although teaching and parenting a child with intellectual disabilities still means meeting and overcoming many challenges, today, there are many more reasons for optimism. Teachers and other professionals are better prepared to use evidence-based treatments, and parents can look around and see examples of adults with intellectual disabilities who are holding jobs in competitive or semi-competitive work environments and living independently or semi-independently in the community.

Much of the success being achieved by people with intellectual disabilities is attributed to a change in philosophy that includes respecting their rights to be a part of decisions affecting their lives and emphasizing the use of natural supports. Later in the chapter, we discuss the important philosophical changes that have brought about the emphasis on self-determination and **natural supports**.

People with intellectual disabilities need more than well-intentioned philosophies to ensure that they reach their full potential with respect to independent employment and community living. They often need years of intensive instruction from special educators, working in tandem with other professionals, including general educators, to put the philosophies of self-determination and natural supports into effect.

Other changes have also had a profound effect on the field of intellectual disabilities in the past several years. Among the most significant is that this field has undergone a name change from *mental retardation* to *intellectual and developmental disabilities*.

WHAT'S IN A NAME? *MENTAL RETARDATION* VERSUS *INTELLECTUAL AND DEVELOPMENTAL DISABILITIES*

In January, 2007, the major professional organization for people with significant cognitive or intellectual disabilities—the American Association on Mental Retardation (AAMR)—changed its name to the American Association on Intellectual and Developmental Disabilities (AAIDD). To understand the reasons for this change, one needs to appreciate that throughout history people with subaverage intellectual abilities have been the subject of ridicule and scorn. Whatever name has been applied to these individuals by professionals has ended up being used pejoratively by the public. For example, it's probably surprising to many that as late as the early 1900s the terms *idiot*, *imbecile*, and *moron* were perfectly acceptable labels for those who, today, would be referred to as having severe, moderate, or mild intellectual disability or mental retardation, respectively. In fact, they were the "official" terms used by professionals and sanctioned by professional

FOCUS ON CONCEPTS ...

"Spread the Word to End the Word"

Conceived at the 2009 Special Olympics World Winter Games, the Spread the Word to End the Word campaign has been a catalyst for drawing attention to and for ending use of "retarded" or "retard" as an insult. The R-Word Website (r-word.org) provides testimonials, videos, and other resources, including a link whereby one can take a pledge not to use the r-word and to discourage others from using it. For example, they include examples of how you can respond when others, even friends and family members, use the r-word. As of November 9, 2017, over 710,998 people have taken the pledge.

The Spread the Word campaign has delivered its message in a number of ways, including public service announcements (http://www.youtube.com/watch?feature=player_embedded&v=oRUOL5Rm2XY).

organizations. Today, of course, very few would accuse someone of being overly politically correct if he viewed these terms as totally inappropriate and demeaning. A somewhat similar history has accompanied the term *mentally retarded*. Over the years it, too, especially its shortened form, *retard,* has come to be used as an insult.

The name change from AAMR to AAIDD did meet with some resistance, some of which continues to linger. Pointing to the historical use and abuse of terms such as *idiot*, some argue that trying to find a "slur-proof" term is fruitless. Others argue that, unlike *idiot*, the term *mentally retarded* has not become a slur except in its shortened form *retard*.

In 2010, federal legislation solidified the use of the term, *intellectual disability*. Public Law 111-256 mandated that *intellectual disability* replace *mental retardation* in many areas of the federal government. As of 2016, the term *mental retardation* was only being used in three states (Polloway, Bouck, Patton, & Lubin, 2017). You will note that we have titled the chapter, "Intellectual and Developmental Disabilities," but within the chapter, like many professionals, we've elected to go with the shortened term, *intellectual disabilities*.

Perhaps most important is that the term *intellectual disability* is actually more accurate than *mentally retarded* in describing the primary limitations of this group of individuals. One can also make the argument that *intellectual* is more accurate than *mental* because the latter is often used to refer to emotions, for example, *mental illness* (Glidden, 2006).

DEFINITION

The issue of defining intellectual disabilities or mental retardation has been contentious. For example, since the 1950s, the AAIDD has endorsed seven different definitions, with each successive clarification reflecting a more cautious approach to designating someone as mentally retarded or intellectually disabled. At least four reasons account for this more cautious attitude:

1. As we discuss later in the chapter, IQ tests are not infallible. Although they are the best measure we have of general intelligence and they are routinely used in the process of identifying people who have intellectual disabilities, a number of factors (e.g., examiner bias or lack of expertise or motivation of person being tested) can lead to their reduced reliability for individuals with low scores (Greenspan & Olley, 2015).
2. Professionals became concerned about the number of children from ethnic minority groups who were being diagnosed as having intellectual disabilities. For example, African American and Native American students are disproportionately identified by the public schools as having intellectual disabilities.
3. Some people believe that the diagnosis of intellectual disability results in a stigma that causes children to have poor self-concepts and to be viewed negatively by others.
4. Some professionals now believe that to a certain extent, intellectual disability is a socially constructed condition. For example, AAIDD conceives of intellectual disability not as a trait residing in the individual but as the product of the interaction between a person and her environment.

It's important to note that some of these points have not gone uncontested. For example, some authorities have argued that the AAIDD has gone too far in denying the existence of intellectual disability as an essential feature *within* a person (Baumeister, 2006). They acknowledge that all disabilities are socially constructed to a degree. For example, a deaf person's inability to hear would not be considered a disability if he were not living in a society in which virtually everyone communicated via spoken language. Likewise, a person with cognitive limitations would not be considered to have a disability except for the fact that intelligence is a critical factor for functioning in society. However, the fact is that not being able to hear what people are saying or to understand and solve problems puts a person at a distinct disadvantage in society at large.

Special educators are tasked with helping a person who has problems hearing or a person who has problems understanding to lead a productive and happy life. And in order to achieve these objectives, special educators address improving the inherent limitations such people have. At the same time, special educators (as well as society as a whole) should also be working to enhance society's awareness, understanding, and accommodation of persons with disabilities.

A number of researchers also have pushed back on the idea that ethnic minority students are overrepresented in special education. In fact, Paul Morgan and his colleagues have made the counterintuitive claim that minority students are *underrepresented* in special education (Morgan et al., 2015). It may be the case that schools are overreacting to criticisms of racial discrimination and, in questionable situations, are leaning toward non-identification.

It's beyond the scope of this textbook for us to go into this debate—the dispute involves relatively intricate statistical analyses. For the interested reader, we encourage you to read Morgan's research as well as those who challenge him (Skiba, Artiles, Lozleski, Losen, & Harry, 2015).

The AAIDD Definition

The current AAIDD definition reads as follows:

> [Intellectual disability] is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18. (AAMR Ad Hoc Committee on Terminology and Classification, 2010, p. 1)

The AAIDD definition underscores two important points: Intellectual disability involves problems in adaptive behavior, not just intellectual functioning, and the intellectual functioning and adaptive behavior of a person with intellectual disabilities can be improved.

ADAPTIVE BEHAVIOR At one time, it was common practice to diagnose individuals as mentally retarded (intellectually disabled) solely on the basis of an IQ score. Today, we recognize that IQ tests are generally accurate but are not perfect. Furthermore, they are only one indication of ability to function. Professionals came to consider **adaptive behavior** in addition to IQ in defining intellectual disability because they began to recognize that some students might score poorly on IQ tests but still function well in their daily environment, e.g., be "streetwise"—able to travel via the subway system and resist involvement in gangs.

No single definition of adaptive behavior is universally accepted. One that many authorities see as theoretically sound is based on the notion that adaptive behavior consists of **social intelligence** and **practical intelligence** (Greenspan, 2006b). Social intelligence involves understanding and interpreting people and social interactions, such as being able to "read" when someone is angry, and not being gullible or easily tricked or manipulated. (We discuss gullibility in more detail later.) Practical intelligence involves the ability to solve everyday problems, such as preparing meals, using transportation systems, making change, using the Internet, and solving problems that are associated with particular job situations.

PEOPLE WITH INTELLECTUAL DISABILITIES CAN IMPROVE In the past, many authorities held little hope for significantly enhancing the functioning of people with

intellectual disabilities; they essentially believed intellectual disability incurable. Today, however, the prevailing opinion is that the functioning of virtually all people with intellectual disabilities can be improved and that very few, especially those with very mild intellectual disabilities, can eventually improve to the point at which they are no longer classified as having an intellectual disability.

In agreement with the notion that intellectual disability is improvable, the developers of the current AAIDD definition hold that how well a person with intellectual disabilities functions is directly related to the amount of support he receives from the environment. The concept of supports is integral to the AAIDD's conceptualization of intellectual disabilities. The AAIDD defines **supports** as those strategies and resources that "a person requires to participate in activities associated with normative human functioning" (Thompson et al., 2009, p. 135). Supports can come in a variety of forms; for example, technological support (e.g., smart phones or tablets to provide a way of keeping in contact with others); social support (e.g., family, friends, and church members to offer assistance and friendship); organizational support (e.g., Best Buddies).

