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INDIVIDUALS WITH EXTENSIVE SUPPORT NEEDS—KEEPING ADULTHOOD IN MIND

CHAPTER OBJECTIVES

After reading this chapter you should be able to do the following:

1.1 Define students with extensive support needs.

1.2 Define quality of life and how it relates to independence and self-determination.

1.3 Summarize adult outcomes for individuals with extensive support needs.

1.4 Compare the history of treatment and services with current services for individuals with extensive support needs.

1.5 Discuss the lifespan development of individuals with extensive support needs.

1.6 Identify the various stakeholders that are involved in educational and adult service programs for students and adults with extensive support needs.

Opening Vignette

Jacob is 24 years old and lives with his parents, Frank and Denise, in a white middle-class home. With them reside Jacob's younger siblings Adam, who is 16, and Adele, who is 13. Frank is a successful home developer, and Denise quit her job as a preschool teacher to provide more direct support for Jacob during his preschool years. Jacob was diagnosed with cerebral palsy when he was born, and later identified as having moderate intellectual disabilities. He uses a combination of word approximations, gestures, and picture communication symbols to communicate and uses a wheelchair for mobility. Frank and Denise began researching services for Jacob after his initial diagnosis of cerebral palsy and secured physical therapy and speech language services in the state's infant program and later in the local district's preschool program. He attended his local public school from kindergarten through 12th grade, including staying past his 18th birthday as allowed by the Individuals with Disabilities Education Act (IDEA), and exited school when he was 20 with a certificate of completion. During most of his school years Jacob was in a self-contained special education classroom. While his parents wanted him to be as "normal" as possible, the school convinced them that he could receive more intense services in the self-contained setting. His only opportunities to be with students without disabilities was during his lunch time, school assemblies, and a few classes including music and physical education. During these "opportunities" he was never included but simply physically with students without disabilities. When Jacob turned 16, the school developed a transition plan as part of his individualized education program (IEP); however, the plan included very little preparation that would have prepared Jacob for life as an adult.

Since exiting high school, Jacob has stayed at home with his parents. There are very limited opportunities for him in his hometown of 45,000 people. The state rehabilitation agency has assigned a vocational rehabilitation counselor to Jacob, but very few services have been offered to him. Jacob attends a segregated **day service program** 3 days each week, but it provides limited opportunities for becoming independent and gaining meaningful employment. Jacob's job at the workshop is to assemble boxes for a local business. His parents want him to be able to live in his own apartment, or at least in a supported living facility in the community, and have a meaningful job; however, they currently believe that he will likely live with them his entire life. They are unsure what Jacob's options will be when they are no longer able to care for him.

Questions to Consider About Jacob

1. How would you describe Jacob's independence and quality of life as an adult?
2. What would be some services that would assist Jacob in becoming more independent and gainfully employed?
3. What could schools have done that would have improved the quality of life for Jacob?
4. How can schools change to better prepare students like Jacob for life after high school?
5. Why is it important for school personnel to consider future opportunities for students with extensive support needs when they become adults?
6. How could school professionals have informed Jacob's parents about different opportunities during his school years?

INDIVIDUALS WITH EXTENSIVE SUPPORT NEEDS

Unfortunately, there are many young adults like Jacob who have extensive support needs but who are very capable of living independently, or at least semi-independently, and having a meaningful job. Too often, many of these individuals are living at home or a **congregate care facility** and are either unemployed or **underemployed**. Too often, schools and families have assumed that students with extensive support needs are incapable of gainful employment or independent living as adults, which results in focusing on current ability levels and less on the futures of these students. Too often, the **quality of life** for these individuals—being happy and satisfied with one's life (McDougall et al., 2016)—is less than it could be if appropriate services and supports are provided throughout a child's life.

The purpose of education has been described in numerous ways. John Dewey (1934) said the purpose "has always been to everyone, in essence, the same—to give the young the things they need in order to develop in an orderly, sequential way into members of society" (p. 1). In other words, education is to prepare children and youth for adulthood so they can be contributing members of society, so they can live independently, engage in productive and meaningful employment, and enjoy quality of life.

The goal of education for students with disabilities should be no different than it is for other children—it should help prepare them for life after school. While the majority of individuals with disabilities have mild disabilities, there is a group of individuals who experience more extensive support needs. This group, which includes those with moderate to profound intellectual disabilities, severe autism spectrum disorders, severe mental health conditions, and significant health and physical problems, makes up a small percentage of the population with disabilities. Yet goals for this group should be the same as for all others: independence and a high quality of life.

Interestingly, when individuals with extensive support needs are asked about their future goals, they respond similarly to how individuals without disabilities respond. They are interested in having a job and being economically independent, living in a home, making their own decisions, and forming relationships with friends and family (Di Maggio, Shogren, Wehmeyer, & Nota, 2019). These goals are all related to **self-determination**, which is associated with having a higher number of future goals (Di Maggio, Shogren, Wehmeyer, & Nota, 2019). In other words, they want the same quality of life as everyone else.

Preparing individuals with extensive support needs to be as independent as possible and enjoy a high quality of life is the responsibility of every **stakeholder** in the lives of these individuals, beginning with services for young children (McDougall et al., 2016). It is often too late to consider the quality of life for individuals with extensive support needs when they reach adulthood; it is also too late to wait until formal **transition planning** begins at the age of 16. Planning and preparing individuals with extensive support needs for successful adulthood must be a focus of all advocates and service providers throughout the child's life, including parents, school personnel, and adult service providers. The best way to ensure a high quality of life for these individuals is to focus on the adult outcomes necessary for independence and a high quality of life during a child's entire lifetime. The widespread lack of success in employment and independent living opportunities for this population as adults confirms that schools are doing less than an adequate job in this area.

Rather than focusing solely on the current needs of students, schools should work collaboratively to project likely futures for students and build educational and support programs around those goals. These projected futures, including self-determination, employment, and independent living, must be driven by the abilities of the individuals as well as their goals and interests and the goals and interests of their families. This textbook focuses on the quality of life and independence of individuals with extensive support needs and the services that must be provided during their entire lifespan to ensure that they achieve a high quality of life and are as independent as possible as adults.

Most individuals with disabilities are classified as having **mild disabilities** and require only minimal supports; however, a small group have disabilities that result in more extensive needs. These students, often referred to as having **severe disabilities**, experience a variety of "deficits in health or functioning that significantly limit a person's performance and participation in major life activities" (Hartshore & Schafer, 2018, p. 422) and result in **extensive support needs.**

There is no single definition of *severe disabilities*. The federal definition of significant disabilities is

> An individual with a disability who has a severe physical or mental impairment which seriously limits one or more **functional capacities** (such as mobility, communication, self-care, self-direction, interpersonal skills, work tolerance, or work skills) in terms of an employment outcome; whose vocational rehabilitation can be expected to require multiple vocational rehabilitation services over an extended period of time; and who has one or more physical or mental disabilities resulting from amputation, arthritis, autism, blindness, burn injury, cancer, cerebral palsy, cystic fibrosis, deafness, head injury, heart disease, hemiplegia, hemophilia, respiratory or pulmonary dysfunction, intellectual disabilities, mental illness, multiple sclerosis, muscular dystrophy, musculo-skeletal disorders, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia, and other spinal cord conditions, sickle cell anemia, specific learning disability, end-stage renal disease, or another disability or combination of disabilities determined to cause comparable substantial functional limitation (29 U.S.C.).

TASH defines individuals with severe disabilities as "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" (TASH, p. 19). For school-age children, the IDEA does not include the category of severe disabilities but defines several specific disabilities that result in eligibility for special education.

IDEA does include a multiple disabilities category, which refers to "concomitant [simultaneous] impairments (such as intellectual disability-blindness, intellectual disability-orthopedic impairment, etc.), the combination of which causes such severe educational needs that they cannot be accommodated in a special education program solely for one of the impairments. The term does not include "deaf-blindness." In addition to the multiple disabilities category of IDEA, there are other IDEA categories that may include children who have extensive support needs. For example, most children with intellectual disabilities present mild intellectual disabilities; however, there are some individuals with intellectual disabilities who require extensive support needs. Similarly, many children on the autism spectrum display mild disabilities while some can be characterized as experiencing more extensive support needs. Additionally, while orthopedic impairments, other health impairments, emotional disturbance, and sensory impairments typically result in mild disabilities, these can also result in the need for extensive supports for some children. What must be remembered is that the term *extensive support needs* does not encompass only one IDEA category or disability label; rather, it includes students with a variety of labels (Kleinert et al., 2015). The designation of extensive support needs focuses more on the impact of the disability rather than a specific type of disability.

Another way of describing the population of students with extensive support needs is through the alternate assessment option provided in the **Every Student Succeeds Act** (ESSA). Under this act, which is a reauthorization of the Elementary and Secondary Education Act and replaces the **No Child Left Behind Act**, students with the most significant cognitive impairments can be assessed using alternate assessments based on grade-level academic standards (Kleinert et al., 2015). ESSA states that this should not exceed 1% of all students tested in a given subject (Every Student Succeeds Act: Summary of Final Regulations). Of the students with disabilities served under IDEA in the 2021–2022 school year, 5.8% of fourth graders, 6.4% of eighth graders, and 6.7% of high school students participated in the alternate math assessment. For alternate reading assessments the numbers were 6.1% of fourth graders, 6.3% of eighth graders, and 7.0% of high school students (45th Annual Report to Congress, 2023). Using this approach, the majority of students with disabilities could be classified as having mild disabilities, while those participating in the alternate assessments—approximately 10% of children served under IDEA—could be classified as having extensive support needs. While well intended, the method of determining eligibility for alternate assessments can be somewhat subjective (Cho & Kingston, 2013).

As can be determined with the previous discussion, defining students with extensive support needs is not an easy task. Professionals may have a different interpretation about whether a disability results in a need for extensive supports. Parents may also have different opinions about the severity of their child's disability, which is likely influenced by how the disability impacts intellectual, behavioral, and emotional functioning of their child (Dovgan, Nowell, & Aguilar, 2019). The reality is that both professionals and parents identify the severity of a disability on various functioning skills, not a particular clinical label. While the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) identifies severity levels for intellectual disability and autism spectrum disorder, the designation of a disability resulting in a severe disability requiring extensive support needs is a professional judgment.

In this text, the term *extensive support needs* is used to describe individuals whose disability results in a substantial functional impact on aspects of their life; it focuses on the functional impact of a particular disability. A diagnosis of a specific disability does not always result in that individual having extensive support needs. Therefore, clinical labels will not be used in the text and the generic *severe disabilities* label will be used sparingly. Rather than focusing on specific labels, the text will focus on individuals whose disabilities result in their needing extensive supports. There is no way to differentiate someone classified as having extensive support needs from one who exhibits only slightly better skills. Ability/disability is on a continuum from very disabled to very able. As a result, while the text will focus on individuals who will have difficulty with independent living, social integration, and employment, it should be kept in mind that there are many individuals whose skills and abilities create independent living and employment challenges but not to the degree of those classified as having extensive support needs.

Another *word* about terminology is the use of person-first or identity-first language. The first self-advocacy movement for individuals with disabilities was called People First and began in the 1970s. This movement emphasized person-first language to underline the importance of not labeling individuals as victims. Person-first language was written into the **Americans with Disabilities Act** in 1990 and the 1997 revision of IDEA (Wooldridge, 2023). First-person language emphasizes the individual, as an individual first. For example, person-first language would use "Bob with an intellectual disability" rather than "intellectually disabled Bob."

While most professionals have adopted person-first language, a recent trend is to use identify-first language. Individuals who prefer identity-first language believe that "if language is needed to separate them from a trait of theirs, it suggests that the trait is negative" (Wooldridge, 2023, p. 2). Identity-first language uses terms like "autistic person" and "deaf individual" rather than "the individual with autism" and "the girl with hearing loss." There is no one-size-fits-all to using person-first or identity-first language; both are appropriate depending on the wishes of the individual with the disability (Wooldridge, 2023). Although person-first language will be used throughout this text to maintain consistency, it in no way is intended to suggest that person-first language is preferable to identity-first language.

QUALITY OF LIFE AND INDIVIDUALS WITH EXTENSIVE SUPPORT NEEDS

The goal for all individuals is to experience a high quality of life. These outcomes are the same for children and adults with disabilities, including those with extensive support needs. McDougall and colleagues (2016) studied the quality of life and self-determination of youths with chronic health conditions and found that they shared the same future goals as their peers without disabilities. These included living independently or more independently, working and having a career, and spending time with friends. Relationships with family and friends were reported to be extremely important.

Gomez and colleagues (2015) acknowledged both the importance of quality-of-life factors as well as the difficulty in measuring this quality. Through a Delphi process, 118 indicators of quality of life, in eight domains, were identified. The domains included (1) self-determination; (2) emotional well-being; (3) physical well-being; (4) material well-being; (5) rights; (6) personal development; (7) social inclusion; and (8) interpersonal relations. Other studies have described satisfaction and happiness as terms describing quality of life, which is impacted by relationships, supportive environments, doing things, personal growth, and accepting one's disability (McDougall et al., 2016).

There are numerous factors that can impact one's quality of life, including the presence of maladaptive behaviors, level of adaptive behavior, and presence of complex physical and health issues. Unfortunately, many of these factors are present in individuals with extensive support needs. The quality of life of children with severe developmental disabilities was investigated by Ncube, Perry, and Weiss (2018). Comparing children with disabilities, aged 4–18, with their chronological age peers without disabilities, the authors found that parents rated the quality of life of children without disabilities significantly higher than parents' ratings of children with severe developmental disabilities. This does not automatically result from the impact of the disability; it could be the result of the lack of services, supports, and adaptations required to enable individuals to achieve a higher quality of life.

McDougall and colleagues (2016) studied the relationship between quality of life and self-determination and found five overarching themes related to the quality of life of adolescents. These included (1) relationships; (2) supportive environments; (3) doing things; (4) personal growth and moving forward; and (5) self-understanding/acceptance of disability. Table 1.1 summarizes these themes. Shogren and colleagues (2015) added that initiating goal setting, making conscious decisions based on personal preferences, making something happen when working toward goals, and believing in one's ability to make decisions to achieve goals are also key components of self-determination.

TABLE 1.1 ■ Quality-of-Life Components

Relationships	Supportive Environments	Doing Things	Personal Growth and Moving Forward	Self-Understanding/ Acceptance of Disability
Having friends and more close friends of similar age were considered important.	Home, school, and community environments	Taking part in leisure and recreational activities	Doing well in school	Understanding one's disability
Knowing that support persons, including family, teachers, and counselors were available when needed was important.	Accessibility	Going to movies and other community events	Being successful in higher education	Acceptance of the disability
—	Opportunities to participate in sports	Participating on sports teams	—	—

Source: Adapted from "Quality of Life and Self-Determination: Youth With Chronic Health Conditions Make the Connection," by J. McDougall, P. Baldwin, J. Evans, M. Nichols, N. Etherington, and V. Wright, 2016, *Applied Research Quality Life, 11,* 571–599. DOI: 10.1007s11482-014-9382-7

Independence is also directly related self-determination and quality of life. It is difficult to be independent without being self-determined or being self-determined without being independent. Living independently requires numerous considerations, which need to be addressed throughout an individual's life. These include: (1) availability of appropriate housing, (2) need for adaptive equipment, (3) adequate financial support, (4) safety, (5) ability to perform daily living tasks, and (6) accessible transportation (Independence & Self-Sufficiency, 2019).