Classification of Intellectual Disabilities

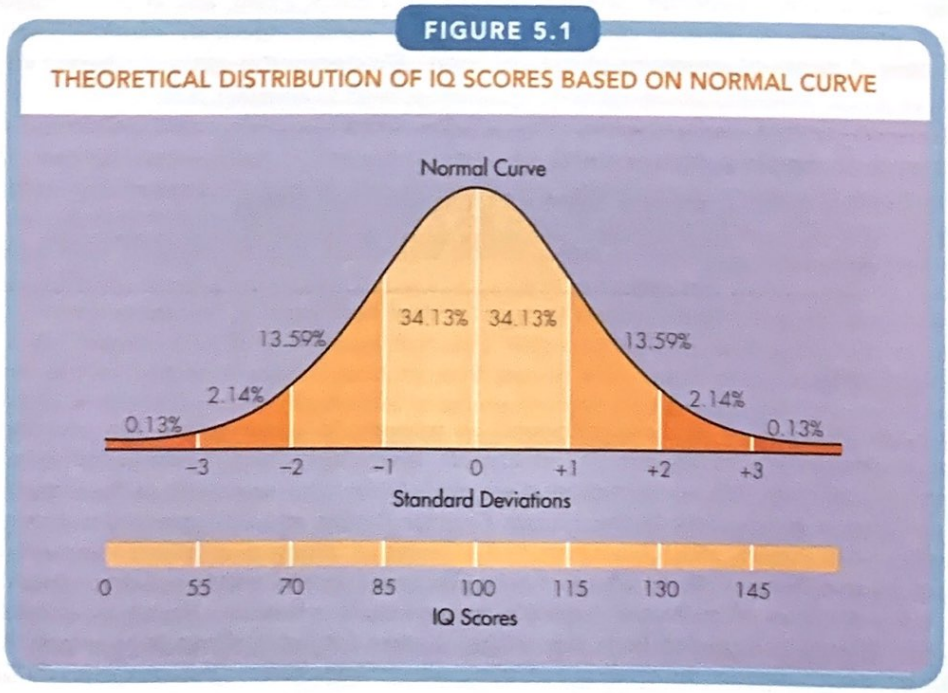
Although AAIDD does not advocate such a classification scheme, most school systems classify students with intellectual disabilities according to the severity of their condition: **mild** (IQ of about 50 to 70), **moderate** (IQ of about 35 to 50), **severe** (IQ of about 20 to 35), and **profound** (IQ below about 20) **mental retardation** or **intellectual disabilities**, or a close approximation.

PREVALENCE

The average (mean) score on an IQ test is 100. Theoretically, we expect 2.27% of the population to fall 2 standard deviations (IQ = 70 on the Wechsler Intelligence Scale for Children, Fourth Edition, WISC-IV) or more below this average. This expectation is based on the assumption that intelligence, like so many other human traits, is distributed along a normal curve. Figure 5.1 shows the hypothetical normal curve of intelligence. This curve is split into eight areas by means of standard deviations. One standard deviation

FIGURE 5.1

THEORETICAL DISTRIBUTION OF IQ SCORES BASED ON NORMAL CURVE



FOCUS ON

The Human Genome and ENCODE Projects: Ethical Issues Pertaining to Intellectual Disabilities

The U.S. Human Genome Project formally started in 1990 and ended in 2003. Among other things, the project has resulted in the identification of the 20,000 to 25,000 genes in human DNA and the sequences of three billion chemical base pairs that make up human DNA. The ENCODE (Encyclopedia Of DNA Elements) Project (http://www.youtube.com/watch?v=TwXX-gEz9o4w) began in 2003, with the goal of identifying all functional elements in the human genome sequence.

Practical benefits of the genome projects are that they help advance the ability to diagnose, treat, and eventually prevent genetic conditions, some of which cause intellectual disabilities. However, such potential breakthroughs have made some people uneasy. In addition to the usual questions related to such things as cloning and the creation of "designer babies," some have raised concerns specific to intellectual disabilities. For example, does the use of genetic information to prevent intellectual disabilities devalue the lives of those who have intellectual disabilities? In other words, does allowing people the option of preventing a disability send the message that people with that disability are less worthy of existence?

On the other hand, some argue that to renounce the use of genetic information to predict a disability in an unborn child can be ethically irresponsible, especially when the condition predicted is very likely to be severe. An example that's been used is that of Lesch-Nyan disease, which involves uncontrolled self-injurious behavior and requires almost constant restraint to prevent self-mutilation (Davis, 1997).

Of course, Lesch-Nyan is extremely rare, and most people with intellectual disabilities don't undergo such extreme suffering. However, these are the cases that make the issue of genetic testing so contentious.

equals 15 IQ points; 2.14% of the population scores between 55 and 70, and 0.13% scores below 55. Thus, it would seem that 2.27% should fall under 70. (See p. 89 for more on intelligence tests.)

However, the actual prevalence figures for students who are *identified* as having intellectual disabilities are much lower. In recent years, they have been well under 1%. Authorities surmise that this lower prevalence figure is due to one or a combination of three things: School officials (1) increased their use of adaptive behavior in addition to an IQ score to diagnose intellectual disabilities; (2) exhibited a preference to label students with IQs in the 70s as having learning disabilities because it's perceived as a less stigmatizing label (MacMillan, Gresham, Bocian, & Lambros, 1998); and/or (3) increased their propensity to identify children as having an autistic spectrum disorder (ASD) because of increased awareness of this condition. (We discuss this again in Chapter 9.)

MyLab Education Self-Check 5.1

MyLab Education Application Exercise 5.1: Changing Terminology

Respond to a question about the shift in terminology used to describe people once categorized as having mental retardation.

CAUSES

The past 20 years or so have witnessed an upsurge in research that has increased our understanding of causes of intellectual disabilities (http://www.youtube.com/watch?v=dyjFJ19DF9Y). Some of these discoveries have come as a result of the mapping of the human genetic code by the Human Genome Project and its continuation through the ENCODE Project, which have provided a wealth of information related to causes of many human illnesses. These advances have also engendered a number of thorny issues.

Not all causes of intellectual disabilities are genetically related, nor are all causes traceable to biological causes. A large percentage of cases (probably about 50%) remain for which we can't pinpoint the cause of a child's intellectual disabilities (Polloway et al., 2017).

FOCUS ON

Down Syndrome and Alzheimer's Disease

Researchers first noted a high prevalence of senility in persons with Down syndrome well over a century ago (Fraser & Mitchell, 1876, cited in Evenhuis, 1990). In the early 20th century, postmortem studies of the brains of people with Down syndrome revealed neuropathological signs similar to those of people with Alzheimer's disease (Carr, 1994). It was not until the 1980s and 1990s, however, that scientists started to address this correlation seriously.

According to the postmortem studies, virtually all people with Down syndrome who reach the age of 35 have brain abnormalities very similar to those of persons with Alzheimer's disease (Alvarez, 2008; Hof et al., 1995). Although not inevitable, behavioral signs of dementia, or mental deterioration, occur in well over half of people with Down syndrome older than 60 years of age (Margallo-Lana et al., 2007). Unfortunately, maladaptive behaviors such as aggression, fearfulness, and sadness often increase as the dementia advances (Urv, Zigman, & Silverman, 2008).

Findings that link Down syndrome to Alzheimer's disease have made researchers optimistic about uncovering the genetic underpinnings of both conditions. For example, researchers have found that a particular protein may be the key to the rapid onset of Alzheimer's in people with Down syndrome (Wallace & Dalton, 2011). Interestingly, no evidence shows that Alzheimer's occurs more frequently in adults whose intellectual disabilities are due to other causes (Alvarez, 2008).

A common way of categorizing causes of intellectual disabilities is according to the time when the cause occurs: **prenatal** (before birth), **perinatal** (at the time of birth), and **postnatal** (after birth).

Prenatal Causes

We can group prenatal causes into (1) **chromosomal disorders**, (2) inborn errors of metabolism, (3) developmental disorders affecting brain formation, and (4) environmental influences.

CHROMOSOMAL DISORDERS As noted previously, scientists are making great strides in identifying genetic causes of intellectual disabilities. A few of the most common of these genetic syndromes are Down syndrome, Fragile X syndrome, Prader-Willi syndrome, and Williams syndrome.

Down Syndrome Many, but not all, genetic syndromes are transmitted hereditarily. However, by far the most common of these syndromes, **Down syndrome**, is usually *not* an inherited condition. Down syndrome involves an anomaly at the 21st pair of **chromosomes**. In the vast majority of cases of Down syndrome, the 21st set of chromosomes (the normal human cell contains 23 pairs of chromosomes) is a triplet rather than a pair; hence, the most common form of Down syndrome is also referred to as **trisomy 21**. Down syndrome is the most common form of intellectual disability that is present at birth (Polloway et al., 2017).

MyLab Education
Video Example 5.1
Down syndrome is associated with a number of physical characteristics and health conditions in addition to intellectual disabilities.