In order to achieve quality of life for individuals with extensive support needs, interventions and supports must begin early in a child's life. Services in preschool, school, and postschool should all focus on factors that impact quality of life. While the quality of life for individuals with extensive support needs has improved dramatically over the past several decades, there is much work that remains if this improvement is to continue (Agran et al., 2018). The focus must remain over the lifespan of the individual.

Implications for Educators

To facilitate persons with extensive support needs achieving an independent quality of life, educators must begin preparing them early in their school career; educators cannot wait until a student with extensive support needs reaches the age when transition is mandated by IDEA.

For example, more students with intellectual disabilities are attending inclusive postsecondary education programs in colleges after they complete their high school program. Attending these postsecondary education programs is associated with quality of life and provides students the opportunity to have relationships, do things typical college students do, enjoy personal growth, and develop an understanding and acceptance of their disability (McDougall et al., 2016). In order to achieve success in these programs individuals need to display numerous characteristics, including self-determination, self-help skills, and independent living skills. They must begin to develop these skills during their P–12 school years, not just the last few years they are in school (Griffin & Papay, 2017). This means that elementary teachers, middle school teachers, and high school teachers must all focus on factors that impact adult quality of life. Focusing on quality-of-life issues through all developmental periods should improve the high quality of life for adults.

There are many different factors linked to quality of life that need to be addressed in a student's **individualized education program (IEP)** throughout their school years. The focus every year should be on self-determination and independence. Ncube, Perry, and Weiss (2018) found that parents' distress and satisfaction with their child's education was directly related to the child's quality of life. This means that school personnel should engage parents in all areas of the child's education. While IDEA requires specific actions to include parents, school personnel need to go beyond those minimal requirements and truly engage them (Smith, 2016). To accomplish this, schools should provide support services for parents and ensure they are actively involved in the child's educational program, not that they simply are invited to attend meetings.

Parents are provided the opportunity to participate in their child's special education program, but the degree they participate is dependent on the parent. Families from diverse cultural and linguistic backgrounds are less likely to participate because of a number of reasons, including language barriers, limited knowledge of their culture from school personnel, and simply not understanding the process. Special education teachers can facilitate parental involvement by initiating and maintaining open communication with families and making them feel comfortable with the special education process (Chang et al., 2022).

One way to facilitate independence and self-determination, and therefore quality of life, is futures planning. While the goal for all students with extensive support needs should be independence, this goal will be achieved differently based on a number of individual characteristics, such as health factors, intellectual functioning levels, and physical skills. For example, a goal for some individuals might be living in an apartment alone while for others it might be living in a community setting with supports. Regardless of specific goals, engaging in futures planning is important for individuals; self-determination has been shown to be related to a number of future goals for that individual. This means that educators should engage individuals with extensive support needs and their families with future goal setting early in the student's educational career. This future-based intervention approach will enable school personnel and family members to focus on the development of skills necessary to live as independently as possible and enjoy a high quality of life.

ADULT OUTCOMES FOR INDIVIDUALS WITH EXTENSIVE SUPPORT NEEDS

As noted previously, the purpose of school is to prepare individuals for successful adulthood. In order to be a successful adult, an individual needs to be able to experience a good social life, live as independently as possible, and enjoy meaningful employment—in other words, have a good quality of life. This is the preferred outcome for all individuals, including those with extensive support needs. Quality-of-life indicators include "relationships, supportive environments, doing things, personal growth and moving forward, and understanding of self/acceptance of disability" (McDougall et al., 2016, p. 574). Unfortunately, many individuals with extensive support needs have experienced lower than desired social, employment, and independent living outcomes. This is even more likely for individuals from diverse backgrounds. For example, a review of the literature by Thoma and colleagues (2011) found that Black students had limited opportunities during transition to develop self-determination, which would result in fewer opportunities as adults to achieve a high quality of life.

Social Outcomes

As might be expected, individuals with extensive support needs engage in social activities less often than their peers without disabilities. While relationships are critical for a good life, children, youth, and adults with extensive support needs often have limited opportunities to develop these relationships (Carter, Bottema-Beutel, & Brock, 2014). This is due to a variety of reasons, including continued segregation in schools, a school focus on current limitations and not on future needs, and limited opportunities for adults to develop social relationships in employment and community living settings. In order to improve social competence of adults, educators must focus on their development during school years. While inclusion provides an excellent opportunity for students to develop social skills, many schools continue to segregate students with extensive support needs from their peers without disabilities. Some of the reasons for this include perceptions of competence, bias, teacher preparation, and lack of knowledge of current research (Agran et al., 2019). Regardless of the reasons, continuing to segregate students with extensive support needs impacts their social skill development and will likely impact social outcomes as adults.

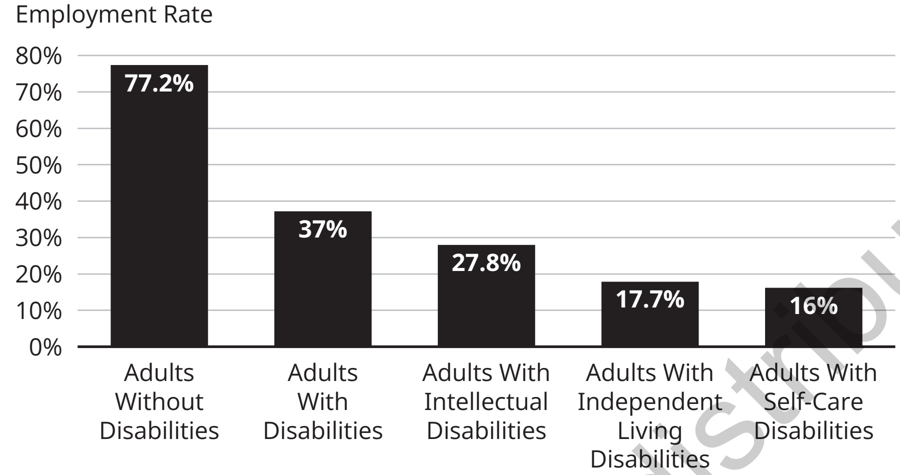
Employment Outcomes

A critical component of quality of life for most adults is employment. Successful employment has multiple purposes—it provides opportunities for social interactions with individuals without disabilities, and possibly more importantly, provides resources that can facilitate independent living. Successful employment can also boost an individual's self-confidence and can be empowering. Although there have been numerous state and federal laws and actions to support the employment of persons with extensive support needs, with many of these having positive results, the overall employment outcomes for this population remain disappointing and successful **integrated employment** continues to be stagnant (Cohen-Hall et al., 2018). Substantial numbers of individuals continue to be unemployed, underemployed, and working in segregated settings (Carter, Bendetson, & Guiden, 2018).

Figure 1.1 features the statistics related to employment of individuals with extensive support needs published by the National Institute on Disability, Independent Living, and Rehabilitation Research (Lauer & Houtenville, 2019).

Adults with self-care disabilities were those who indicated difficulty dressing or bathing; those with independent living disabilities indicated difficulty doing errands alone such as visiting a doctor's office or shopping. Additionally, adults with disabilities who were employed received only 64% of the same wages received by adults without disabilities (Yin, Shaewitz, & Megra, 2014).

FIGURE 1.1 ■ Rates of Employment for Adults With and Without Disabilities



Source: Adapted from data in E. A. Lauer and A. J. Houtenville, 2019, "Annual Disability Statistics Compendium: 2018." University of New Hampshire, Institute on Disability.

There are many things that could improve these employment outcomes. McConnell and colleagues (2021) completed a literature review and found that the main factor in improving postsecondary outcomes for individuals with extensive support needs was the identification of the individual's greatest strengths and needs during the transition planning process. They found family expectations and support; in-school experiences including supervised, paid, and community-based jobs; and improvement in self-determination, self-care, and social skills could lead to improved outcomes. School programs could include training for specific careers, job shadowing in and outside the school, and job placement with job coaches. Providing work-based learning experiences during high school and transition has been shown to result in better employment outcomes for students after exiting high school (Wissel, Tulikangas, & Guy, 2019).

While the goal for most adults with disabilities is integrated employment, professionals need to be aware that some parents and adults with extensive support needs actually prefer segregated work settings. Carter and colleagues (2019) studied the reasons for this preference and found that a sense of safety, availability of individualized support, promotion of social interactions and relationships, and provision of a structured environment were the reasons most mentioned by families. Adults with extensive support needs listed similar reasons for preferring segregated work settings—sense of security, fostering of friendships, structured environment, and promotion of social interactions. School personnel and adult service providers, including vocational rehabilitation counselors, need to be aware of these concerns in order to encourage a more positive attitude about integrated employment.

Independent Living Outcomes

In addition to social and employment opportunities, individuals with extensive support needs should have independent living opportunities to experience a higher quality of life. Since the early 1970s, the number of individuals living in large, congregate care facilities for persons with extensive support needs has declined dramatically. After reaching a peak of more than 194,000 in 1967, the population had decreased to slightly more than 30,000 by 2010 (Larson et al., 2021; Prouty, Smith, & Lakin, 2005) to 21,103 in 2015 (Lulinski & Tanis, 2018) and 17,557 in 2018, with 17 states having closed all large institutions (Larson et al., 2021). The trend continues to be declining numbers of individuals in large residential facilities.

Concomitant with the decrease in the number of individuals living in large institutions is the growth of smaller community living options, which grew from 20,400 in 1977 to more than 350,000 in 2010 (Larson et al., 2021). From 1987 to 2017, four of every five individuals who lived in a large institution moved to a community living option (Larson et al., 2021). While the movement from large institutions to smaller **community-based programs** represents significant improvement, some smaller facilities continue to limit individual choice-making and utilize control over individuals in ways similar to larger facilities. Therefore, just because individuals are more likely to be living in community-based facilities currently than 10 years ago doesn't mean that their level of independence may be significantly different (Romer & Walker, 2014). Providers of these programs need to adopt services that will encourage and support more independence.

Living in the community, independently or in small, supported living options, greatly facilitates independence and quality of life. Larson, Lakin, and Hill (2013) reviewed 43 studies that assessed the adaptive behavior and challenging behavior outcomes of individuals moving from an institutional setting to a community-based setting. The majority of these studies found that individuals improved their adaptive behavior skills after making this transition, suggesting that living in communities benefited individuals. As noted above, however, living in community-based programs does not guarantee more independence or a higher quality of life. Programs need to focus on development of independent living skills and encourage choice-making to facilitate an improvement in quality of life.

SERVICES FOR PERSONS WITH EXTENSIVE SUPPORT NEEDS

The following sections cover the history and current services available to individuals with extensive support needs.

History of Services

For most of history, individuals with disabilities have been treated poorly, while individuals with extensive support needs were treated even more harshly. The Minnesota Council on Developmental Disabilities developed a document, *Parallels in Time*, that summarizes the treatment of individuals with disabilities beginning in 1500 B.C. In ancient Rome, individuals with disabilities were often abandoned or killed and often used as objects of entertainment. By the Middle Ages, when Christianity had taken hold, the first asylum was established and the Catholic Church began providing refuge for individuals. In 1563 and 1601, Queen Elizabeth I supported Parliament's passage of the Elizabethan Poor Laws, which provided unemployable poor almshouses, while others urged patience and gentle treatment. In 1799, a French physician, Jean Itard, worked with Victor, the wild boy of the Averon Forest, marking one of the first efforts to educate individuals with cognitive disabilities. Although living conditions were harsh, the number of institutions began to grow in the 1800s, which marked, at the time, a positive trend toward providing for the basic needs of individuals with disabilities. During that same period several schools were started for children with sensory impairments and intellectual disabilities; unfortunately, many of these schools became more segregated. In the early 20th century, the **eugenics movement** became popular and resulted in thousands of **involuntary sterilizations** of individuals with extensive support needs. As part of the eugenics position, many individuals with disabilities were killed in Nazi Germany in the 1930s.

The latter half of the 20th century saw significant positive gains in how individuals with disabilities, including those with extensive support needs, were treated. After being elected U.S. president in 1960, John F. Kennedy, whose interest was rooted in having a sister with disabilities, started a period when several organizations, including the Association for Retarded Citizens (now the Arc) and the American Association for Mental Retardation (currently the AAIDD), began strong advocacy movements that resulted in state and federal legislation and litigation mandating equal opportunities and educational programs for persons with disabilities.

Although major progress has been made regarding the treatment of individuals with disabilities, there are still vestiges of history regarding their treatment. For example, some fetuses continue to be aborted because of a prenatal diagnosis of a disability. While this is a difficult decision for many parents, and may be justified in many cases when the fetus would not be survivable, it still has some similarities to eliminating individuals because of their disabilities. Also, some individuals with disabilities continue to be ridiculed, and the continued segregation of students with extensive support needs in general education classes and restricted living and employment options for adults in the community lead to negative outcomes.

Current Services for Persons with Extensive Support Needs

Beginning in the 1970s, legislation, litigation, and parental advocacy greatly impacted how persons with disabilities were educated and provided services. While none of these factors proved to be the primary reason for change, they all came together to create a political force that resulted in major changes. Three major legislative acts were passed between 1973 and 1990 that revolutionized services and opportunities for children and adults with disabilities—the *Education for All Handicapped Children Act* (EHA), passed in 1975, which was reauthorized as the *Individuals with Disabilities Education Act* (IDEA), **Section 504 of the Rehabilitation Act of 1973**, and the *Americans with Disabilities Act* (ADA), passed in 1990 (Smith, Polloway, & Doughty, 2020). While there were several federal legislative acts impacting individuals with disabilities, none have had more of an impact on school-age children than IDEA.

The Individuals with Disabilities Education Act (IDEA)

IDEA revolutionized how children and adolescents with disabilities are served in public schools. Prior to its passage, many schools provided little or very limited special education services to children with disabilities while other schools did not provide any special education. When Congress first passed IDEA in 1975 as EHA, it noted that of the 8 million children in the United States with disabilities, 3 million were receiving less than adequate services and another 1 million received no services. The law provided federal funding to provide students with disabilities with a **free appropriate public education (FAPE)**. While reauthorized numerous times since its passage, the basic components of the law have remained the same (Smith, 2016). This legislation required states that receive federal IDEA funding to comply with the requirements of IDEA.