Down syndrome is associated with a range of distinctive physical characteristics, but it's important to keep in mind that they vary considerably in number and extent from one individual to another, making each person with Down syndrome unique, just as each individual without disabilities is unique. People with Down syndrome may have thick epicanthal folds in the corners of their eyes, making the eyes appear to slant upward slightly at the outside corners. Other common characteristics include small stature, decreased muscle tone (hypotonia), hyperflexibility of the joints, a small oral cavity that can result in a protruding tongue, short and broad hands with a single palmar crease, heart defects, and susceptibility to upper respiratory infections (R. L. Taylor, Richards, & Brady, 2005). Evidence also indicates a link between Down syndrome and Alzheimer's disease.

The degree of intellectual disability among people with Down syndrome varies widely (Stancliffe et al., 2012), but most individuals fall in the moderate range. In recent

years, more children with Down syndrome have achieved IQ scores in the mild intellectual disability range than previously, presumably because of intensive special education programming.

The likelihood of having a child with Down syndrome increases with the age of the mother (Weijerman et al., 2008). In addition to the age of the mother, researchers point to other variables as possible causes, such as the age of the father, exposure to radiation, and exposure to some viruses. Research on these factors is still preliminary, however.

Methods are available for screening for Down syndrome and some other birth defects. These methods include the following:

- **Maternal serum screening (MSS):** A blood sample is taken from the mother and screened for the presence of certain elements that indicate the possibility of **spina bifida** (a condition in which the spinal column fails to close properly) or Down syndrome. If the results are positive, the physician can recommend a more accurate test, such as amniocentesis or chorionic villus sampling.
- **Amniocentesis:** The physician takes a sample of amniotic fluid from the sac around the fetus and analyzes the fetal cells for chromosomal abnormalities. In addition, the amniotic fluid can be tested for the presence of proteins that may have leaked out of the fetus's spinal column, indicating the presence of spina bifida.
- **Chorionic villus sampling (CVS):** The physician takes a sample of villi (structures that later become the placenta) and tests them for chromosomal abnormalities. One advantage of CVS is that it can be done earlier than amniocentesis.
- **Nuchal translucency ultrasound:** This non-invasive procedure allows the physician to see the fluid from behind the fetus's neck; this can also be done earlier than amniocentesis. A greater than normal amount of fluid indicates the possibility of Down syndrome.

Fragile X Syndrome **Fragile X syndrome** is the most common known hereditary cause of intellectual disabilities. And it's the second most common syndrome, after Down syndrome, that causes intellectual disabilities (Polloway et al., 2017). In association with intellectual disabilities, Fragile X syndrome occurs in 1 in 4,000 males and 1 in 6,000 females (Meyer & Batshaw, 2002). In association with milder cognitive deficits, such as learning disabilities, the prevalence may be as high as 1 in 2,000 (Hagerman, 2001). It is associated with the X chromosome in the 23rd pair of chromosomes. In males, the 23rd pair consists of an X and a Y chromosome; in females, it consists of two X chromosomes. This disorder is called Fragile X syndrome because in affected individuals, the bottom of the X chromosome is pinched off in some of the blood cells. Fragile X occurs less often in females because they have an extra X chromosome, giving them better protection if one of their X chromosomes is damaged. People with Fragile X syndrome may have a number of physical features, such as a large head; large, flat ears; a long, narrow face; a prominent forehead; a broad nose; a prominent, square chin; large testicles; and large hands with nontapering fingers. Although this condition usually results in moderate rather than severe intellectual disabilities, the effects are highly variable; some people have less severe cognitive deficiencies and some, especially females, score in the normal range of intelligence (Dykens, Hodapp, & Finucane, 2000).

Prader-Willi Syndrome **Prader-Willi syndrome** is the result of a genetic abnormality, but very few cases are inherited. Prader-Willi syndrome has two distinct phases. Infants are lethargic and have difficulty eating. Starting at about 1 year of age, however, they become obsessed with food. In fact, Prader-Willi is the leading genetic cause of obesity. Although a vulnerability to obesity is usually their most serious medical problem, people with Prader-Willi are also at risk for a variety of other health problems, including short stature due to growth hormone deficiencies; heart defects; sleep disturbances, such as excessive daytime drowsiness and **sleep apnea** (cessation of breathing while sleeping); and **scoliosis** (curvature of the spine). The degree of intellectual disability varies, but the majority of individuals with Prader-Willi fall within the mild intellectual disability range, and some have IQs in the normal range (R. L. Taylor et al., 2005).

Williams Syndrome Williams syndrome is caused by the absence of material on the seventh pair of chromosomes. People with Williams syndrome have intellectual disabilities in the mild to moderate range (Mervis & Becerra, 2007). In addition, they often have heart defects, an unusual sensitivity to sounds, and "elfin" facial features. Williams syndrome typically occurs without any prior family history of the condition. In other words, it's not typically inherited; however, people who have Williams syndrome can pass it on to each of their children (Haldeman-Englert, 2008).

INBORN ERRORS OF METABOLISM Inborn errors of metabolism result from inherited deficiencies in enzymes used to metabolize basic substances in the body, such as amino acids, carbohydrates, vitamins, or trace elements (Medline Plus, 2007). One of the most common of these is phenylketonuria (PKU). PKU involves the inability of the body to convert a common dietary substance—phenylalanine—to tyrosine; the consequent accumulation of phenylalanine results in abnormal brain development. All states routinely screen babies for PKU before they leave the hospital. Babies with PKU are immediately put on a special diet, which prevents the occurrence of intellectual disabilities. For example, milk, eggs, and the artificial sweetener aspartame are restricted because they contain significant amounts of phenylalanine. The need for a special diet often requires that parents and the rest of the family become involved in the treatment. At one time, physicians thought that the diet could be discontinued in middle childhood. However, authorities now recommend continuing the diet indefinitely, for two important reasons: Those who stop the diet are at risk for developing learning disabilities or other behavioral problems, and women with PKU who go off the diet are at very high risk of giving birth to children with PKU.

DEVELOPMENTAL DISORDERS OF BRAIN FORMATION A number of conditions can affect the structural development of the brain and cause intellectual disabilities. Some of these are hereditary and accompany genetic syndromes, and some are caused by other conditions such as infections. Two examples of structural development affecting the brain are microcephalus and hydrocephalus. In microcephalus, the head is abnormally small and conical in shape. The intellectual disability that results usually ranges from severe to profound. No specific treatment is available for microcephaly, and life expectancy is short (National Institute of Neurological Disorders and Stroke, 2008).

Hydrocephalus results from an accumulation of cerebrospinal fluid inside or outside the brain. The blockage of the circulation of the fluid results in a buildup of excessive pressure on the brain and enlargement of the skull. The degree of intellectual disability depends on how early the condition is diagnosed and treated. Two types of treatment are available: surgical placement of a shunt (tube) that drains the excess fluid away from the brain to the abdomen or insertion of a device that causes the fluid to bypass the obstructed area of the brain.

ENVIRONMENTAL INFLUENCES A variety of environmental factors can affect a woman who is pregnant and thereby affect the development of the fetus she is carrying. One example is maternal malnutrition. If the mother-to-be doesn't maintain a healthy diet, fetal brain development might be compromised.

A variety of substances, from obvious toxic agents, such as cocaine and heroin, to more subtle potential poisons, such as tobacco and alcohol, have harmful effects on a fetus. In particular, fetal alcohol spectrum disorders (FASD) include a range of disorders in children born to women who have consumed alcohol while pregnant. One of the most severe of those disorders is fetal alcohol syndrome (FAS). Children with FAS are characterized by a variety of abnormal facial features and growth retardation, as well as intellectual disabilities. Although it's difficult to predict the effects of particular amounts of alcohol on the fetus, virtually all authorities (e.g., the Centers for Disease Control and the American Congress of Obstetricians and Gynecologists) are urging women who are pregnant or likely to become pregnant to refrain from drinking any alcohol.

The hazards of radiation to an unborn fetus have been recognized for some time. For example, physicians are cautious not to expose pregnant women to X-rays unless absolutely necessary, and the public has become concerned over the potential dangers of radiation from improperly designed or supervised nuclear power plants.

Infections in the mother-to-be can also affect the developing fetus and result in intellectual disabilities. A highly publicized relatively recent example is that of the outbreak of the **Zika virus** (spread by mosquito bites) in 2015 and 2016 in South America (especially Brazil) and Central America. When pregnant women are infected, they are at a very high risk of giving birth to babies with microcephaly and its resulting intellectual disability (McNeil, Romero, & Tavernise, 2016).

Rubella (German measles), in addition to being a potential cause of blindness, can also result in intellectual disabilities. Rubella is most dangerous during the first trimester (3 months) of pregnancy.

Perinatal Causes

A variety of problems occurring while giving birth can result in brain injury and intellectual disabilities. For example, if the child is not positioned properly in the uterus, brain injury can result during delivery. One problem that sometimes occurs because of difficulty during delivery is **anoxia** (complete deprivation of oxygen).

Low birthweight (LBW) can result in a variety of behavioral and medical problems, including intellectual disabilities (H. G. Taylor, Klein, Minich, & Hack, 2000). Because most babies with LBW are premature, the two terms—*LBW* and *premature*—are often used synonymously. LBW is usually defined as 5.5 pounds or lower, and it is associated with a number of factors: poor nutrition, teenage pregnancy, drug abuse, and excessive cigarette smoking. LBW is more common in mothers living in poverty. And surprisingly, worldwide, only Africa has a higher rate of premature births than North America (United States and Canada combined), with Asia and Latin America having a lower rate than the United States (Beck et al., 2010).

Infections such as **syphilis** and **herpes simplex** can be passed from mother to child during childbirth. These venereal diseases can potentially result in intellectual disabilities. (Herpes simplex, which shows as cold sores or fever blisters, is not usually classified as a venereal disease unless it affects the genitals.)

Postnatal Causes

We can group causes of intellectual disabilities occurring after birth into two very broad categories: those that are biological in nature and those that are psychosocial in nature.

BIOLOGICAL POSTNATAL CAUSES Examples of biological postnatal causes are infections, malnutrition, and toxins. **Meningitis** and **encephalitis** are two examples of infections that can cause intellectual disabilities. Meningitis is an infection of the covering of the brain that may be caused by a variety of bacterial or viral agents. Encephalitis, an inflammation of the brain, results more often in intellectual disabilities and usually affects intelligence more severely. One of the toxins, or poisons, that's been linked to intellectual disabilities is lead. Although lead in paint is now prohibited, in impoverished areas where lead paint is common in housing, infants still become poisoned by eating lead-based paint chips. The effect of lead poisoning on children varies; high lead levels can result in death.

PSYCHOSOCIAL POSTNATAL CAUSES Children who are raised in poor environmental circumstances are at risk for intellectual disabilities. It should be obvious that extreme cases of abuse, neglect, or understimulation can result in intellectual disabilities. However, most authorities believe that less severe environmental factors, such as inadequate exposure to stimulating adult–child interactions, poor teaching, and lack of reading materials, also can result in intellectual disabilities, especially mild intellectual disability. For example, in one large-scale study of 267,277 children, those who were born to teenage mothers who had fewer than 12 years of education were at increased risk for mild and moderate intellectual disabilities (Chapman, Scott, & Mason, 2002).

Although environmental causes of mild intellectual disabilities are undeniable, heredity can also play a role. For example, in a major study of heredity and mild intellectual disabilities, researchers looked at the degree of similarity in intellectual performance of monozygotic twins versus similarity in performance of dizygotic twins (Spinath, Harlaar,

Ronald, & Plomin, 2004). Monozygotic, or identical, twins come from the same egg and have the same genetic makeup. Dizygotic, or fraternal, twins come from separate eggs. In those who scored in the mild intellectual disability range, the degree of similarity was much higher in monozygotic twins than in dizygotic twins, thus indicating high heritability.

For many years, it's been assumed that psychosocial factors are the cause of the vast majority of cases of mild intellectual disabilities, whereas organic, or biological, factors are the cause of more severe intellectual disabilities. In recent years, however, authorities have begun to suspect that many cases of mild intellectual disabilities might be caused by specific genetic syndromes (Dykens et al., 2000; Hodapp & Dykens, 2007; Polloway, Smith, & Antoine, 2010). They point to the many cases of people with Prader-Willi syndrome and Williams syndrome, as well as females with Fragile X syndrome, who have mild intellectual disabilities, and they speculate that in the near future, new genetic syndromes will be discovered as causes of mild intellectual disabilities.

MyLab Education Self-Check 5.2

MyLab Education Application Exercise 5.2: Overview of Causes

This exercise asks you to create a graphic organizer to represent the causes of intellectual disabilities.

IDENTIFICATION

Assessment to determine whether a person has an intellectual disability addresses two major areas: intelligence and adaptive behavior.

Intelligence Tests

Many types of IQ tests are available. Because of the accuracy and predictive capabilities of IQ tests, school psychologists use individually administered tests rather than group tests when identifying students for special education. One of the most commonly used IQ tests for children is the WISC-V (Wechsler, 2003). The WISC-V consists of a Full-Scale IQ, as well as four composite scores: Verbal Comprehension, Perceptual Reasoning, Working Memory, and Processing Speed.

Although not all IQ tests call for this method of calculation, dividing **mental age** (the age level at which a person is functioning) by **chronological age** and multiplying by 100 provides a rough approximation of a person's IQ score. For example, a 10-year-old student who performs on an IQ test as well as the average 8-year-old (and thus has a mental age of 8 years) would have an IQ score of 80.

Compared to many psychological tests, IQ tests such as the WISC-V are among the most valid: The instrument measures what it is supposed to measure. A good indicator of the validity of an IQ test is the fact that it is generally considered the best single index of how well a student will do in school. It's wise to be wary, however, of placing too much faith in a single score from any IQ test. There are at least four reasons for caution:

1. An individual's IQ score can change from one testing to another, and although not common, sometimes the change can be dramatic (Whitaker, 2008).
2. All IQ tests are culturally biased to a certain extent. Largely because of differences in language and experience, people from minority groups are sometimes at a disadvantage in taking such tests.
3. The younger the child, the less validity the test has. Infant intelligence tests are particularly questionable.
4. IQ tests are not the absolute determinant when it comes to assessing a person's ability to function in society. A superior IQ score does not guarantee a successful and happy life, and a low IQ score does not doom a person to a miserable existence. Other variables are also important determinants of a person's coping skills in society. That is why, for example, professionals also assess adaptive behavior.

Adaptive Behavior

The basic format of instruments used to measure adaptive behavior requires that a parent, teacher, or other professional answer questions related to the person's ability to perform adaptive skills. We discuss some of these measures later in the section entitled, "Assessment of Adaptive Behavior."

PSYCHOLOGICAL AND BEHAVIORAL CHARACTERISTICS

Some of the major areas in which people with intellectual disabilities are likely to experience deficits are attention, memory, language, self-regulation, motivation, and social development. In considering psychological and behavioral characteristics, remember that a given individual with intellectual disabilities may not display all of these characteristics.

The importance of attention for learning is critical. A person must be able to attend to the task at hand before he can learn it. Often attending to the wrong things, persons with intellectual disabilities have difficulty allocating their attention properly.

People with intellectual disabilities have widespread memory difficulties, but they often have particular problems with working memory (Levorato, Roch, & Florit, 2011). **Working memory (WM)** involves the ability to keep information in mind while simultaneously doing another cognitive task. Trying to remember an address while listening to instructions on how to get there is an example of working memory.

Virtually all persons with intellectual disabilities have limitations in language comprehension and production. The exact types of problems depend largely on the cause of their intellectual disabilities (Abbeduto, Keller-Bell, Richmond, & Murphy, 2006).

Self-regulation is a broad term referring to the ability to regulate one's own behavior. People who have intellectual disabilities also have difficulties with metacognition, which is closely connected to the ability to self-regulate (Bebko & Luhaorg, 1998). **Metacognition** refers to a person's awareness of what strategies are needed to perform a task, the ability to plan how to use the strategies, and the evaluation of how well the strategies are working. Self-regulation is thus a component of metacognition. (We discuss metacognition again in Chapter 6.)

A key to understanding the behavior of persons with intellectual disabilities is to appreciate their problems with motivation (Switsky, 2006). Having usually experienced a long history of failure, they are likely to believe that they have little control over what happens to them. Therefore, they tend to look for external rather than internal sources of motivation.

People with intellectual disabilities are prime candidates for a variety of social problems. In addition to having difficulties making friends due to inappropriate behavior, they often lack awareness of how to respond in social situations (Snell et al., 2009). In fact, some researchers maintain that it is more accurate to consider social-emotional problems, such as mood disorders, obsessive-compulsive behaviors, and the like, as typical rather than rare (Woods, Freedman, & Derning, 2015).

UP CLOSE With The Late Robert Perske The only non-lawyer to be the recipient of the American Bar Association's Paul Hearne Award for Services to Persons with Disabilities, Robert Perske (1928—2016) (http://www.robertperske.com/Index.html) was a staunch advocate for people with disabilities for over 50 years. Perske attributed his dedication to society's most vulnerable citizens to his experiences as a 17-year-old soldier in the post–World War II, war-torn Philippine Islands. Perske's early career as the chaplain of the Kansas Neurological Institute, which served 250 children and young adults with intellectual disabilities, honed his sensitivities to people with intellectual disabilities. In his later years, Perske focused on exonerating people with intellectual disabilities who had provided false confessions to murder and/or rape.

FOCUS ON

Gullibility: From Puppets to the Supreme Court

One particular problem of responding in social situations that has received a great deal of research, especially in individuals with intellectual disabilities who have higher IQ scores, is gullibility. **Gullibility** can be defined as the "tendency to believe something, usually a highly questionable statement or claim, despite scanty evidence" (Greenspan, Loughlin, & Black, 2001, p. 102).