In general, IDEA requires schools to provide a free appropriate public education to all students with disabilities, including those with extensive support needs, in the **least restrictive environment**. This includes requiring that all students, including those with extensive support needs, have access to the general education curriculum and are educated with their peers without disabilities as much as possible (Bowman et al., 2019).

The key components of IDEA include:

- Providing FAPE for children with one of 13 specified disabilities who need special education.
- Determining eligibility and programming decisions using **nondiscriminatory assessments**.

- Developing **individualized education programs** (IEPs) for each student served in special education.
- Serving all students with disabilities in the **least restrictive environment** (**LRE**).
- Participation and procedural safeguards.
- Providing parents and students **due process** rights.

The focus of IDEA is to ensure that all children with disabilities receive a free appropriate public education in the least restrictive environment. Although IDEA is clear in requiring schools to serve students in the least restrictive environment, there are still many students with extensive support needs whose primary educational setting is a self-contained classroom or other segregated environment (Agran et al., 2019). The placement decision for students should always be based solely on the needs of the student, not a clinical label or an option convenient to the school; clinical labels must not be the basis for a placement decision.

As a result of the LRE requirement, most students with disabilities are currently educated in general education classrooms with their age peers without disabilities. The *45th Annual Report to Congress on the Implementation of the IDEA* reported that 95.2% of students with disabilities were educated in general classrooms at least a portion of each day. In fall 2021, 66.7% of students with disabilities were educated in general education classrooms 80% or more of the school day, and only 12.5% were in regular classes less than 40% of the school day. Unfortunately, the frequency of placement in general education classes for students with more extensive support needs was significantly less. Table 1.2 provides the placement statistics for each disability category.

TABLE 1.2 ■ Percentage of Time in General Education Classrooms, Fall 2021

Disability	Percentage of day inside the regular class[a]			
	80% or more of the day[b]	40% through 79% of the day	Less than 40% of the day	Other environments[c]
All disabilities	66.6	16.0	12.6	4.8
Autism	40.8	17.1	34.2	7.8
Deaf-blindness	30.1	11.0	32.2	26.7
Developmental delay	69.8	14.6	13.8	1.7
Emotional disturbance	54.7	17.0	14.6	13.7
Hearing impairment	64.5	13.3	10.2	12.0
Intellectual disability	18.7	27.7	47.2	6.4
Multiple disabilities	15.3	17.9	43.5	23.2
Orthopedic impairment	57.6	14.5	20.1	7.8
Other health impairment	70.2	18.1	7.7	4.0
Specific learning disability	75.3	19.1	3.8	1.9

(*Continued*)

TABLE 1.2 ■ Percentage of Time in General Education Classrooms, Fall 2021 (*Continued*)

Disability	Percentage of day inside the regular class[a]			
	80% or more of the day[b]	40% through 79% of the day	Less than 40% of the day	Other environments[c]
Speech or language impairment	88.3	3.7	3.7	4.3
Traumatic brain injury	51.5	20.8	19.6	8.2
Visual impairment	69.7	11.3	8.7	10.2

Notes: [a] "Percentage of day spent inside the regular class" is defined as the number of hours the student spends each day inside the regular classroom, divided by the total number of hours in the school day (including lunch, recess, and study periods), multiplied by 100.

[b] Students who received special education and related services outside the regular classroom for less than 21 percent of the school day were classified in the inside the regular class 80% or more of the day educational environment category.

[c] "Other environments" consists of separate school, residential facility, homebound/hospital, correctional facilities, and parentally placed in private schools. Children with disabilities who are parentally placed in private schools may be educated to varying degrees, including the majority of the day, with their peers without disabilities.

Source: U.S. Department of Education, "45th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2023," https://sites.ed.gov/idea/files/45th-arc-for-idea.pdf

The data indicate that most students with disabilities are educated in general education classes with their age peers without disabilities. This represents success from the segregated special education classes that were the predominant placement option before IDEA was passed. However, the number for students with extensive support needs are not included in general education classrooms nearly as often. In 2021, 47.2% of students with intellectual disabilities, 34.2% of students with autism, and 43.5% of students with multiple disabilities were in general education classes less than 40% of the school day.

One other consideration in serving students with disabilities in general education settings is that just because a student is physically included in a classroom does not mean he or she is included in classroom activities. Often, students with extensive support needs are placed in general education classes but remain isolated and are not integrated into the class activities. Physically locating a student in a general education classroom does not guarantee *engagement* of the student with his or her peers nor meaningful access to the general education curriculum with necessary adaptations.

Section 504 and the Americans with Disabilities Act

Section 504 of the Rehabilitation Act of 1973 is a civil rights legislation for individuals with disabilities. The law prohibits discrimination against individuals with disabilities from entities that receive federal funds. The *Americans with Disabilities Act* (ADA), passed in 1990, is also civil rights legislation and similar to Section 504 prohibits discrimination against individuals with disabilities. However, unlike Section 504, which only applies to entities that receive federal funds, the ADA applies to all entities except churches and private clubs, regardless of whether they receive federal funds. Public schools, because they receive federal funds, must comply with Section 504, and since Title II of the ADA applies to governmental agencies, schools must also comply with the ADA (Smith, 2020). Both laws are similar in that they require schools to identify students who would be eligible, conduct an assessment to determine their eligibility, and provide accommodations and modifications to ensure that protected students receive a free appropriate public education. The laws also ensure that students with disabilities have equal opportunities to participate in all activities afforded students without disabilities, such as extracurricular activities, as long as they are *otherwise qualified* (Smith, 2020).

One major difference between IDEA and Section 504 and the ADA is the definition of disability (Smith, 2016). While IDEA eligibility requires students to be diagnosed with one of the 13 specific disabilities, and need special education, Section 504 and the ADA only require that an individual have a physical or mental impairment that substantially limits a major life activity. In order to be eligible under IDEA, learning must be impacted because one criterion for eligibility is needing special education. Under Section 504 and the ADA, the impairment must substantially limit only one major life activity, and while learning is a major life activity there are many additional major life activities including walking, talking, seeing, hearing, and others. Therefore, students with a physical or mental impairment may be eligible for protections and services under Section 504 and the ADA and not need any academic services, meaning that some students eligible under 504 and the ADA are not eligible under IDEA.

Another difference between IDEA and Section 504 and the ADA is the age group eligible for services and protections. While IDEA only applies to children and adolescents ages birth to 22, Section 504 and the ADA apply to all ages, birth to death. As a result, these laws impact adults with extensive support needs in areas of employment, housing opportunities, and access to goods and services. The purpose is to ensure that individuals with disabilities are not discriminated on the basis of their disability. Table 1.3 summarizes some of the key components of IDEA, Section 504 and the ADA.

TABLE 1.3 ■ Key Components of IDEA Compared to Section 504, ADA

	IDEA	Section 504/ADA
Applies to	All public schools in states participating receiving IDEA funding	All entities receiving federal funds*
Eligibility	Students with one of 13 specific disabilities who need special education and related services	Individuals with physical or mental impairments that substantially limit a major life activity
Eligibility ages	Birth–22	No limit: birth to death
Basic requirement	Provide a free appropriate public education	Prohibits discrimination; provides equal access opportunities
Individual planning	IEP for every student	Provision of individual accommodations to ensure equal access and opportunities
Transition requirement	Transition planning begins no later than when student is 16 years of age	No requirement
Parent participation	Parents' right to notice and consent until student reaches majority age	Same as IDEA
Due process rights	Parents' right to notice and consent until student reaches majority age Right to due process hearing Right to mediation	Same as IDEA

*All entities except churches and private clubs.

Litigation

In addition to legislation, there have been numerous court cases that have had significant impact on persons with extensive support needs. The first U.S. Supreme Court case dealing with equal educational opportunities, *Brown vs Board of Education of Topeka* (Kansas), found segregation on the basis of race unconstitutional; this case was used as a legal basis for securing educational access for students with disabilities. Other court cases have focused on a variety of topics, including the intent of *free appropriate public education*, nondiscriminatory assessment, least restrictive environment, related services, discipline, housing discrimination, and employment discrimination. Table 1.4 summarizes some of the landmark cases impacting students with disabilities.

TABLE 1.4 ■ Landmark Court Cases

Case	Summary
Brown v. Board of Education of Topeka (1954)	U.S. Supreme Court ruled that separate educational facilities based on race was unconstitutional. While the case dealt with racial discrimination, it was used as a basis to protest placement decisions based on disability.
PARC v. Pennsylvania (1972)	This case resulted in a consent decree that prohibited schools in Pennsylvania from denying public school access to students with intellectual disabilities
Board of Education v. Rowley (1982)	U.S. Supreme Court reversed previous court rulings and held that the school district did not have to provide Amy Rowley, a student with a hearing impairment, a sign language interpreter because she was making adequate progress without the use of an interpreter. Ruling was used as major precedent to determine the definition of "appropriate education."
Honig v. Doe (1988)	U.S. Supreme Court case ruled that students with disabilities could not be removed from school for more than 10 days without a determination of the impact of a disability on behavior.
Irving Independent School District v. Tatro (1984)	U.S. Supreme Court ruled that intermittent catheterization was a required related service.
Timothy W. v. Rochester, New Hampshire (1989)	First Circuit Court of Appeals reversed district court ruling finding that no child is too severely disabled to benefit from special education.
Diana v. California Board of ED (1970)	1970 case focused on labeling Mexican American children as having intellectual disabilities based on discriminatory testing. Resulted in consent decree to test children in their native language.
Larry P. v. Riles (1972)	Federal District Court of Northern California ruled that schools must use nondiscriminatory tests and other means that do not discriminate based on race.
Cedar Rapids Community School District v. Garret F. (1999)	U.S. Supreme Court ruled that students with extensive health needs are still the responsibility of the school district for FAPE.
Endrew F. v. Douglas County School District RE-1 (2017)	U.S. Supreme Court rejected the interpretation of FAPE that only requires minimum progress from year to year.

DISABILITY THROUGH THE LIFESPAN

The presence of a severe disability impacts individuals, as well as their families, at each stage of their life, beginning in early childhood through aging adulthood. In order to understand how to improve the quality of life of adults with extensive support needs, an understanding of how extensive support needs impact individuals through the lifespan is important. Although school personnel may only be involved directly with children with extensive support needs until they exit high school, services and supports provided during the school years have a huge impact on the quality of life of these individuals during adulthood.

Early Childhood

The needs of young children with extensive support needs vary depending on the age of onset or diagnosis, severity of the disability, and existence of other disabilities. For example, many children with autism spectrum disorders do not display characteristics of the disorder until the age of 18–24 months. Therefore, services for many of these children are not provided until the child begins to manifest the condition. On the other hand, a child born with severe cerebral palsy or spina bifida would be recognized and need services almost immediately after birth. Another factor impacting services for preschool children is the presence of concomitant disabilities. For example, children with intellectual disabilities and physical disabilities typically have greater needs than those with just intellectual disabilities (Aguayo et al., 2019) and children with physical and sensory disabilities would likely be identified early and require support services.

In addition to age of onset and concomitant disabilities impacting early services, the severity of the disability is also an important factor. Children with extremely low levels of cognitive abilities require more extensive services than those with milder intellectual disabilities, and children with spina bifida that does not result in paralysis need different supports than those with paralysis.

One of the major challenges during early childhood is the acceptance among family members that the child has a severe disability. This acceptance could be impacted by the educational experiences of family members, their socioeconomic status, linguistic access to information about disabilities, access to screening services, religion, and cultural factors. Whitby (2020) found that children with autism spectrum disorders in low socioeconomic areas often go undiagnosed because of lack of access to services. Religion and cultural factors can also impact perceptions of the condition and result in families being unwilling to agree on screening or diagnosing their child. One study reported that many early childhood workers and church leaders hesitated to suggest a child in a Korean household should be screened for autism for fear that the families would resist professional assistance, while others thought that if church leaders made recommendations to seek service it could damage the family's image in the community (Kang-Yi et al., 2020). Regardless of cause, some families either do not receive a diagnosis of a severe disability for their child or refuse to accept the diagnosis as accurate. While the presence of a severe disability may be obvious, it still presents major challenges to parents and other family members. The mere financial and psychological impact of a young child with a severe disability can be devastating. In our society, **ableism** can negatively impact the family of a child or adult with extensive support needs.

Services for young children with extensive support needs have grown over the past 30 years, primarily thanks to legislation. Part C of IDEA, established by Congress in 1986, focuses on services for children ages birth to 2 years of age while Section 619 of IDEA provides services for children ages 3–5. The 45th Annual Report to Congress (2023) noted that in 2021, 741,510 children ages 3–5 were provided services and 406,000 ages birth through 2 years were served. Services provided included family support, speech therapy, physical therapy, behavior therapy, and occupational therapy.

School-Age

School-age students with extensive support needs receive services through IDEA and are also protected from discrimination by Section 504 and the Americans with Disabilities Act. A wide variety of services are provided under IDEA, including special education and related services such as speech-language therapy, physical therapy, occupational therapy, mobility instruction, and behavior supports. The specific services for each child are determined after a comprehensive assessment is conducted and the development of the student's IEP.

IDEA requires schools to enable students with disabilities, including those with extensive support needs, to have access to the general education curriculum. While the best way to provide this access is through inclusive placements in general education classrooms, many of these students continue to be placed in segregated settings as their primary placement (Kleinert et al., 2015). Table 1.2 shows the percentage of time students, by disability category, are placed in general education classrooms. It is clear that students who are likely considered to have more extensive support needs spend less time in general education classrooms than students with milder disabilities. Kurth and colleagues (2019) studied the least -restrictive statements in IEPs for students with extensive support needs. They found that many of the IEPs did not address the least-restrictive-environment mandate; focused on why students should not be included in general education classrooms; and indicated that the need for services by these students resulted in their exclusion from the general education classroom.

Although some students with extensive support needs are excluded from general education classrooms, research has shown that these students can be successful when included in general education courses (Bowman et al., 2019). To facilitate students' success, general education teachers need to take steps to ensure students are engaged both academically and emotionally (Hollingshead, Williamson, & Carnahan, 2018). Examples of these steps include task analysis; time delay for teaching discrete responses and chaining procedures; systematic prompting and fading procedures; using manipulatives; providing different response opportunities; and using real-life teaching opportunities (Agran et al., 2018). The Universal Design for Learning (UDL) format is a good model to facilitate this success. UDL provides students with different ways to represent knowledge, express knowledge, and stay engaged in the classroom (Kurth, 2013).

Although adolescents with extensive support needs are often included in general education classrooms to facilitate their access to the general education curriculum, there is still a position that they need a more community-based, independent living curriculum to prepare them for a successful transition to adulthood (Carter, Swedeen, & Moss, 2012). Because many of these students have difficulties generalizing skills from one setting to another, providing instruction in settings where they will use learned skills gives them the opportunity to learn skills in natural community environments and contexts where they will be used. Using this community-based instruction approach may be more important for some students than always placing them in inclusive classrooms (Steere & DiPipi-Hoy, 2012). These decisions should be a consideration during IEP and transition planning meetings and need to be made on an individual basis focusing on the needs of the student. The philosophy of always including students with extensive support needs in inclusive settings should be weighed in consideration with the individual needs of the student.