Stephen Greenspan, a prominent researcher in the field of intellectual disabilities, has made a strong case for social intelligence, gullibility in particular, as being the hallmark of intellectual disability, especially in those who have mild intellectual disabilities (Greenspan, 2004, 2006a, 2006b, 2009; Greenspan et al., 2001). Greenspan believes that gullibility likely results from a combination of cognitive and personality factors. The cognitive limitation is the inability to determine when something is a deceptive claim, and the personality factors relate to an overreliance on external motivational sources. Greenspan points to the character Pinocchio, from the classic 19th-century Italian children's novel of the same name, as the perfect example of someone who has mild intellectual disabilities by virtue of his gullibility. Made of wood, Pinocchio wants to be a "real" boy. He succumbs all too easily to temptation and being duped, with the outcome being his enduring a number of indignities. He eventually develops "social intelligence" and is able to return to his carpenter-maker, Gepetto, and turns into a flesh-and-bone boy.

The implications of gullibility beyond just marionettes from a children's fable are demonstrated by its role in how people with intellectual disabilities are dealt with by the legal system. Gullibility has figured into the wrongful conviction of numerous persons with intellectual disabilities. For example, false confessions are documented in at least 75 instances. Renowned advocate for persons with intellectual disabilities, Robert Perske, collected detailed information on dozens of these cases (Perske, 2008). (For more information on Perske, see *Up Close With Robert Perske*.) Just one example is of the case of Anthony Caravella, who was apparently harassed and beaten with a phone book by two policemen before confessing to the rape and murder of a woman in Miramar, Florida. There was no physical evidence tying Caravella to the crime, and he was found guilty primarily on police testimony. He said that he'd used a Pepsi bottle to hit her over the head—she had actually been stabbed and strangled. He referred to her as being a "girl"—she was actually 58 years old. Perske notes that a reporter, Maurice Possley from the *Chicago Tribune*, reported that Caravella said she was taller than he—she was eight inches shorter. He said he'd taken off her panties—they were partially on. Caravella served 26 years of a life sentence before being released based on DNA evidence.

The issue of gullibility of persons with intellectual disabilities has also been the topic of a landmark U.S. Supreme Court decision. After several years of debate in the courts, in 2002 the U.S. Supreme Court in *Atkins v. Virginia* ruled against the use of the death penalty for persons who have intellectual disabilities. Many of the arguments in favor of this decision focused on gullibility. Experts argued that, among other things, gullibility made such individuals vulnerable to being tricked into committing crimes without realizing their ramifications or to confessing to crimes that they had not actually committed (Patton & Keyes, 2006). The *Atkins* decision has also reinforced the claims of Greenspan and others that adaptive behavior, gullibility in particular, should figure more prominently in any future changes to the definition of intellectual disabilities (Greenspan & Switsky, 2006).

Linking Genetic Syndromes to Particular Behavioral Phenotypes

Until recently, most authorities paid little attention to the type of intellectual disability when considering behavioral characteristics. However, researchers have begun to find general patterns of behavioral characteristics, or **behavioral phenotypes**, associated with some of the genetic syndromes.

Researchers have identified the four genetic syndromes that we discussed in the section about the prenatal causes of intellectual disabilities—Down syndrome, Williams syndrome, Fragile X syndrome, and Prader-Willi syndrome—as having relatively distinctive behavioral phenotypes (Abbeduto, Murphy, et al., 2003, 2006, 2007; Dykens, 2001; Dykens et al., 2000; Fidler, Hepburn, Most, Philofsky, & Rogers, 2007; Hatton et al., 2003; Hodapp & Fidler, 1999; Mervis & Becerra, 2007; Moldavsky, Lev, & Lerman-Sagie, 2001; Roberts, Price, & Malkin, 2007). For example, people with Down syndrome often have significant impairments in language and grammar compared to visual-spatial skills; for individuals with Williams syndrome, the reverse is often true. In fact, the storytelling ability of the latter, including their ability to modulate the pitch and volume of their voices to interject emotional tone in their stories, together with their sociability and

TABLE 5.1 • **Links between genetic syndromes and behavioral phenotypes**

GENETIC SYNDROME	BEHAVIORAL PHENOTYPE	
	RELATIVE WEAKNESSES	RELATIVE STRENGTHS
Down syndrome	Receptive and expressive language, especially grammar Problems interpreting facial emotions Cognitive skills tend to worsen over time Early onset of Alzheimer's disease	Visual-spatial skills Visual short-term memory
Williams syndrome	Visual-spatial skills Math skills Fine-motor control Anxieties, fears, phobias Overly friendly Social relationships	Expressive language, vocabulary Verbal short-term memory Imitation of emotional responses Facial recognition and memory Musical interests and skills
Fragile X syndrome	Short-term memory Sequential processing Repetitive speech patterns Reading Social anxiety and withdrawal	Receptive and expressive vocabulary Long-term memory Adaptive behavior
Prader-Willi syndrome	Auditory processing Feeding problems in infancy Overeating, obesity in childhood and adulthood Sleep disturbances Obsessive-compulsive behaviors Math skills Working memory Social withdrawal	Relatively high IQ score (average about 70) Visual processing Facility with jigsaw puzzles

Based on data presented in: Abbeduto et al., 2003, 2007; Abbeduto, Murphy, et al., 2006; Bailey, Raspa, Holiday, Bishop, & Olmsted, 2009; Belser & Sudhalter, 2001; Dimitropoulos, Feurer, Butler, & Thompson, 2001; Dykens et al., 2000; Fidler et al., 2007; Fidler, Hodapp, & Dykens, 2002; Hatton et al., 2003; Hodapp & Dykens, 2007; John, Rowe, & Mervis, 2009; Kasari, Freeman, & Hughes, 2001; Mervis & Becerra, 2007; Mervis, Klein-Tasman, & Mastin, 2001; Moldavsky et al., 2001; Roberts et al., 2007.

elflike faces, have led to some speculation that the pixies, elves, or fairies depicted in folktales were people with Williams syndrome.

Table 5.1 lists some of the major behavioral characteristics associated with Down syndrome, Williams syndrome, Fragile X syndrome, and Prader-Willi syndrome. It's important to keep in mind that no one-to-one correspondence exists between the diagnosis and the characteristics. Not all individuals with each of these conditions will have all of the symptoms.

MyLab Education Self-Check 5.3

FOCUS ON

Williams Syndrome: An Inspiration for Pixie Legends?

English folklore is known for its depiction of "wee folk"—pixies, elves, fairies. The fact that people with Williams syndrome tend to possess facial characteristics similar to these figures —small stature, extreme sociability, and in fact, excessive friendliness (http://www.youtube.com/watch?v=gF4DiqEdN3w)—has sparked speculation among folklorists and biologists alike about whether the two were one and the same. Adding to this supposition is the fact that even though people with Williams syndrome usually have intellectual disabilities, sometimes they have a tendency to be lively storytellers and musically talented.

Historians and biologists have noted that folklore often serves the purpose of explaining real-life phenomena that are not very well understood. It is, therefore, not surprising that Williams syndrome has been linked to folktales of pixies and elves (Lenhoff, 1999). What's not clear is whether belief in elves and the like laid the foundation for society to consider people with Williams syndrome to be elves or vice versa. Given the extremely long history of many kinds of other-worldly beings, such as trolls, fairies, mermaids, and leprechauns, living in a variety of countries, such as Scandinavia, Germany, Ireland, Scotland, and England (see https://en.wikipedia.org/wiki/Thomas_Keightley), it's a good guess that it's the former.

EDUCATIONAL CONSIDERATIONS

In general, the focus of educational programs varies according to the degree of the student's intellectual disability or how much support the student requires. For example, the lesser the degree of intellectual disability, the more the teacher emphasizes academic skills; the greater the degree of intellectual disability, the more the teacher stresses functional skills, such as self-help, community living, and vocational skills. In practice, however, all students who have intellectual disabilities, no matter the severity level, need some instruction in academic, self-help, community living, and vocational skills. We focus on the elementary school level here; we discuss preschool and secondary programming in later sections.

A major issue facing special educators is how to ensure that students with intellectual disabilities have access to the general education curriculum, as dictated by the Individuals with Disabilities Education Act (IDEA; see Chapter 1), while also being taught functional skills. The more severe the level of intellectual disability, the more complex the issue of access. Authorities recommend a merger of functional and academic curricular standards. Blending academics and functional skills is embodied in **functional academics**, teaching academics in the context of daily living skills. Whereas children who do not have disabilities are taught academics (e.g., reading) to learn other academic content (e.g., history), the child with intellectual disabilities is often taught reading to learn to function independently. In functional reading, the child learns academics to do such things as read a newspaper or the telephone book, read labels on goods at the store, and fill out job applications.

Educational programming for students with intellectual disabilities often includes two features: systematic instruction and reinforcement.

MyLab Education
Video Example 5.2
This video shows a lesson focused on functional academics.

Systematic Instruction

Research documents that **systematic instruction** is critical for students with intellectual disabilities (Drasgow, Wolery, Chezan, Halle, & Hajiaghamohseni, 2017). Systematic instruction involves the teacher:

1. selecting a well-defined target behavior (e.g., student will learn to read 8 consonant-vowel-consonant words, student will learn to sort socks, underwear, and t-shirts in a dresser);
2. implementing instruction consistently with respect to such things as sequencing and prompting/cueing;

MyLab Education
Video Example 5.3
This video shows a teacher using systematic instruction along with reinforcement.

3. teaching foundational skills before teaching more advanced behaviors;
4. having a plan for how much to assist the student with verbal (e.g., "Put your socks in the bottom drawer.") or physical prompts/cues (pointing to the socks and the bottom drawer;) or modeling (e.g., the teacher puts the socks in the bottom drawer);
5. monitoring student performance and using that information to make changes to instruction as needed.

Reinforcement

Research has consistently shown that students who are positively reinforced for correct responses learn faster. Positive reinforcement ranges from verbal praise to tokens that can be traded for prizes or other rewards. For students with severe intellectual disabilities in particular, the more immediate the reinforcement, the more effective it is. The goal is to reach a point when the student doesn't have to rely on prompts and can be more independent.

Service Delivery Models

Placements for school-age students with intellectual disabilities range from general education classes to residential facilities. The degree of integration into general education tends to be determined by the level of severity; students who have less severe intellectual disabilities are the most integrated. Although schools have come a long way since passage of Public Law 94-142 (now IDEA), which prevented schools from turning away students with intellectual disabilities, there are many who believe that much of the momentum to educate students with intellectual disabilities in general education has begun to stall (Wehmeyer & Shogren, 2017).

The most recent report to Congress on the Implementation of IDEA (U.S. Department of Education, 2016) indicated that only 16.9% of students served under the category of intellectual disability spend 80% or more of their day in general education classrooms. Almost half (49.2%) of students with intellectual disability are educated in the general education classroom less than 40% of the day.

Even students with severe disabilities, however, are sometimes placed in general education classrooms, with schools providing extra support services (e.g., a special aide or special education teacher) in the class. Researchers have found classwide peer tutoring to be an effective technique for helping to integrate students with intellectual disabilities into general education classrooms (Delquadri et al., 1983; Greenwood, 1991). (See the accompanying Responsive Instruction feature.)

Although not all authorities agree on how much inclusion should be practiced, virtually all agree that placement in a self-contained class with no opportunity for interaction with students in general education classes is inappropriate. When students with intellectual disabilities are included in general education classes, it's important that special and general educators work together to plan for students to succeed. Without this planning the students are likely to be inattentive and socially isolated (Carter, Hughes, Guth, & Copeland, 2005; Kemp & Carter, 2006).

ASSESSMENT OF PROGRESS

Assessment of students with intellectual disabilities focuses on a variety of domains, including academic skills, adaptive behavior, and quality of life. The academic skills of students with intellectual disabilities may be assessed using methods that are common across disability categories, such as curriculum-based measurement (CBM). Some students with intellectual disabilities participate in standardized academic assessments. Many students with intellectual disabilities, however, require accommodations to participate in standardized assessments or receive an alternative assessment method if they cannot participate in traditional assessments with accommodations.

RESPONSIVE INSTRUCTION

Meeting the Needs of Students With Intellectual Disabilities

CLASSWIDE PEER TUTORING

What the Research Says

In an effort to meet the instructional needs of students with mild intellectual disabilities within inclusive settings, researchers have explored instructional methods that provide the necessary structure, individualization, and level of corrective feedback critical for success for this population. One such method is classwide peer tutoring (CWPT) (Delquadri, Greenwood, Stretton, & Hall, 1983). CWPT involves the use of peers to provide instruction and feedback in a reciprocal format. Paired students have the opportunity to serve as a tutor and as a tutee during each session. CWPT procedures were designed to address the need for higher levels of active academic engagement for all students, but particularly for students with the greatest academic deficits (Greenwood, 1991).

Research Study

A team of researchers conducted a study to examine the effectiveness of CWPT on the spelling performance of eight students (four students with mild intellectual disabilities and four students with no disabilities) participating in a general education class (Mortweet et al., 1999). The students with mild intellectual disabilities were included in general education classrooms for spelling, a social activity period, and lunch. The CWPT model was compared to traditional teacher-led instruction during the spelling period. The investigators used the following structure for the CWPT sessions:

1. Each student with mild intellectual disabilities was paired with a peer without disabilities.
2. Tutoring sessions occurred four times a week for 20 minutes per day.
3. Tutoring materials included the list of spelling words, point sheets, and practice sheets.
4. The teacher assigned each pair to one of two competing classroom teams. (Points earned by the pairs contributed to daily team point totals.) Partners and teams were reassigned on a weekly basis.
5. During each session, students served as the tutor for 10 minutes and as the tutee for the other 10 minutes.
6. Instruction consisted of the tutor reading the spelling word to the tutee. The tutee wrote the spelling word while saying each letter aloud. If the word was spelled correctly, the tutor awarded the tutee 2 points; if the word was spelled incorrectly, the tutor spelled the word correctly and the tutee wrote the word three times while naming each letter. The tutee could receive 1 point for correctly spelling the practice word. After 10 minutes, the roles were reversed.
7. The teacher assigned bonus points for pairs that were working cooperatively and following the instructional protocol.
8. When the 20-minute session was over, the teacher calculated team points on the basis of partner points. The winning team received privileges such as lining up first for recess.
9. Modifications made for the students with mild intellectual disabilities included shortened word lists, enlarged practice sheets, and tutee reading of words when the student with mild intellectual disabilities was the tutor and was unable to read the word.

Research Findings

When compared to the teacher-led condition, the CWPT resulted in improved academic performance for all students, increased amount of engaged academic time (approximately 5 to 10 minutes more per student per session), and positive acceptance from the teachers and students. Thus, CWPT provides teachers with a flexible instructional strategy to meet the varying needs of an inclusive classroom.

Applying the Research to Teaching

Given the effectiveness of CWPT, teachers can establish similar procedures in their classes. Tasks such as math facts, spelling, letter sounds, and word identification make great CWPT topics. Following the model established in the study, teachers can create their own tutoring materials. Key features of CWPT include partnering of a higher and a lower skilled student, explicit instruction in the tutoring activities (i.e., ample training before independent partner work), structured tasks for the tutor to guide the tutee in completing, reciprocal roles so the tutee has the opportunity to be a tutor, and use of points to reward desired behavior.

BY KRISTIN L. SAYESKI

Assessment of Adaptive Behavior

Assessments of adaptive behavior may be integrated with interventions so that services are provided in a data-based decision framework. One can use these assessments to provide outcome data on an individual's success following intervention. Typically, special educators or other professionals measure adaptive behavior indirectly, in that an "informant"

who is intimately familiar with the student provides information on a rating scale or in an interview (e.g., a parent, grandparent, teacher, or other primary caregiver). Several psychometrically sound instruments exist (Tasse et al., 2012). The Vineland Adaptive Behavior Scales—Third Edition (Vineland-3; Sparrow, Cicchetti, & Saulnier, 2016) is a popular measure of adaptive behavior for individuals from birth to 18 years. It includes several domains: communication, daily living skills, socialization, motor skills, and maladaptive behavior.

mple
ng
tary-

Assessment of Quality of Life

With the current emphasis on self-determination (which we discuss later in this chapter), more and more professionals are concerned with measuring the quality of life of persons with intellectual disabilities. However, measuring quality of life presents a challenge because a particular individual's perceived quality of life may differ from that of larger society (Brown & Brown, 2005; Cummins, 2005a). Consequently, outcome measures should include both objective and subjective measures that consider society's view of quality of life along with an individual's perceived level of satisfaction.

One measure commonly used to assess adolescents and adults with intellectual disabilities is the Quality of Life Questionnaire (QOL-Q; Schalock & Keith, 1993), which can be used with both English- and Spanish-speaking populations (Caballo, Crespo, Jenaro, Verdugo, & Martinez, 2005). It addresses five factors: satisfaction, well-being, social belonging, dignity, and empowerment/control (Schalock et al., 2002). A more objective scale is the BILD Life Experiences Checklist (Ager, 2003), which measures the extent to which an individual has ordinary life experiences. It comprises five areas including home, relationships, freedom, leisure, and opportunities for self-enhancement (Cummins, 2005b).

Testing Accommodations and Alternate Assessment

Testing accommodations are more likely to be used for students with milder intellectual disabilities, whereas alternate assessments are more likely to be used for students with more severe intellectual disabilities. Accommodations for students with intellectual disabilities on standardized tests can include modifications in scheduling, presentation format, and response format. Common scheduling accommodations include granting extended or unlimited time, or breaking the assessment into smaller, more manageable portions over several days. A typical presentation accommodation involves reading directions and problems to the student. Some students with intellectual disabilities may have physical difficulties and require response accommodations. For example, a student may dictate responses or use a tablet.

Alternate assessments are for students who can't be tested using traditional methods, even if accommodations are provided. Students with intellectual disabilities who participate in an alternate curriculum (e.g., life skills, vocational skills) instead of the general (more academic) curriculum may participate in alternate assessments. Alternate assessments should measure authentic skills, cover a variety of domains, and include multiple measures across time (Ysseldyke & Olsen, 1999). They can include direct observations of specific behaviors, checklists, rating scales, and curriculum-based measures. Several domains should be covered, for example, functional literacy, communication, leisure-recreation skills, domestic skills; and vocational skills (Spinelli, 2006).