In addition to skills learned in the classroom and in the community, adolescents with extensive support needs also need to have work-based learning experiences. Since research has shown that postschool outcomes improve for students who participate in work-based learning experiences, "it is critical for students with disabilities to have these experiences as part of their high school transition services" (Cease-Cook, Fowler, & Test, 2015, p. 353).

Young Adulthood

Despite IDEA-mandated services for students with disabilities, ages birth to 22, there is evidence that many students are still unprepared for independence and employment when they exit high school, meaning that transition programming has been inadequate. In one study, Kucharczyk and colleagues (2015) found a general dissatisfaction among parents of services provided students with autism spectrum disorders in secondary schools because of this unpreparedness. While the graduation rates of students with extensive support needs has been improving, it still lags behind students with milder disabilities and students without disabilities. In 2021, 75.4% of students with disabilities received a regular diploma compared to only 48.4% for students with intellectual disabilities and 44.2% of students with multiple disabilities (U.S. Department of Education, 2018).

Young adults with extensive support needs face outcomes related to independent living, employment, and meaningful social relationships. A transition goal for many students with extensive support needs is independent or semi-independent living. Independence can be defined as living life based on an individual's own goals, which includes making choices about where they live, where they work, what activities they do, and how they spend their money (Independence and Self-Sufficiency, 2019). Larson and colleagues (2018) recently reported that the trend for individuals with intellectual disabilities is more independent living. In a 2018 report they found that 58% of adults with intellectual disabilities lived with a family member; 25% lived in a group home, intermediate care facility, or other group setting; 5% lived in a host or foster family home; and 12% owned or leased their own home. Although these numbers may appear less than optimal, they represent an improvement over an 18-year period. The trend is definitely toward more independence and fewer individuals living in nursing homes or psychiatric facilities.

There is also a trend for college-age individuals with intellectual disabilities to attend **inclusive postsecondary education (IPSE)** programs at 2- and 4-year colleges and universities. Currently there are more than 300 IPSE programs in the country, a huge increase over the past several years (Lazo, 2025). The Higher Education Opportunities Act of 2008 supported the increase of inclusive postsecondary education programs and made available federal financial aid to students attending programs that had been approved as a Comprehensive Transition and Postsecondary program (Kleinert et al., 2012). Attendance at inclusive postsecondary programs has been shown to increase independent living skills, social skills, and employment opportunities (ThinkCollege).

Employment during the transition period is a critical predictor of successful transition from high school to post-high school and directly related to the level of independence and quality of life an individual can achieve. Unfortunately, many students with extensive support needs exit high school without the necessary skills and experience to be successfully employed. Carter and colleagues (2012) found that students who were employed in the community during their high school years, and who exhibited greater independent skills in health care, social skills, and household responsibilities, were more likely to have successful employment opportunities than their peers who had not had these experiences. Shogren and colleagues (2018) also found a relationship between the development of self-determination skills in high school and successful integrated employment, two important components of quality of life. The implication is that transition programming that improves these skills will lead to a more optimistic employment outcome and a higher quality of life. The good thing is that these skills can be taught in inclusive, general education classrooms (Raley, Shogren, & McDonald, 2018).

Unfortunately, the goal for successful, competitive, integrated employment has not been achieved for many adults with extensive support needs. The 2015 National Autism Indicators Report: Transition into Young Adulthood (Roux et al., 2015) found that 28% of individuals in their early 20s were not employed nor attending any postsecondary education or training and were not receiving any services or supports. Fewer than 30% of individuals with independent living and cognitive disability were employed (Shepard, 2019). Reasons for this reality include:

- Perceived support needs of individuals (Brooke et al., 2018)
- Limited collaboration among agencies (Hall et al., 2018)
- Lack of preparation
- Lack of self-determination

Regardless of reasons why there are small numbers of individuals with extensive support needs in integrated employment, studies have shown that these individuals can be successful when provided with appropriate long-term support services (Brooke et al., 2018).

Learning skills for employment and independence are within the capability of adults with extensive support needs. In a recent study a group of college students with extensive support needs was taught how to effectively use an automated external defibrillator during a cardiopulmonary crisis. The individuals learned how to use the procedure with 100% accuracy; more importantly, these skills were generalized to a novel setting and maintained after supports were removed (Kearney et al., 2019).

Middle and Later Adulthood

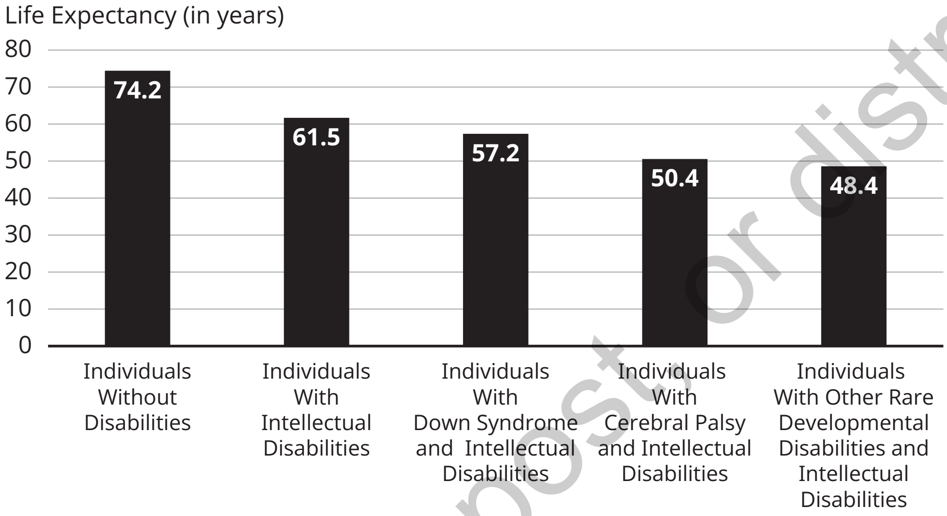
Middle-aged adults experience many of the same issues faced by young adults, namely housing, employment, and social engagement. The emphasis has traditionally been on identifying and matching the support needs of individuals with formal supports, such as those provided by vocational rehabilitation agencies and community support agencies.

Despite the emphasis on vocational rehabilitation and community agencies, there has been a decline in some of these supports resulting in many individuals being placed on waiting lists. The result is the increased importance on identifying and providing informal supports, including parents and friends (Sanderson et al., 2019). Sanderson and colleagues (2019) studied the informal supports available for adults with intellectual disabilities. Their findings indicated that

- Unpaid, informal supports supplement formal supports.
- Informal supports are organized around the domains of recreation, employment, and housing, with the most extensive supports related to recreation and the least to housing.
- The overall level of informal supports is low.

As a group, individuals with extensive support needs have a shorter life expectancy than individuals without disabilities. However, recent factors have resulted in the increased life expectancy for this group of individuals. Some of these factors include community inclusion and the movement away from large residential facilities, increased legal rights, increased employment and independent living opportunities, expanded research, and improved medical care. Lauer and colleagues (2019) found that the life expectancy of this group improved from the mid-40s to mid-60s from 1960 until 2000. However, despite these increases, individuals with extensive support needs continue to have a much lower life expectancy than adults without disabilities. The 2012–2016 U.S. Multiple Cause-of-Death Mortality Files for Adults showed the following life expectancies for individuals with and without intellectual disabilities (Figure 1.2; Landes, Stevens, & Turk, 2019).

FIGURE 1.2 ■ Life Expectancies for Individuals With and Without Intellectual Disabilities, 2012–2016



Source: Adapted from data in S. D. Landes, J. D. Stevens, and M. A. Turk, 2019, "Heterogeneity in Age at Death for Adults With Developmental Disability," *Journal of Intellectual Disability Research, 63*(12), 1482–1487.

While improving life expectancy for individuals with extensive support needs is a positive, the quality of life of older adults with extensive support needs becomes an issue. Friedman (2019) studied the quality-of-life outcomes for older adults with extensive support needs using the *Personal Outcomes Measures* developed by the Council on Quality and Leadership (2017). The *Personal Outcomes Measures* includes 21 quality-of-life outcomes organized around five domains—my human security, my community, my relationships, my choices, and my goals. Results indicated the majority of older adults with extensive support needs had fewer than half of the outcomes and fewer than 3% had all 21 outcomes. While most of the adults in the study were healthy, safe, and free from abuse, they often did not have community integration, relationships, choice, and opportunities. The study concluded that "the quality of life of older adults with extensive support needs is significantly impacted by the receipt of organizational support" (Friedman, 2019, p. 247).

With increased age comes increased risks for a variety of issues, including health, friendships, and independence for all individuals. These are also increased risks for individuals with extensive support needs. One area that has recently been researched for older adults with extensive support needs is the risk for falling. While all older adults experience an increased risk for falls, individuals with extensive support needs have a higher risk factor (Ho et al., 2019). As a result of the increased risks for older adults with extensive support needs, health care workers need to be aware of this increased risk and take precautions to help prevent unexpected falls.

STAKEHOLDERS INVOLVED WITH INDIVIDUALS WITH EXTENSIVE SUPPORT NEEDS

The most important stakeholder in educational and adult service programs for students and adults with extensive support needs is the individual with the needs. In order to prepare students for successful adulthood and the opportunity for a high quality of life, the entire focus of educational programs must center around each individual student. Providing a student-focused approach facilitates individuals becoming self-advocates and self-determined, two key elements in quality of life. This student-centered approach should be provided throughout a student's educational program, beginning as early as preschool programs. Focusing on the preparation for the future will enable students with extensive support needs to have many years to become as independent as possible in adulthood.

Adults with extensive support needs should also be the focus of supports and services provided by adult service agencies, family members, and friends. Focusing on the quality of life for this group should be the driving force for all services and supports and must take into consideration the choices of the individuals. Service agency personnel, educators, family members, and friends must understand that adults with extensive support needs should still be the primary consideration in making decisions about his or her life. Using a person-centered approach, both in school and in postschool services, requires individuals with extensive support needs to be self-advocates and self-determined. Therefore, it is the responsibility of school personnel to begin early in the student's program to develop these skills.

Because of the numerous needs of individuals with extensive support needs there are many stakeholders needed to provide services and supports. The first group are parents and other family members. Parents and other family members are obviously the first teacher and support for children with extensive support needs and play a critical role in their children's early development. While most parents, especially those who are parents the first time, face challenges such as how to feed the baby, change diapers, and keep the baby well, when the child has a severe disability the learning curve for caregivers can be steep (Hartshore & Schafer, 2018). These increased challenges often compound the typical stress of parents, and studies have found a complex association between parental stress, parenting behaviors, and children's behavior (Shawler & Sullivan, 2017). With parent level of stress and satisfaction directly linked to the quality of life of individuals with extensive support needs (Ncube et al., 2018), it is critical that parents are empowered to provide the support needed by their children (Hsiao, Higgins, & Diamond, 2018).

Many parents continue to be involved with their children with extensive support needs as they move into adulthood. Reasons for this continued involvement include: (1) ensuring safety and success, (2) collaborating with professionals, and (3) advocating for their adult child (Francis & Reed, 2019). Hall and colleagues (2018) found that families often play an integral role in their child's employment by modeling good work behaviors during the child's life and participating in employment-focused decisions. Families often view formal support systems, such as vocational rehabilitation agencies, as actually creating barriers to employment, thus creating the need to develop informal support systems.

As a result of the critical role played by parents, family members need to be supported by school and adult service professionals. Parent training and positive behavioral supports have been shown to provide family members with the support that enables them to be more supportive of their children with extensive support needs. Professionals need to develop service systems that provide for these support services (Agran et al., 2018).

During the preschool years, there are several professionals who are often engaged in providing services to children and their families. These include preschool teachers and a wide variety of therapists, including speech-language therapists, occupational therapists, physical therapists, behavior therapists, etc. When children with extensive support needs become school age, the school is responsible for ensuring the child receives FAPE. This includes providing special education in the least restrictive setting and ensuring that necessary related services are provided. Professionals providing specialized services may include applied behavior analysts, occupational therapists, and physical therapists. For children with special health care needs, school nurses play an important role. As a result of the inclusion movement, which is based on the premise that all students *belong* with their chronological-aged peers (Smith et al., 2020), most students with disabilities, including those with extensive support needs, are educated at least part of each school day in general classroom settings with their peers without disabilities. This requires general education teachers to be key stakeholders.

In addition to special education, general education teachers, and therapists, school administrators play a critical role in the education of students with extensive support needs. They impact the education of these students through their attitude, level of support, and vision of instruction. They also set the overall school climate, which impacts how students with extensive support needs are educated in inclusive settings (Smith, 2016). Unfortunately, a recent study found that administrators too often have only a surface-level of understanding of educating students with extensive support needs. They did not reflect an understanding or support for a truly inclusive model for this group of students (Roberts, Ruppar, & Olson, 2018).

As children with extensive support needs become adults, other stakeholders become involved. These include agencies that provide community-based services, vocational rehabilitation, and health services. States that utilize a collaborative approach to employment, including vocational rehabilitation, education, and agencies focusing on individuals with intellectual disabilities, have been shown to have better results with integrated employment than those that do not use such a collaborative model (Hall et al., 2018). And finally, community members and employers are key stakeholders to facilitate a high quality of life for individuals with significant support needs. The old adage—it takes a village—definitely applies to the need for a wide group of stakeholders to provide supports of individuals with extensive needs.

FINAL THOUGHTS ON INDIVIDUALS WITH EXTENSIVE SUPPORT NEEDS—KEEPING ADULTHOOD IN MIND

Defining individuals with extensive support needs is challenging because these individuals are a very diverse group and there is not a specific disability category that results in an individual having extensive support needs. Individuals classified as having extensive support needs are those whose disability substantially impacts various aspects of their life and results in their needing long-term, often life-long support. A diagnosis of a specific disability does not always result in that individual having extensive support needs. Rather than focusing on a particular disability, it focuses on the functional impact of a particular disability.

Identifying an individual as having extensive support needs is primarily a professional judgment, and professionals and family members may not agree with the designation. Its primary purpose is simply to identify individuals who need a high level of services and supports that are necessary to assist an individual experiencing a high quality of life during childhood and throughout adulthood. The purpose of identifying individuals as having this level of needs is to highlight their needs so that adequate supports can be provided.

Final Thoughts on Jacob

The opening vignette about Jacob reflects a failure of the educational and adult service systems to provide appropriate services and supports for Jacob and his family. It's obvious that the limited focus on inclusion throughout his lifetime impacted his current life—living at home and receiving only minimal supports from a segregated day service program. The quality of life for Jacob and his family cannot be considered nearly optimal. What would have been different with Jacob's life as an adult had school personnel supported his inclusion with his nondisabled peers? What would have been different with Jacob's life as an adult had school professionals explained the importance of inclusion to Jacob's family? Although the scenario reflects Jacob's life as an adult, hopefully it shows the critical importance for all service providers, beginning with those who provide preschool services, to focus on the futures for students like Jacob. A future-focused program for Jacob and others with extensive support needs can greatly facilitate a high quality of life as an adult.

SUMMARY

Individuals With Extensive Support Needs

- Most individuals with disabilities have mild disabilities.
- Individuals with extensive support needs have health or functioning that limits a person's performance in numerous areas.
- IDEA does not use a category called severe disabilities or extensive support needs but includes a multiple disabilities category.
- Several IDEA categories, such as intellectual disabilities, include students with extensive support needs.
- Extensive support needs means one that results in functional limitations.

Quality of Life and Individuals With Extensive Support Needs

- Goal for all individuals, including those with extensive support needs, is to experience a high quality of life.
- Students with and without disabilities share similar goals.
- There are numerous factors that impact quality of life.
- Quality of life is related to independence and self-determination.
- Service providers and family members at every stage of a person's life should be involved in improving the quality of life of individuals with extensive support needs.

Adult Outcomes for Adults With Extensive Support Needs

- Service providers at every level, beginning with preschool, should focus on the adult outcomes of individuals with extensive support needs.
- Adult outcomes focus on social outcomes, employment outcomes, and independent living outcomes.

Services for Persons With Extensive Support Needs

- Throughout much of history the treatment of persons with extensive support needs has been negative.

- Churches began providing basic services for individuals with disabilities several hundred years ago.
- Individuals were institutionalized and the eugenics movement resulted in hundreds of involuntary sterilizations of individuals with extensive support needs.
- The latter half of the 20th century saw a positive move in how individuals with disabilities, including those with extensive support needs, were treated and educated.
- Three factors greatly influenced the treatment of persons with extensive support needs in the latter half of the 20th century.
- Legislation in the form of IDEA, Section 504, and the ADA revolutionized the treatment of individuals with extensive support needs.
- Numerous court cases laid the foundation for changes in how individuals with extensive support needs were treated.
- Parent advocacy was very involved in service delivery model changes for persons with extensive support needs.

Disability Through the Lifespan

- In order to achieve the best quality of life possible, attention to quality-of-life factors have to be addressed during the entire lifespan of individuals with extensive support needs.
- Preschool services include community-based and educational programs.
- During the school years, IDEA requires appropriate services for students with extensive support needs.
- During early and late adulthood, attention is focused on social skills, employability, and independence.

Stakeholders Involved With Individuals With Extensive Support Needs

- Numerous stakeholders are involved in ensuring a quality of life for persons with extensive support needs.
- The ultimate stakeholders are individuals with extensive support needs.
- Parents are early stakeholders who influences quality of life for individuals with extensive support needs.
- Stakeholders include teachers, school administrators, rehabilitation counselors, therapists, and a host of additional professionals.

REVIEW QUESTIONS

1. How do you define “extensive support needs”?
2. What factors influence the quality of life of individuals?
3. What influenced changes in how individuals with extensive support needs are served and treated?

4. Describe the different stakeholders in the lives of individuals with extensive support needs.
5. Why is it important for professionals and family members to focus on quality of life for adults with extensive support needs early in the individual's life?

CRITICAL THINKING QUESTIONS

1. How is the quality of life of individuals with extensive support needs different from the quality of life for individuals without disabilities?
2. What actions could be taken to improve the quality of life for individuals with extensive support needs?
3. What is the purpose of schools for students with extensive support needs and does this differ from the purpose for students without disabilities?
4. Should adults with extensive support needs have the right to (1) vote, (2) marry, (3) have children?

KEY TERMS

ableism
Americans with Disabilities Act (ADA)
congregate care facility
day service program
due process
eugenics movement
Every Student Succeeds Act
extensive support needs
Free Appropriate Public Education (FAPE)
functional capacities
inclusive postsecondary education programs (IPSE)
Individuals with Disabilities Education Act (IDEA)
independence
individual education program
integrated employment
involuntary sterilization
least restrictive environment
mild disabilities
No Child Left Behind Act
nondiscriminatory assessment
Section 504 of the Rehabilitation Act of 1973
self-determination
stakeholder
transition planning
underemployed

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2

DISABILITIES REQUIRING EXTENSIVE SUPPORT NEEDS

CHAPTER OBJECTIVES

After reading this chapter you should be able to do the following:

2.1 Explain the overall concept of individuals with extensive support needs.

2.2 Summarize the characteristics of individuals with autism spectrum disorder.

2.3 Define and describe individuals with intellectual disability.

2.4 Examine the impact of multiple disabilities.

2.5 Define and describe individuals with emotional/behavioral disorders and mental health issues.

2.6 Summarize the different physical disabilities that can impact children and adults.

2.7 Explain the impact of special health care needs for individuals with extensive support needs.

Opening Vignette

Caitlin was diagnosed with Down syndrome when she was just 1 week old. Her parents, Gary and Melinda, had made the choice to skip the prenatal screening because they were only 27 and 24 years old, and were therefore not old enough to be considered at risk for having a child with Down syndrome. They did not know much about the condition but did know that it mainly impacted older couples. Caitlin displayed the obvious physical characteristics at birth, and a chromosome analysis confirmed trisomy 21. Now, at age 27, Caitlin is doing well and enjoying her life. She lives in her own apartment, which is part of a community-based supported living program. Her roommate, Fran, is 5 years older than Caitlin and also has Down syndrome. Caitlin has a full-time job at a local restaurant as a hostess. She has held the job for 5 years and looks forward to going to work every day. When Caitlin originally started at the restaurant she had a job coach from the state vocational rehabilitation agency. The job coach worked on site with Caitlin for 3 weeks until she was ready to do the job without any assistance. The hostess job fits Caitlin very well. She is extremely friendly and outgoing and loves to be with people. Regulars at the restaurant enjoy Caitlin greeting them; they always look forward to seeing her. And Caitlin knows all the regulars by name, something the customers enjoy.

Caitlin has had a boyfriend for 2 years. Charlie, who has mild intellectual disabilities, lives in another apartment in the supported living program. Caitlin and Charlie enjoy going to the movies, eating out at their favorite restaurants, and just hanging out at each other's apartments. They have discussed getting married and have the support of their parents. They are waiting until they save enough money to go on a honeymoon trip.

Caitlin's parents did not know anything about the education system for students with disabilities but were informed by their pediatrician that services should be available for Caitlin in an infant–toddler program. As a result of this information, they reached out to the local office of the state's human services office, which resulted in Caitlin receiving special education services in the infant–toddler program when she was 6 months old;

she transitioned to the preschool program when she was 3. During the preschool years she received speech therapy and special education services. Her parents always believed that the services Caitlin received before kindergarten were very important to her later school and adult success. Beginning in kindergarten, Caitlin's parents were adamant that she be fully included in regular classrooms. They had joined a parent support group for Down syndrome families and became strong advocates for inclusion. As a result of their advocacy, Caitlin received 1–2 hours of resource room time each day but was mainly included in all of the general classroom activities. In high school, Caitlin was a member of the homecoming court and was voted "most friendly" by her classmates. Her transition plan focused on her becoming gainfully employed and living independently. Caitlin's parents have always been her strongest advocates. They always wanted Caitlin to be treated like any other child and encouraged her siblings to treat her like their other siblings, including her with their friends and in their general activities.

Questions to Consider About Caitlin

1. How did Caitlin's parents' attitudes about inclusion during her school years impact Caitlin's current level of independence?
2. How different do you think Caitlin's future would be had she been isolated in self-contained classrooms during her P12 education?
3. What kind of supports would Caitlin need to live independently and maintain a competitive job?
4. Do you think Caitlin should be able to get married? If so, what kinds of supports would she and her husband need to be successfully independent?

UNDERSTANDING THE CONCEPT OF EXTENSIVE SUPPORT NEEDS

As noted in the previous chapter, defining individuals who have extensive support needs has its challenges. While most individuals with disabilities are classified as having mild disabilities, there are some individuals whose disabilities require more support services. Although it is difficult to define extensive support needs, in general, individuals are considered to have extensive support needs if they display "deficits in health or functioning that significantly limit a person's performance and participation in major life activities" (Hartshorne & Schafer, 2018, p. 422). Of the approximately 6.4 million children, aged 3–21, served in special education programs, approximately 1–2% have extensive support needs resulting in their being classified as having severe disabilities (Taub, McCord, & Ryndak, 2017).

Federal assistance programs that target individuals with extensive support needs have resulted in the need for a federal definition of *severe disabilities*. This definition requires an individual to have a physical or mental impairment that seriously limits functional capacities of the individual. While there is not an exhaustive list of these capacities, examples include **mobility**, communication, self-care, interpersonal skills, and work skills. There is also not an exhaustive list of physical or mental impairments that could seriously limit functional capacities, but some would include autism, blindness, cerebral palsy, cystic fibrosis, deafness, intellectual disabilities, mental disability, musculo-skeletal disorders, neurological disorders, or a combination of disabilities (29 U.S.C.).

In addition to the definition of severe disabilities, the Developmental Disabilities Assistance and Bill of Rights Act of 1990, Public Law 101-496, provides a definition for **developmental disability** that is also based on functional impact. It defines developmental disability as

> a severe, chronic disability of a person 5 years of age or older which: (a) Is attributable to a mental or physical impairment or is a combination of mental and physical impairments; (b) Is manifested before the person attains age twenty-two; (c) is likely to continue indefinitely; (d) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self care; (ii) receptive and expressed language; (iii) learning; (iv) mobility; (v) self-direction; (vi) capacity for independent living; and (vii) economic self-sufficiency; and (e) reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are lifelong or extended duration and are individually planned and coordinated; except that such term, when applied to infants and young children (meaning individuals from birth to age 5, inclusive), who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

The definition of *developmental disability* recognizes that individuals with this diagnosis will likely have to deal with its manifestations throughout their entire life (Smith, 2008). Approximately 17% of children aged 3–17 have developmental disabilities, although the majority would not be classified as having extensive support needs (Zablotsky et al., 2019).

As noted in Chapter 1, IDEA does not include a separate category called *severe disabilities*. It does, however, include **multiple disabilities** as one of the 13 separate categories eligible for IDEA services. In its description of multiple disabilities, IDEA refers to a combination of disabilities that results in the needs of these students not being able to be met simply by focusing on one of the disabilities. In addition to the multiple disabilities category, the impact of several of the other IDEA-recognized disabilities may rise to the classification of "severe" because of their substantial impact. For example, while most students with intellectual disabilities are classified as having mild disabilities, there are students with severe intellectual disabilities who would meet the criteria for extensive support needs. Similarly, while many students classified as having autism spectrum disorder are classified as having mild disabilities, there are others who experience a serious impact on functional skills and would therefore be classified as having extensive support needs.

The majority of students who take alternate assessments, those approved by the Every Student Succeeds Act (ESSA) for students with more extensive support needs, fall into the IDEA categories of intellectual disability, autism, and multiple disabilities (Kleinert et al., 2015). While there are some disability categories that are more likely to result in extensive support needs than others, the focus is the functional impact of the impairment. The National Center and State Collaborative (2012) described students with severe disabilities as those requiring "extensive repeated individualized instruction and support that is not of a temporary or transient nature" who need "substantially adapted materials and individualized methods of accessing information in alternative ways to acquire, maintain, generalize, demonstrate and transfer skills across multiple settings" (p. 1). The main thing to remember when describing individuals with extensive support needs is that this classification is the result of a substantial impact of a disability and not on a specific clinical category. Determining that an individual has extensive support needs is a professional judgment decision; there are no specific criteria resulting in this label. The following sections describe a few of the categories of disabilities that can result in extensive support needs.

AUTISM SPECTRUM DISORDER

Autism has only recently been identified as a disability. Leo Kanner introduced the term *autism* in 1943; Hans Asperger described individuals with higher functioning autism in 1944, which resulted in some individuals diagnosed with **Asperger's syndrome**. Autism was associated with schizophrenia until the third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), published in 1980 by the American Psychiatric Association, which described the condition as a pervasive developmental disorder (PDD). The fourth edition of the DSM added Asperger's syndrome to the PDD category (Smith, Schaefer-Whitby, & Mrla, 2017). The fifth edition of the **Diagnostic and Statistical Manual of Mental Disorders, DSM**-5-TR, introduced **autism spectrum disorder** as a category. The autism spectrum disorder category eliminated specific types of disorders, including pervasive developmental disorder, autism, and Asperger's syndrome, preferring to provide an overarching umbrella that included various degrees of the disorder. "Viewing autism as a multifaceted spectrum with varying dimensions allows for clarification when diagnosing, identifying resources, and completing research" (Smith et al., 2017, p. 30).

Definition and Identification of Autism Spectrum Disorder

The categorization of autism spectrum disorder has reflected the "psychosocial culture of the times" (Smith et al., 2017, p. 24). There was no separate category for autism in IDEA until it was added in the 1990 reauthorization. Prior to this change children with autism were served under different categories, including intellectual disability and severe emotional disturbance. IDEA states that

> (i) Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engaging in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.
>
> (ii) Autism does not apply if the child's educational performance is adversely affected primarily because the child has an emotional disturbance.
>
> (iii) A child who manifests the characteristics of autism after age three could be identified as having autism if the criteria (above) are satisfied (34 C.F.R. § 300.8(c)(1)).

This enables a child to receive special education services under this classification if they develop signs of autism after their third birthday.

In addition to the IDEA definition of autism, the DSM-5 describes the essential features of autism spectrum disorder as "persistent impairment in reciprocal social communication and social interaction . . . and restricted, repetitive patterns of behavior, interests, or activities" (DSM-5, p. 53). DSM-5-TR also notes that the characteristics begin in early childhood and impair everyday functioning. The Centers for Disease Control and Prevention (CDC) follow the DSM-5-TR definition and describe autism spectrum disorder as a "developmental disability that can cause significant social, communication, and behavioral challenges."

The DSM-5-TR organizes the diagnostic criteria for autism spectrum disorder into two major categories: (1) deficits in social communication and social interactions and (2) restricted repetitive patterns of behavior, interests, or activities. To be diagnosed as having deficits in social communication and social interactions, individuals must exhibit challenges in social-emotional reciprocity, nonverbal communicative behaviors, and developing and maintaining relationships. A diagnosis based on restrictive patterns of behavior, interests, or activities requires individuals to exhibit challenges in two of the following: stereotyped behaviors or speech, adherence to routines, restricted interests, or hyper/hypo-sensitivity to sensory stimuli.