MyLab Education Self-Check 5.4

MyLab Education Application Exercise 5.3: Who Is Star?

Watch a video featuring a little girl named Star, think about characteristics of students with intellectual disabilities, and then answer the questions that follow.

MyLab Education Application Exercise 5.4: Mini Case Study

Read a case study about Carrie, and respond to questions about the characteristics of students with intellectual disabilities.

SUCCESS STORIES: Nolan's Team of Parents and Professionals Helps Him Gain Access to the General Education Curriculum

Special Educator Sheryl Simmons: "Members of Nolan's team, including his parents, tailor materials to meet his needs in learning the general curriculum."

Nine-year-old Nolan Patrick Smith attends Sunflower Elementary School in Kansas.

These are the keys to his success:

- Intensive and strategic instruction
- Relentless collaboration among team members
- Specific goals and social supports

Nolan Smith, who has Down syndrome, is the second oldest of Kris Kohnke's and Sean Smith's four children. Within 3 weeks of his birth, Nolan started speech and language early intervention services. Intensive language and literacy instruction is still important to his success. Since he was an infant, Nolan has thrived on intensive, relentless, and specific special education.

- **Intensive and Strategic Instruction.** Nolan is now an outgoing 9-year-old boy with a broad range of cognitive abilities not easily summarized by a single score. He enjoys participating with children his age, but he struggles with reading, writing, and mathematics. Nolan reads at a first-grade level, and helping him move beyond sight words is a challenge. He's eager to decode text, and he has some strategies, but cognitive problems impede his progress. Handwriting is also challenging for Nolan, and he uses an adaptive keyboard for written assignments. "Nolan loves the computer," says Sean Smith. "Now the question is, how is he going to use it?"

  Nolan is easily distracted. Frequent prompts help keep him on task. "He can be silly, and the structure of the school day can be difficult for him," says Kris Kohnke. Nolan spends half the school day in third grade with 20 of his classmates. This year the focus of his inclusion is on academics (science and social studies) and social development. Nolan is learning that reading has a purpose, and he's eager to demonstrate what he knows. With the help of a paraprofessional, Nolan starts the morning with his classmates and goes to a quiet room for 60 minutes of intensive instruction in reading and mathematics with special educator Sheryl Simmons. He also gets strategic instruction in the resource room before joining his classmates for science, health, or social studies. "A visual approach works well for Nolan," says Mrs. Simmons, who adapts materials in visually stimulating formats to ensure he comprehends and can apply what he learns. According to his individualized education program (IEP), another successful strategy for Nolan is practicing answers to content-based questions with an adult before sharing them with the class. This strategy reinforces his recall and reduces his tendency to stutter when he speaks.
- **Relentless Collaboration.** Much of Nolan's success depends on coordinated support from his parents, teachers, and therapists. "A real strength for Nolan is that he can understand concepts if we present them in multiple ways and in formats other than print," says Sean Smith. Nolan learned about rain forests through the efforts of relentless collaboration between home and school. His teachers modified a science study guide so Nolan's parents and his speech therapist could help him practice rain forest vocabulary. "By the time he took the pretest, he already knew the concepts of camouflage, endangered species, and global warming," says Sheryl Simmons. "He was so proud of his accomplishment."

  Collaboration with school personnel is a high priority. Nolan's parents meet every 3 weeks with Mrs. Simmons and Nolan's general education teacher to stay on top of communication and expectations for his progress. Nolan's annual goals are addressed but in the context of the third-grade classroom and curriculum. "With inclusion too many meetings happen 'on the fly,' and most IEP meetings are formal and nerve wracking," says Sean Smith. "By scheduling regular, informal meetings, we can talk more easily about Nolan and better target what he needs at school, and how we can support his learning at home."
- **Specific Goals and Social Supports.** Kris Kohnke and Sean Smith are strong advocates who want Nolan's goals to be practical and meaningful for him. This year's annual goals target sight-word vocabulary, reading fluency and comprehension, and building numeracy skills with money and time so Nolan can solve real-world math problems. Every other week he has a Lunch Bunch social skills group with the school counselor to strengthen his peer relationships. Nolan's goals for adapted physical education, and occupational and speech therapies help improve his physical coordination, self-care, and communication.

  Strengthening academic, functional, and social skills helps Nolan in his busy life outside of school. The four Smith children are active in their community, and Nolan is no exception. Lawrence Parks and Recreation's All-Star Sports and Special Olympics are a big part of his life, as are play-dates with teammate and best buddy, George. Nolan's parents

Continued

SUCCESS STORIES: Nolan's Team of Parents and Professionals Helps Him Gain Access to the General Education Curriculum

also make sure he participates in typical activities with his brother and sisters. "Sometimes it's hard on siblings when one child needs so much attention. Celebrations like the Down Syndrome Association's 'Buddy Walk' let Nolan's siblings see him in a positive way as part of a larger community," says Sean Smith. "This year 7000 people participated in Kansas City's celebration, and Nolan's sister said, 'look at all those other people with Down syndrome and their families and friends!'"

Reflecting on Your Own Professional Development:
If you were Nolan's teacher . . .

- What are some areas about educating students with intellectual or developmental disabilities that you would need to know more about?
- What are some specific skills that would help you address his academic and behavioral challenges?
- What personal dispositions do you think are most important for you to develop in teaching students with limited cognitive abilities?

By Jean B. Crockett and Sean Smith

EARLY INTERVENTION

We can categorize preschool programs for children with intellectual disabilities as those intended to prevent intellectual disabilities or those designed to further the development of children who have already been identified as having intellectual disabilities. In general, the former address children who are at risk for mild intellectual disabilities, and the latter are for children with more severe intellectual disabilities.

Early Childhood Programs Designed for Prevention

Toward the end of the 20th century, the federal government began providing funds for several infant and preschool programs for at-risk children and their families, with the goal being to research their effects. Most such programs have focused on families in poverty. The Rand Corporation conducted a thorough analysis of 19 of these programs and concluded that most were highly effective for children and parents alike (Karoly, Kilburn, Cannon, 2005). Some of the programs were center-based, some home-based, and some were a combination of center- and home-based. They improved such things as academic achievement and employment while reducing poverty, special education placement, delinquency, and crime. And these outcomes yielded cost savings to society ranging from $1.80 to $17.07 for each dollar spent on the program.

Early Childhood Programs Designed to Further Development

Early childhood programs designed to enhance the development of children already identified with intellectual disabilities place a great deal of emphasis on language and conceptual development. Because these children often have multiple disabilities, other professionals—for example, speech therapists and physical therapists—are frequently involved in their education. Also, many of the better programs include opportunities for parent involvement.

Note in the accompanying Success Stories feature, for example, how much Nolan Smith's parents have collaborated with his teachers and therapists. Through practice with their children, parents can reinforce some of the skills that teachers work on. For example, parents of infants with physical disabilities, such as cerebral palsy, can learn from physical therapists the appropriate ways of handling their children to further their physical development. Similarly, parents can learn appropriate feeding techniques from speech therapists.

TRANSITION TO ADULTHOOD

In secondary school, the vast majority of students with intellectual disabilities take at least one vocational course and a life skills/social skills course. And when they do take general education courses, the majority receive a modified general education curriculum (Institute of Education Sciences, National Center for Special Education Research, 2009).

Although most authorities agree that the degree of emphasis on transition programming should be greater for older students, they also believe that such programming should begin in the elementary years. Three major areas to consider in planning for adulthood are life skills, employment skills, and self-determination skills. (See Figure 5.2.)

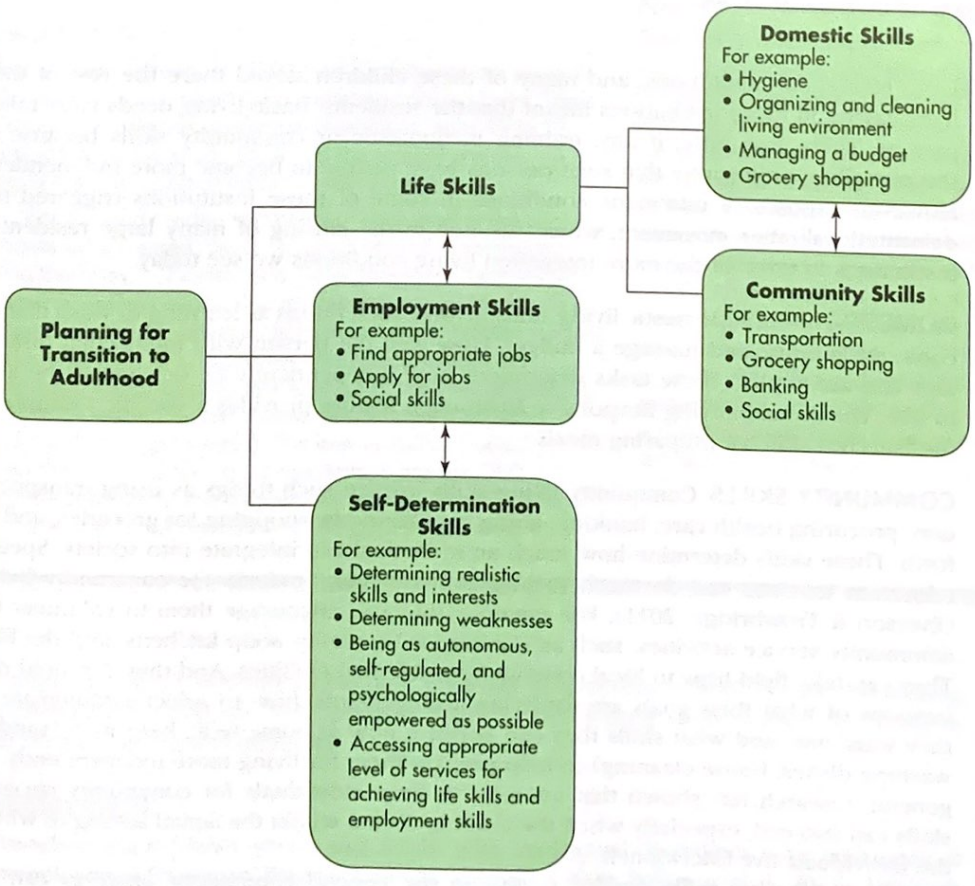
Life Skills

Life skills are one of those concepts that fit the colloquial expression, "I know it when I see it." Life skills are observable but hard to pin down with a precise definition. Most adults need these skills to live a fulfilling life by taking care of themselves and functioning in society. We have divided them into two categories: domestic skills and community skills.

Domestic and community skills have become more and more important with each passing year. It wasn't that long ago that professionals advised parents to place children with intellectual disabilities, even those with moderate intellectual disabilities, into

FIGURE 5.2

TRANSITION TO ADULTHOOD



FOCUS ON

The Changing Face of Living Options for People with Intellectual Disabilities

The early part of the 20th century in the United States witnessed an increase in the number of large residential institutions for people with intellectual disabilities. However, this growth was brought to a halt in the late 1960s. Not only was society beginning to be more accepting of individuals with intellectual disabilities, but there were several reports of overcrowding and sometimes abusive practices in these institutions. One of the most dramatic reports was *Christmas in Purgatory*, a pictorial essay on the squalid conditions of institutional life. Authored by Burton Blatt, a renowned advocate for persons with intellectual disabilities, and photographed by Fred Kaplan, this exposé was a major catalyst in turning the tide of public and professional opinion against large institutions (Blatt & Kaplan, 1966).

Although large residential facilities for people with intellectual disabilities still exist, as we noted earlier, they are fast disappearing. The trend is toward smaller **community residential facilities (CRFs)** (Lakin, Prouty, & Coucouvanis, 2006; Prouty, Coucouvanis, & Lakin, 2007). For example, since the 1970s, the number of residents with intellectual disabilities in CRFs has increased more than ten-fold, while those living in facilities of 16 or more has decreased more than three-fold. CRFs, or group homes, accommodate small groups (3 to 10 people) in houses under the direction of "house parents." Placement can be permanent, or it can serve as a temporary arrangement to prepare individuals for independent living. In either case, the purpose of the CRF is to teach independent living skills in a more normal setting than a large institution offers.

Some professionals question whether CRFs go far enough in offering opportunities for integration into the community. They recommend **supported living** (http://www.youtube.com/watch?v=9AWhEvWGrqY) in which persons with intellectual disabilities receive supports to live in more natural, noninstitutional settings, such as their own home, mobile home, condominium, or apartment. The idea is to enable them to choose to live in places that are available to typical residents in the community (Everson & Trowbridge, 2011). Some evidence shows that supported living arrangements lead to residents having more control over everyday choices (Ticha et al., 2012).

large residential institutions, and many of these children stayed there the rest of their lives. Living in these institutions meant that the residents' basic living needs were taken care of. There was little, if any, training in domestic or community skills because of the prevailing philosophy that such persons were unable to become more independent. However, exposés of inhumane conditions in some of these institutions triggered the **deinstitutionalization movement**, which resulted in the closing of many large residential institutions in favor of the more integrated living conditions we see today.

DOMESTIC SKILLS Domestic living skills involve such things as learning to wash dishes, cook, do laundry, and manage a budget. How well the person with intellectual disabilities can accomplish these tasks determines how independently he or she will be able to live. The accompanying Responsive Instruction feature provides a specific example of the "survival skill" of preparing meals.

COMMUNITY SKILLS Community living skills involve such things as using transportation, procuring health care, banking, going to restaurants, shopping for groceries, and so forth. These skills determine how much an individual can integrate into society. Special education teachers can do much to help prepare their students for community living (Everson & Trowbridge, 2011). For example, they can encourage them to volunteer for community service activities, such as Habitat for Humanity, soup kitchens, and the like. They can take field trips to local community residential facilities. And they can hold discussions of what their goals are for living arrangements, how to select a roommate, if they want one, and what skills they can perform now at home (e.g., help with laundry, washing dishes, house cleaning) to help prepare them for living more independently. In general, research has shown that attempts to train individuals for community survival skills can succeed, especially when the training occurs within the actual setting in which the individuals live (McDonnell, 2017).

In addition to skills needed to live in the general community, students can be encouraged to learn skills to engage in the school community (Dymond, 2017). For

RESPONSIVE INSTRUCTION

Meeting the Needs of Students with Intellectual Disabilities

USING TECHNOLOGY TO SUPPORT COOKING

What the Research Says

Independence is an important goal for many students with intellectual disabilities. Transition planning for students with intellectual disabilities typically includes strategies for promoting self-reliance through self-management and self-monitoring techniques (Sands & Wehmeyer, 2005). The process of food preparation, a valuable and economical aspect of independent living, has been studied by researchers for decades (Agran, Fodor-Davis, Moore, & Deer, 1989; Lancioni, O'Reilly, Seedhouse, Furniss, & Cunha, 2000; Martin, Rusch, James, Decker, & Trtol, 1982). The ability to prepare food creates the opportunity for both self-sufficiency and job employment. Researchers have used a variety of approaches, ranging from the use of static pictures to video modeling to video prompting to promote the development of independent cooking skills. Recent research has also looked to more portable, student-directed tools such as iPads, smart phones, or portable DVDs to promote multi-step skills such as cooking (Dymond, 2017). These technologies provide new avenues for support and independence.

Research Study

Mechling and colleagues (2008) had participants use portable DVD players as a support for completing cooking tasks. Three adults with moderate intellectual disabilities, ages 19 to 22, participated in the study. Each had the goal of preparing a simple meal as a part of his or her transition plan.

For the study, video segments of each step in the cooking process were created. Students could control the video by using the "Play," "Pause," and "Skip (Previous)" buttons on the portable DVD player. The modeling was provided from a subjective point of view (i.e., from the viewpoint of the student performing the task). To prepare the video, researchers conducted a step-by-step task analysis of the various cooking tasks (e.g., making grilled cheese, preparing a ham salad, cooking Hamburger Helper). The intervention included three phases: (1) teaching the students to use the DVD player—particularly, the play and repeat sequence process—to mastery, (2) cooking following the DVD self-prompting procedure, and (3) following the cooking steps without the DVD player. For each step in the video-prompting phase, students were evaluated as to whether they (a) successfully completed the step, (b) failed to complete the step, or (c) did not respond to the prompt. If a student failed to complete the step, three levels of prompting could occur. For the first prompt, a self-prompt, the student could replay the step using the skip/repeat function of the DVD player. For the second level of prompt, the instructor gave a verbal prompt. In the final level of prompt, the instructor completed the step.

Research Findings

All participants benefited from the intervention, as evidenced by an overall increase in the percentage of correctly completed steps. The steps that presented the greatest challenges were setting the digital timer, operating the stove dial, and waiting for the timer—all tasks involved in preparing the grilled cheese sandwich. Students did experience success in their ability to use the skip/repeat function of the DVD, but in many instances required instructor prompting to do so.

Applying the Research to Teaching

Teachers of students with intellectual disabilities can make use of the portable DVD player to support independent living tasks such as cooking. The dual advantages of relatively low-cost technology and student control through the play, pause, and repeat functions make portable DVD players a useful tool for teaching, which can transition with students as they move out of their educational settings. Teachers can create their own video models with prompts by following the steps established in the study by Mechling and colleagues (2008). After conducting a task analysis of skill, record simple video segments of each step. At the conclusion of each step, provide an auditory cue, "PAUSE," to prompt students to pause the video and conduct the step. Mechling and colleagues recommend identifying foods students like or activities students want to learn to increase student motivation and success with the tool.

BY KRISTIN L. SAYESKI

example, teaching students to become involved in attending school events and joining extracurricular clubs can help prepare them for developing skills needed for living in the broader, general community.

Employment

Overwhelming evidence shows that adults with intellectual disabilities have high rates of unemployment (Newman, Wagner, Cameto, & Knokey, 2009; Polloway et al., 2017). Although employment statistics for workers who have intellectual disabilities have been discouraging,