There is no one diagnostic instrument used to diagnose autism spectrum disorder, including no specific medical tests. Rather, diagnoses are made based on the presence of a myriad of characteristics typically observed by a psychiatrist, clinical psychologist, physician, or other highly qualified professional. Because of the tremendous increase in the number of children diagnosed with autism, the American Academy of Pediatrics recommends that all children should be screened for autism during wellness visits at 18 and 24 months (Centers for Disease Control and Prevention, 2020).

Prevalence of Autism Spectrum Disorder

Until recently, autism had been considered a low-incidence disability (Smith et al., 2020). As recently as 2000–2002, the prevalence of autism was 1 in 150. This number increased to 1 in 68 children in 2010–2012 and 1 in 54 in 2016 (Maenner et al., 2020). In 2020, the CDC estimated the prevalence of children 8 years old as 2.76%, or one in every 36 children. This represented 1% of girls and 4% of boys (Maenner et al., 2023). The percentage of students aged 521 identified as having autism and served under IDEA in 2011 was only 7%. This number had increased to 12.2% in 2021, when it accounted for approximately 10% of all students in special education (U.S. Department of Education, 2022). Maenner et al. (2020) reported that 33% of children with autism were also classified as having an intellectual disability (**IQ** below 70). While autism has a history of overrepresentation among some racial groups (i.e., white) this ratio has leveled off across racial groups. In fall 2021, the risk factor for white students was 0.8 while 1.2 for Asian and Black American students, and 1.1 for Latino American students (U.S. Department of Education, 2023). The CDC noted that beginning in 2018 there were no racial differences in the number of 8-year-old children identified as having autism. During the same year the number of Black and Latino 4-year-old children identified as having autism was actually higher than white children. Black children identified as having autism and intellectual disabilities among 8-year-olds was 50.8%, compared to 34.8% of Latino children and 31.8% of white children. The CDC expressed concern over this trend and emphasized the need to develop awareness and improve identification of all children (Maenner et al., 2023).

Etiology of Autism Spectrum Disorder

Although the prevalence of autism has been growing exponentially over the past 10–20 years, the exact cause of this disorder is still unknown. While a genetic predisposition impacted by environmental factors appears to be the most likely factor, there is no one identified cause (Smith et al., 2020). There are, however, certain factors that appear to increase the risk for autism, including the following (Centers for Disease Control and Prevention, 2020a):

- genetic predisposition
- children with a sibling with ASD
- presence of certain genetic disorders, such as fragile X
- prescription drugs taken during pregnancy that can increase risk
- children born to older parents

The only conclusion regarding **etiology** is that there is no known cause. Several theories regarding the cause of autism have been debunked. One theory, that autism is caused by the **measles, mumps, and rubella (MMR) vaccines**, was determined to be invalid after a series of epidemiological studies found no relationship between vaccines and autism (DeStefano & Shimabukuro, 2019). Another early theory, that autism was caused by mothers who did not bond with their newborn, resulting in their being called "refrigerator mothers," was also debunked but only after causing guilt for many families. It is likely that within the next several years, with increased research due to increased prevalence of the disorder, more evidence will result in more knowledge regarding the causes of autism.

Characteristics of Autism Spectrum Disorder

Because autism spectrum disorder includes multiple disorders there is a wide range of characteristics associated with this diagnosis (Maye, Kiss, & Carter, 2017). However, the major areas impacted by autism spectrum disorder are deficits in social communication and interaction, communication, and behavior difficulties. Examples of social communication and interaction characteristics include (Smith et al., 2020):

- not responding to name
- limiting eye contact
- treating people as objects
- resisting cuddling or touching
- not acknowledging others
- displaying socially inappropriate behaviors

Examples of communication challenges experienced by children, youth, and adults include no oral language, echolalia, idiosyncratic speech, literal interpretation of language, flat monotone speech, and not demonstrating communication reciprocity (Smith et al., 2020).

Behavior difficulties include stereotypical behaviors, adherence to routines, restricted interests, and hyper- or hyposensitivity to sensory stimuli. For example, many children with autism spectrum disorder display stereotypical behaviors, such as hand flapping, rocking, and a lack of eye contact. They also become agitated if their daily routines are interrupted and often are interested in a very small number of things, such as clouds (Smith et al., 2020).

A diagnosis of autism spectrum disorder does not always result in high levels of support needs. There are many different experiences of individuals diagnosed with this disability, with some displaying characteristics requiring few supports, accommodations, and modifications to support learning while others have substantial support needs in many life activities, including self-care, independent living, and self-sufficiency. These differences in experience may be the result of an accompanying intellectual disabilities and/or language and communication diagnosis. The DSM-5-TR (2022) describes three levels of severity of autism spectrum disorder. Levels one and two result in individuals needing support or substantial support, while level three includes individuals who need very substantial supports. These individuals display severe problems in verbal and nonverbal communication and exhibit repetitive behaviors, have difficulties coping, and difficulty with change. Many individuals classified in level 3 are also likely to have cognitive disabilities.

Adult Outcomes for Individuals with Autism Spectrum Disorder

Adult outcomes for individuals with autism spectrum disorder vary a great deal, depending on the level of severity of the disorder and services that have been received. While adult outcomes have generally not been positive (Mason et al., 2021), with appropriate early intervention and access to effective transition planning outcomes can be improved. It's important to note that adult outcomes are a concern for youth and adults with autism spectrum disorder who may have been diagnosed a level 1 who are struggling to maintain supportive employment and active friendships, as they are a concern for the families of children, youth, and adults at level 3 who may experience high needs for support in augmentative and alternative communication and robust, community-based instruction in order to live the lives they and their families desire.

Many adults with ASD can be employed successfully in competitive integrated employment jobs with proper supports. Studies have found that the most critical factor in keeping adults with ASD successfully employed is employment-specific supports that are specifically related to the job along with individual and community supports. Unfortunately, many employers do not want to hire adults with ASD because of this need for extensive social supports (Brooke et al., 2018).

Bury and colleagues (2024) notes that regular paid employment for adults with autism has been difficult. One study of 162 young adults with autism spectrum disorder found that only 12% were in full-time unsupported employment, while another 12% were in part-time unsupported employment. Of the remaining sample, 7% were in **supported employment**, 14% in sheltered employment, 3% in a day program, and 20% were completely unemployed. Fourteen individuals in the sample had as many as nine different jobs but could not sustain their employment. In another study, Ohl and colleagues (2017) found that 61.4% of adults were employed and nearly 40% were unemployed. Supporting peer mentorship and inclusion in schools not only provides children and youth with autism opportunities for important skills, but also prepares peers to be future employers and coworkers with greater capacity to support autistic employees in the job setting (Sreckovic et al., 2024).

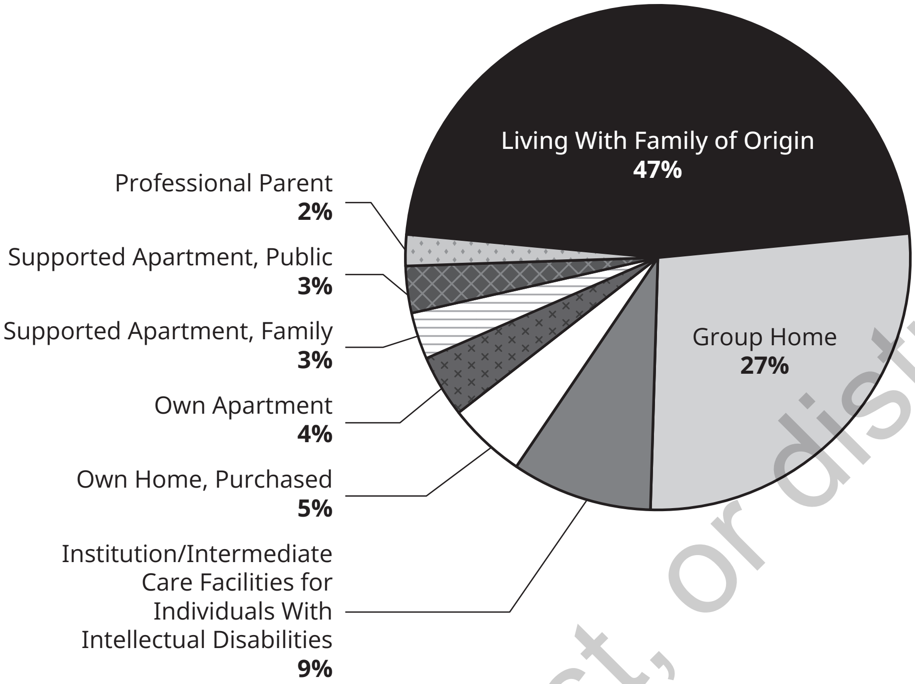
Adults with autism spectrum disorder also experience difficulties with **independent living**. Farley and colleagues (2018) studied the mid-life social outcomes of adults with ASD with a mean age of 35.5 years and found the following specific living arrangements, outlined in Figure 2.1.

Studies have also found that young adults with autism spectrum disorder experience difficulties with social interactions and friendships. Farley and colleagues (2018) found that 75% had no experience dating, while 13% dated in group settings, 5% dated in a single couple arrangement, and another 6% dated in both group and single arrangements. Findings showed that some relationships lasted from 6 months to 10 years with a variety of reasons for the relationships ending, including immaturity and high levels of dysfunction for both partners. Many parents of these individuals reported that their son or daughter did not understand the importance of having a relationship; only 19% of the parents felt their son or daughter even wanted a relationship (Farley et al., 2018).

Many autistic adults also have limited involvement with friendships. Fifty-nine percent of parents indicated that their son or daughter was in some sort of organized group, ranging in 4% spending time in one organization or club, 15% in two clubs or organizations, and 3% in three or more clubs or organizations. Regarding time spent with peers, parents reported the following (Farley et al., 2018):

- 47% little or no time
- 20% 1 to 10 hours per week
- 13% 11 to 40 hours
- 20% more than 40 hours

FIGURE 2.1 ■ Adults With ASD With a Mean Age of 35.5 With Specific Living Arrangements



Source: Adapted from data in M. Farley, K. J. Cottle, D. Bilder, J. Viskochil, H. Coon, & W. McMahon, 2018, "Mid-Life Social Outcomes for a Population-Based Sample of Adults With ASD," *Autism Research*, 142152.

INTELLECTUAL DISABILITIES

Individuals with intellectual disabilities have been identified longer than those with many other disabilities. In 1790 Jean Itard, the French physician, worked with Victor, dubbed the Wild boy of the Averon Forest, in an attempt to educate the young adolescent. This was the first recorded effort to educate someone who was recognized as having an **intellectual disability**. Since Itard's efforts, many individuals with intellectual disabilities have been educated in a variety of settings, including regular and self-contained classrooms in public schools, special schools, and residential programs. For many years the term **mental retardation** was used to describe this category; however, this term resulted in numerous negative stereotypes among the general public that caused professionals and advocates to advocate for its replacement (Polloway et al., 2017a). The movement away from the term resulted in the terminology changing to *intellectual disability*.

Although the term *mental retardation* remains in use in some organizations, "the term has mostly disappeared along with *idiocy* and *feeblemindedness* which were classifications of *mental deficiency*, and other terms that at one time may have been appropriate and/or benign but acquired negative connotations and were therefore discarded" (Thompson & Wehmeyer, 2008, p. 21). In a study of the terms used in schools to identify children and adults with intellectual disabilities, Polloway and colleagues (2017b) found that only three states continued to use the term *mental retardation*, with 42 states using the term *intellectual disability*. Additional states have since abandoned the term *mental retardation* for *intellectual disability*. The AAIDD uses the term *intellectual disability* while the American Psychiatric Association uses the term *intellectual developmental disorder*.

Defining and Identification of Intellectual Disabilities

Intellectual disability describes individuals whose ability to learn at expected levels and whose functional daily life skills are impacted. It is a neurodevelopmental disorder that manifests during an individual's development that impacts intellectual and adaptive functioning (DSM-5-TR, 2022). The Centers for Disease Control and Prevention noted that intellectual disability could cause a child to learn and develop more slowly than other children of the same age and take longer to learn to speak, walk, dress, or eat without help. Children with intellectual disabilities also have trouble learning in school without necessary supports.

Two sources are typically used to define intellectual disabilities, the **American Association on Intellectual and Developmental Disabilities (AAIDD)** and the **American Psychiatric Association (APA)** that publishes the *Diagnostic and Statistical Manual* (Tassé, 2015). The AAIDD has provided definitions and eligibility criteria for intellectual disabilities since 1959, and its definition is often used as the basis for diagnosis, especially in schools (Polloway et al., 2017b). The AAIDD and DSM-5-TR definitions are similar in that they each include three-tier criteria that include intellectual functioning, adaptive behavior, and time of onset (Tassé, 2015).

The AAIDD defines intellectual disability as "a condition 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 22" (Schalock, Luckasson, & Tassé, 2021, p. 1). The American Psychiatric Association (APA), in its *Diagnostic and Statistical Manual* (DSM-5-TR), defines intellectual disability as a "disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains" (2013, p. 33). Both the AAIDD and APA operationalize their definitions with the following criteria: (1) **IQ score** of 70+ or –5 (65–75) or below; (2) deficits in **adaptive behavior**; and (3) occurring during the developmental period. The AAIDD defines the developmental period as birth to age 22; the DSM does not provide an age limit.

While a diagnosis of intellectual disability is determined using the three criteria, the IQ score is the most commonly cited factor in determining eligibility. While common, a single score is insufficient and has contributed to significant racial bias in assessment and diagnosis leading to overrepresentation of some disabilities in racial groups. For example, at present Black children are twice as likely as white children to be classified as having an intellectual disability (U.S. Department of Education, 2023). An early federal court case in California, *Larry P. v. Riles* (1979), actually banned the use of **IQ tests** to identify students as having an intellectual disability. On appeal, the Ninth Circuit Appeals Court upheld the ruling in 1984.

Polloway and colleagues (2017a) noted that most states use an IQ of 70 as the cut-off for an intellectual disability diagnosis but provide no specific criteria for deficits in adaptive behavior. Adaptive behavior is generally organized into three domains: conceptual, social, and practicaland includes communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional, academic skills, work, leisure, health, and safety. Greenspan (2017) defined adaptive behavior as "how well a person meets community standards of personal independence and social responsibility, in comparison to others of similar age and sociocultural background" (p. 23). The most recent edition of the DSM calls for one of the three domains to be "impaired resulting in ongoing support" (American Psychiatric Association, 2022), and notes that deficits impact an individual's ability to conform to developmental and sociocultural standards; the AAIDD definition does not specify how deficits in adaptive behavior are used in determining the diagnosis.

Levels of Support Needs for Intellectual Disabilities

Individuals with intellectual disability exhibit a wide range of characteristics, depending on the level of the disability. As a result, professionals have established subcategories of intellectual disability to more specifically describe this population. Terms previously used to subcategorize these individuals have included **borderline, educable, trainable**, and even terms considered extremely offensive including **idiot, moron, and imbecile** (Smith et al., 2020). Subcategories more recently used in the DSM-5-TR to describe the severity levels include **mild, moderate, severe, and profound**.

The DSM-5-TR uses a deficit-oriented medical perspective and describes individuals with severe and profound intellectual disabilities as those displaying substantial limitations in functional skills (American Psychiatric Association, 2022). A problem with using subcategories of intellectual disabilities, including these four groups, is an overreliance on IQ scores for classification. The AAIDD uses a different approach, which focuses on levels of support, intermittent, limited, extensive, and pervasive, rather than a deficit model (Schalock, Luckasson, & Tassé, 2021).

A newer approach is simply to organize individuals with intellectual disabilities into *mild* and *significant* based on adaptive behavior domains rather than IQ scores (McNicholas et al., 2018). While less precise than IQ scores, this approach provides a more meaningful classification system (Smith et al., 2020). Regardless of terminology, it is important to understand that individuals with higher levels of intellectual disability, those often classified as having mild or moderate levels of impairment, are capable of independent or semi-independent abilities, while those with lower levels of capacity, often classified as having severe or profound intellectual disability, require extensive supports (Smith et al., 2020).

Individuals are diagnosed with intellectual disability using individual intelligence tests and measures of adaptive behavior (see Chapter 3). As with many disabilities, the earlier children can be identified as having an intellectual disability and provided services, the most optimistic the outcome. There are several early indicators that could suggest the possibility of an intellectual disability. These include, according to the Centers for Disease Control and Prevention (n.d.):

- sitting up, crawling, or walking later than other children
- learning to talk later, or having trouble speaking
- finding it hard to remember things
- having trouble understanding social rules
- having trouble seeing the results of their actions
- having trouble solving problems

While displaying these characteristics would not result in a diagnosis of intellectual disability, it could result in a referral for a more comprehensive assessment of intelligence and adaptive behavior.

Prevalence of Intellectual Disabilities

The Centers for Disease Control and Prevention estimated that the prevalence of children aged 3–17 diagnosed with intellectual disabilities was 1.7% in 2019, 2.20% in 2020, and 1.65% in 2021 (National Center for Health Statistics [NCHS] Data Brief, 2023). In 2021, 6.1% of students in special education programs under IDEA were classified as having an intellectual disability (U.S. Department of Education, 2023). It should be noted that the risk factor for students classified as having an intellectual disability differs by race, with students who are Black American having more than 3 times and Hispanic/Latino American students almost double the chance compared to white American students (U.S. Department of Education, 2023). Because of the less than precise means for differentiating among the different levels of intellectual disability, it is difficult to arrive at a firm prevalence for those classified as having extensive support needs. Polloway, Bouck, and Yang (2019) suggest that the prevalence of individuals with this level of support needs is 0.4%.

Etiology of Intellectual Disabilities

Using the AAIDD and DSM-V definition, an individual can be classified as having an intellectual disability if the condition occurs any time before a child turns 22 years old. This includes the prenatal period of development. While there are many known causes of intellectual disability, the exact cause in many cases is still unknown. Causes can occur prenatally, perinatally, or postnatally. Some of the most commonly known causes of intellectual disability are described in Table 2.1.

TABLE 2.1 ■ Examples of Known Causes of Intellectual Disabilities

Cause	Examples
Chromosomal disorders	Down syndrome, fragile X syndrome, Klinefelter's syndrome, Turner's syndrome, Prader-Willi syndrome
Prenatal infections	Rubella, sexually transmitted diseases
Postnatal infections	Encephalitis, meningitis
Intoxications	Legal drugs, illegal drugs
Gestational disorders	Pre-maturity, low birth weight, and post-maturity
Unknown prenatal	Anencephaly, microcephaly, macrocephaly, hydrocephaly
Metabolic disorders	phenylketonuria, Tay Sachs disease

Source: Adapted from *Teaching Students With Special Needs in Inclusive Settings*, 8th ed, by T. E. C. Smith, E. A. Polloway, and T. Doughty, 2020, Pro-Ed.

Characteristics of Intellectual Disabilities

Individuals with intellectual disability exhibit a wide range of characteristics, depending on the level of disability. Usually, the more severe the degree of intellectual disability, the earlier characteristics can be noticed. Individuals with intellectual disability with extensive support needs exhibit a diverse set of characteristics and are likely to display substantial limitations in many life skills (Smith, Polloway, & Doughty, 2020). Students with intellectual disability may experience challenges in academic performance, attention and engagement in school, delayed language development, short- and long-term memory challenges, and in effective social skills if not provided necessary supports and specialized instruction. Individuals with intellectual disabilities with extensive support needs may experience challenges in use of language, social skills, cognition, independent living skills, and motor skills without effective supports and instruction

(Smith et al., 2020). The DSM-5 lists the following as characteristics for individuals with severe and profound intellectual disabilities who would have extensive support needs (DSM-5):

- require extensive supports in problem-solving
- have limited spoken language ability
- have limited understanding of symbolic language, including speech and gestures
- require support in all aspects of daily living, such as bathing, dressing, eating, and toileting
- are dependent for all areas of daily physical care, such as bathing, dressing, eating, and toileting

Adult Outcomes for Individuals with Intellectual Disabilities

Intellectual disability, especially resulting in extensive support needs, has a major impact on adults. It impacts their independent living, employment, and social interactions. The quality of life of adults with intellectual disability resulting in extensive support needs is significantly lower than that for individuals without disabilities and even individuals with mild intellectual disabilities. During the 1960s, the number of individuals with intellectual disabilities living in large institutions peaked at nearly 200,000. Because of the deinstitutionalization movement, advocacy, and increased research, this number declined to approximately 19,000 in 2017 (Administration for Community Living, 2021). Of those continuing to live in large institutional settings, the majority will continue to have extensive support needs. The trend to move individuals from large institutions to community-based settings is very positive, as research has shown that individuals with intellectual disability have better quality of life when living in the community, with improvements in their adaptive behavior (Larson, Lakin, & Hill, 2013).

While the number of individuals with intellectual disability living in large institutions has been dramatically reduced, many adults continue to live in supported settings. In 2017, 60% of individuals with intellectual disabilities receiving long-term support services lived in the home of a family member, 23% lived in a group home or other group setting, 12% lived in a home they owned or leased, and 5% lived in a host or foster family home (Larson et al., 2020). One problem for adults with intellectual disabilities who want to live more independently is limited affordable housing. The Arc noted that approximately 4.8 million individuals with intellectual disabilities needing extensive supports who are not living in institutions rely on $9,156 per year they receive through Supplemental Security Income (SSI), which is insufficient to afford independent living options.

The past 50 years have seen major progress in providing independent living options for individuals with intellectual disabilities (Braddock et al., 2015). However, in order to live successfully in the community, adults with intellectual disabilities require community supports. Individuals with extensive support needs may require assistance in basic self-care, including bathing, dressing, meal preparation, medication management, and money management. Unfortunately, many of these services are not available in many communities. Currently, there are more than 500,000 individuals with disabilities who are on state waiting lists to receive these needed services, waiting up to 10 years in some states. Without support services the ability of individuals who need extensive supports to live successfully in the community is extremely limited (The Arc, n.d.).

Another key component of quality of life that impacts individuals with intellectual disability who need extensive supports is employment. Many of these individuals rarely achieve successful competitive employment. Wehman and colleagues (2018) found that after years of efforts, competitive employment for individuals with intellectual disabilities remains low. There are numerous reasons for such limited employment opportunities, including the level of support some employers believed would be required to enable these individuals to be successful (Brooke et al., 2018).

In addition to independent living and employment, social engagement is a critical component of quality of life. After the World Health Organization introduced a classification system based on a social-ecological model of disability in 2001, the level of social engagement of individuals with disabilities has been of interest. Participation, while not conclusively defined, includes activities such as leisure time, working, and independent living. Participation cannot occur without access, meaning that as individuals with intellectual disabilities gain more access their level of participation can increase (Dean, Fisher, Shogren, & Wehmeyer, 2016).

MULTIPLE DISABILITIES

Some individuals exhibit more than one disability. For these individuals, the impact of each disability is compounded by the presence of one or more other disabilities. While not all individuals with multiple disabilities are considered to have extensive support needs, many would be, especially if one or more of the disabilities is intellectual disability, autism spectrum disorder, or others that impact cognitive abilities.

Defining and Identification of Multiple Disabilities

While not including a category of extensive support needs, IDEA does include the *multiple disability* category. According to IDEA, multiple disabilities refers to “concomitant [simultaneous] impairments (such as intellectual disability-blindness, intellectual disability-orthopedic impairment, etc.), the combination of which causes such severe educational needs that they cannot be accommodated in a special education program solely for one of the impairments. The term does not include **deaf-blindness** (34 C.F.R., sec. 300(b)(6). Students classified as having multiple disabilities can be diagnosed and exhibit characteristics associated with more than one disability. The exception is the combination *deafness and blindness*, as this pair of impairments has its own classification under IDEA.

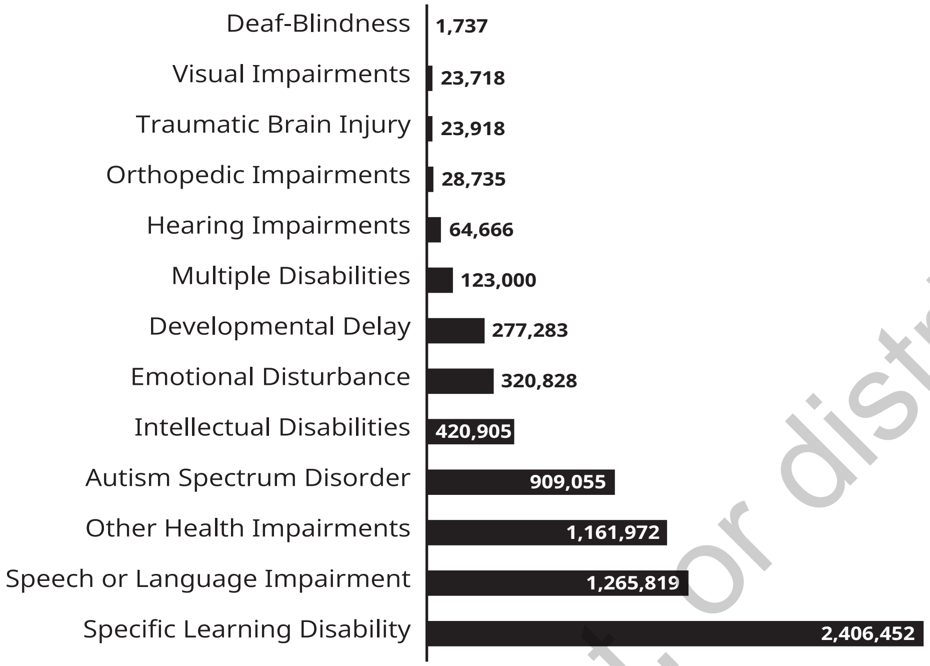
Prevalence of Multiple Disabilities

In the 2022–2023 school year, 123,000 students with multiple disabilities were served under IDEA (Figure 2.2). In the 2021–2022 school year, multiple disabilities accounted for 1.8% of all students aged 5–21 who were served in special education (U.S. Department of Education, 2023). Adults can be classified as having multiple disabilities if they exhibit more than one disability. Stevens and colleagues (2016) studied adults with disabilities in the United States and found that 51% of their sample had one functional disability, while 21% (4.8 million) had two functional disabilities, 12% (2.7 million) had three, and another 10% (2.2 million) had four functional disabilities. The most common disabilities among those with multiple disabilities were in the areas of mobility, cognition, and independent living.

Etiology of Multiple Disabilities

There is no specific etiology for students with multiple disabilities because this is a category composed of several specific disabilities. Therefore, the causes of multiple disabilities are the causes of the individual disabilities exhibited by the individual.

FIGURE 2.2 ■ Number of School-Age Students (Aged 5–21) Served Under IDEA, Part B, by Disability 2022–2023



Source: Adapted from "45th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2023," by U.S. Department of Education Office of Special Education Programs, 2024.

Characteristics Associated with Multiple Disabilities

Similar to etiology, there are no characteristics specifically associated with individuals with multiple disabilities. People with multiple disabilities exhibit a wide range of characteristics, depending on the combination and severity of the different disabilities they exhibit and the person's age. In other words, characteristics of individuals with multiple disabilities are those associated with the specific disabilities they manifest. Due to individuals exhibiting more than one disability, characteristics are generally exacerbated by the combination of more than one disability. Cognitive challenges are common among students with multiple disabilities, as well as difficulties with mobility and communication. While there are no universal characteristics of individuals with multiple disabilities, National Dissemination Center for Children with Disabilities (NICHCY, 2017) has identified several that appear to be common, including:

- Limited speech or communication;
- Difficulty in basic physical mobility;
- Tendency to forget skills through disuse;
- Trouble generalizing skills from one situation to another; and
- A need for support in major life activities, e.g., domestic, leisure, community use, vocational

The presence of having multiple disabilities impacts educational services for students because they usually have more extensive support needs. The U.S. Department of Education (2019) noted that students with multiple disabilities are educated in general education classrooms with peers without disabilities less than students with most other disabilities and also have lower graduation rates among all students with disabilities except those with intellectual disabilities. The low graduation rate and low levels of inclusion in general education classrooms are likely to result in negative adult outcomes in the areas of employment, independent living, and social interactions.

Adult Outcomes for Individuals with Multiple Disabilities

The impact of multiple disabilities on adults varies considerably, depending on the types and extent of the disabilities exhibited. For example, individuals with intellectual disabilities or autism who also exhibit a second disability will need more extensive services and supports than those with only one of these disabilities. The support needs of adults with multiple disabilities, as well as lack of knowledge and resources for employers to accommodate people with various needs, make it even more difficult for them to be gainfully employed, live interpedently, and be included in the community.

EMOTIONAL/BEHAVIORAL DISORDERS AND SERIOUS MENTAL HEALTH ISSUES

Mental health issues can result in significant challenges for children during the school years and for adults in employment, independence, and social interactions. The field of mental health is plagued by difficulties in definitions, differences in labels, difficulties in assessment, and problems in providing appropriate services. For example, IDEA includes a category of **emotional disturbance** that does not exist in the DSM, and IDEA does not include categories labeled mental disabilities or mental health problems. The result is often confusion that can impact the identification of this group of individuals and the services they are provided, especially as students transition from public school services to adult services.

Defining and Identification of Serious Emotional Disturbance and Serious Mental Health Issues

The term *emotional disturbance* is used to identify students for services under IDEA who experience **emotional/behavioral disorders** and mental health issues. IDEA defines serious emotional disturbance as

- a condition exhibiting one or more of the following characteristics over a long period of time and to a marked extent, which adversely affects educational performance:
- An inability to learn which cannot be explained by intellectual, sensory, or health factors;
- An inability to build or maintain satisfactory relationships with peers and teachers;
- Inappropriate types of behavior or feelings under normal circumstances;
- A general pervasive mood of unhappiness or depression; or
- A tendency to develop physical symptoms or fears associated with personal or school problems.

The term includes children who are schizophrenic. The term does not include children who are socially maladjusted unless it is determined that they are also seriously emotionally disturbed.

Although this definition has been widely used by states and local educational agencies, it can be problematic because of its vagueness, often leaving school personnel unsure about its meaning (Mattison, 2015; Shepherd, 2010).

While schools use the IDEA category of emotional disturbance, most other agencies providing services to children, adolescents, and adults with mental health problems use the DSM to define and diagnose individuals (Mattison, 2014).

The DSM-5-TR defines mental disorder as "a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities" (American Psychiatric Association, 2023).

As with all disabilities, there are varying degrees of mental health issues that impact functional abilities. While the majority of individuals only experience mild mental disability, a smaller subset is classified as having serious mental disability. Serious mental disability is often defined by the duration and disability it produces (Behavioral Health Evolution, 2014); it "is an umbrella term used by researchers to categorize the most serious mental disorders that share basic characteristics, including intense symptom severity and severe functional impairment when the condition goes untreated" (Whitley, Palmer, & Gunn, 2015, p. 951).

The National Institute on Mental Health (NIMH) defines serious mental disability as a "mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities" (National Alliance on Mental Illness [NAMI], 2020). NAMI lists several conditions that could result in serious mental disability, including anxiety disorders, attention deficit hyperactivity disorder (ADHD), bipolar personality disorder, depression, dissociative disorders, eating disorders, obsessive-compulsive disorder, post-traumatic stress, psychosis, schizoaffective disorder, and schizophrenia (NAMI, 2020).

The fact that the DSM-5 does not include the category *emotional disturbance*, and IDEA does not include the category *mental disability*, only causes confusion when addressing the needs and services for this group of children. In a study by Polloway and colleagues (2017b) it was concluded that while states use different terms to identify students with these issues the term that best describes school-age students is *emotional and behavioral disorders*. Using different terminology can result in confusion among professionals serving this group of individuals, especially as they move from school-based services to adult-based services.

Prevalence of Emotional and Behavioral Disorders

The precise number of individuals with emotional and behavioral disorders is difficult to identify due to different terminology, different definitions, different assessment methods, and different service models. Adding to these factors is the reality that the concept of mental disability is simply difficult to diagnose, often requiring substantial subjective interpretations of behaviors. As a result, the literature reports a broad range of prevalence estimates. In 2022–2023, the number of students aged 5–21 served as emotionally/behaviorally disordered through IDEA was 0.5%, which accounted for 4.8% of all students served in special education (U.S. Department of Education, 2023). However, students with emotional and behavioral disorders are considered the most underidentified group of students served through special education, meaning that the true prevalence is likely more than 0.5% (Kauffman, 2016; Smith et al., 2020). Kauffman and Landrum (2018) reported prevalence rates of emotional/behavioral disorders ranging from 0.5% to 20%, and the Center for Behavioral Health Statistics and Quality (2016) reported rates ranging from 6.8% to 11.5%. Taking these estimates together, a reasonable estimate would be 3% to

6% of the student population may be impacted by emotional/behavioral disorders (Kauffman & Landrum, 2017). Students who are Indigenous, Black, and of two or more races are more likely to be diagnosed with emotional/behavioral disorders than their peers of other racial groups. The risk factor for Black American students is 1.8 compared to 1.0 for white students (U.S. Department of Education, 2023). The significant subjectivity included in the diagnosis process raises concerns for these discrepancies across groups.

Determining the prevalence of mental disability in adults is also difficult. Mental disability is common in the United States, with approximately one in five adults or more than 46 million-experiencing some degree of mental disability. The Centers for Disease Control and Prevention estimated that 50% of all Americans experience some level of mental disability or disorder in their lifetime (2020a). While the majority of individuals experience mild mental disability, there is a subset who experience serious mental disability (SMI). Regarding this population, the National Institute of Mental Health (NIMH) (2024) noted:

- In 2022, there were an estimated 15.4 million adults aged 18 or older in the United States with SMI. This number represented 6.0% of all U.S. adults.
- The prevalence of SMI was higher among women (7.1%) than men (3.9%).
- Young adults aged 18–25 years had the highest prevalence of SMI (11.8%) compared to adults aged 26–49 years (7.6%) and adults aged 50 and older (3.0%).
- The prevalence of SMI was highest among the adults reporting two or more races (11.8%), followed by American Indian/Alaskan Native (AI/AN) adults (7.3%). The prevalence of SMI was lowest among Native Hawaiian/Other Pacific Islander (NH/OPI) adults (3.5%).
- In 2019, among the 13.1 million adults with SMI, 8.6 million (65.5%) received mental health treatment in the past year.
- More women with SMI (70.5%) received mental health treatment than men with SMI (56.5%).
- The percentage of young adults aged 18–25 years with SMI who received mental health treatment (56.4%) was lower than adults with SMI aged 26–49 years (65.1%) and aged 50 and older (74.3%).

Assessment and Identification of Emotional and Behavioral Disorders

Assessment of mental health and emotional issues presents several challenges. While there are numerous diagnostic instruments, some of these have questionable reliability and validity because of the subjective process they include. Diagnosis of mental and emotional problems requires trained professionals, often using an interview format.

Etiology of Emotional and Behavioral Disorders

There is no one cause of mental health disorders, and in many cases, the cause for a specific case cannot be determined. Some of the causes could include (Centers for Disease Control and Prevention, 2020b):

- Early adverse life experiences such as trauma or a history of abuse (for example, child abuse, sexual abuse, witnessing violence, etc.)

- Experiences related to other ongoing (chronic) medical conditions, such as cancer or diabetes
- Biological factors, such as genes or chemical imbalances in the brain
- Use of alcohol or recreational drugs
- Having few friends
- Having feelings of loneliness or isolation

Characteristics of Emotional and Behavioral Disorders

Individuals with emotional/behavioral disorders and serious mental disability exhibit a wide range of characteristics depending on the form of the mental impairment. For example, students classified as having emotional/behavioral disorders may exhibit acting out and disruptive behaviors while adults with schizophrenia could experience hallucinations, delusions, paranoia, and reduced motivation (National Institute of Mental Health, 2020a). Smith and colleagues (2020) organized characteristics of individuals with emotional/behavioral disturbance into externalizing and internalizing. Externalizing characteristics include aggression, tantrums, defiance, noncompliance with rules, disobedience, lying and stealing, destructiveness, bullying, and self-control difficulties; internalizing characteristics include withdrawal, limited activity levels, fixation on certain thoughts, avoidance of social situations, anxiety, depression, inappropriate crying, and being bullied.

Adult Outcomes for Individuals with Emotional and Behavioral Disorders

Adults with serious mental disability experience a wide variety of negative outcomes. The National Alliance on Mental Illness (2025) listed some of these outcomes as follows:

> 33.5% of U.S. adults with mental illness also experienced a substance use disorder in 2021.
>
> The rate of unemployment is higher among U.S. adults who have mental illness (7.4%) compared to those who do not (4.6%).
>
> People with depression have a 40% higher risk of developing cardiovascular and metabolic diseases than the general population. People with serious mental illness are nearly twice as likely to develop these conditions.
>
> Caregivers of adults with mental or emotional health issues spend an average of 32 hours per week providing unpaid care.
>
> 21.1% of people experiencing homelessness in the United States have a serious mental health condition.
>
> 19.7% of U.S. veterans experienced a mental illness in 2020.
>
> 46% of people who die by suicide had a diagnosed mental health condition.

Research has shown that adults with mental disability want to work, and many are very capable of successful employment. Unfortunately, employment rates for these individuals are very low and appear to be getting worse (Luciano & Meara, 2014). In 2003, only 23% of individuals with serious mental disability held a job. While successful employment is a possibility for adults with serious mental disability, with supports, only 1.7% of people served in state mental health systems received supported employment services in 2012 (NAMI, 2014). Lehman and colleagues (2002) found that individuals with severe mental disability, even with supports, had difficulty maintaining their employment. The more serious the mental disability the more of a negative impact on employment (Luciano & Meara, 2014).

Adults with serious mental disability experience a myriad of negative outcomes. Esposito (2016) found that individuals with severe mental disability are overrepresented in the prison population; the prevalence of severe mental disability in the general population is 5% while it is 17% in jails. Also, adults with serious mental disability have difficulty finding affordable housing and many live in arrangements that do not support independence, including licensed care homes, assisted living facilities, and nursing homes, while others live in group homes and supported housing. Although severe mental disability was once thought of as a chronic and deteriorating condition, it is now considered a disorder that can improve with appropriate services using a recovery model. The recovery model is based on severe mental disability not being a lifelong or chronic condition, but one where individuals can function with reduced symptoms and experience independence (Whitley, Palmer, & Gunn, 2015). This new outlook for adults with serious mental disability could result in improved outcomes; however, the recovery model has still not been universally adopted.

PHYSICAL DISABILITIES

In addition to cognitive and mental health disorders, there is a large group of **physical disabilities** that can lead to an individual needing extensive supports. Physical disabilities include a wide range of disorders that can impact several functional capacities including mobility, communication, self-care, and work skills, which in turn have an impact on independent living, employment, and community inclusion. Not all physical disabilities result in individuals needing extensive supports; the level of supports needed is dependent on the type and severity of the physical disability.

Defining and Identification of Physical Disabilities

A wide variety of physical disabilities could result in individuals having extensive support needs. These include muscular degenerative disorders, such as multiple sclerosis, amputations, cerebral palsy, spina bifida, and spinal cord injury. Under IDEA, the corresponding disability category to physical disabilities is **orthopedic impairment**. IDEA defines orthopedic impairment as “a severe orthopedic impairment that adversely affects a child’s educational performance. The term includes impairments caused by congenital anomaly (e.g., clubfoot, absence of some member, etc.), impairments caused by disease (e.g., poliomyelitis, bone tuberculosis, etc.), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures)” (Sec. 300.8 (c) (8)).

The manifestation of physical impairments that result in limited or total loss of the extremities often results in the need for extensive support services. Paraplegia, limited or total loss of both legs, and quadriplegia, limited or total loss of both legs and arms, result in substantial impact on numerous functional skill areas and therefore likely result in extensive support needs (*Medical News Today*, 2020).

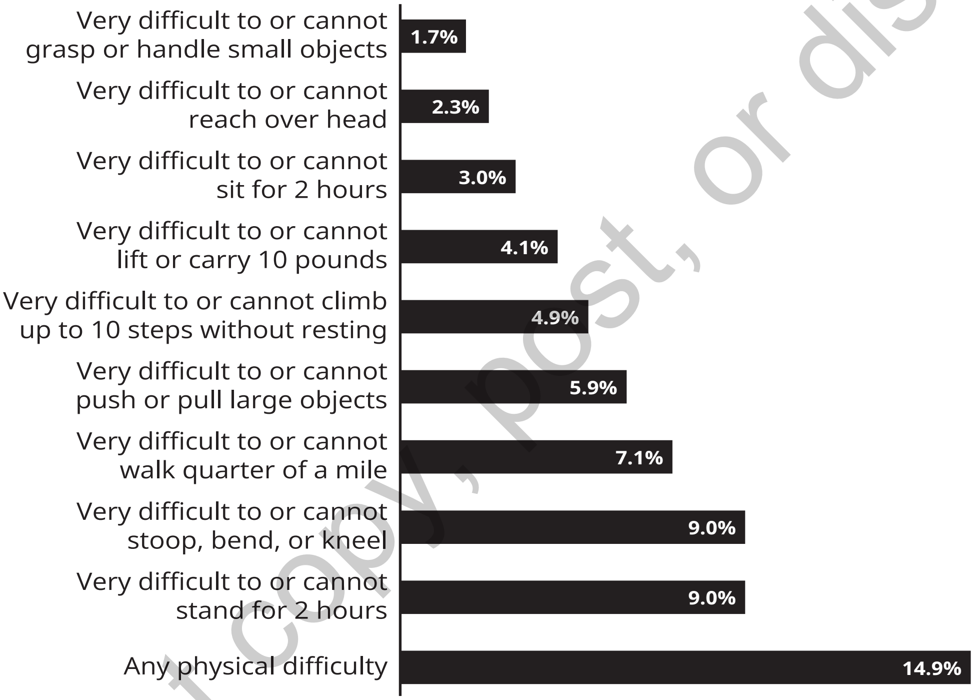
Prevalence of Physical Disabilities

During the 2022–2023 school year, 28,735 students with orthopedic impairments were served in special education programs, which accounted for 0.1% of the school population and less than .01% of students receiving services under IDEA (U.S. Department of Education, 2023). The rather low rate of special education students classified as orthopedically impaired is likely the result of students having to need special education in order to be eligible for IDEA services.

Many students may exhibit an orthopedic impairment, such as spina bifida resulting in a mobility impairment, but not need special education. Therefore, these students would not be eligible and would not receive services under IDEA. However, if the impairment resulted in a substantial limitation of a major life activity, such as walking or caring for oneself, it would result in eligibility for protection under Section 504 and the ADA.

The National Health Interview Survey (2018) found that 14.9% of adults had a range of physical difficulties. Figure 2.3 summarizes the percentage of adults with various physical limitations. In 2023, the CDC reported that 12.1% of the adult population had mobility problems (Courtney-Long et al., 2015). In 2010, 3.6 million adults, or 1.5% of the population, used a wheelchair and 11.6 million, or 4.8%, used a walker (Brault, 2012). Not all of these individuals would be classified as having extensive support needs.

FIGURE 2.3 ■ Age-Adjusted Percentages of Difficulties in Physical Functioning in Adults Aged 18 and Older



Source: Adapted from Summary Health Statistics: National Health Interview Survey, 2018, by U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics.

Etiology of Physical Disabilities

Physical disabilities can be caused by a myriad of factors, depending on the type of impairment. These include

- neurological disorders, which is the cause of cerebral palsy,
- congenital condition when the vertebral column does not close properly resulting in spina bifida,
- amputations, congenital and later-onset, and
- accidents resulting in spinal cord injuries

Regarding spinal cord injuries, the most frequent cause is motor vehicle accidents and serious fall. Other causes include acts of violence, sports injuries, medical or surgical injuries, industrial or workplace accidents, diseases, and conditions that damage the spinal cord (National Institute of Neurological Disorders and Stroke, 2025). Characteristics of Physical Disabilities

Individuals with physical disabilities display numerous characteristicsagain, depending on the type of disability. Many physical disabilities are classified as mild while others result in the need for extensive support services because they impact one or more functional capacities. Areas likely impacted by physical disability include mobility, self-care, independent living, and work skills. While the exact nature of physical disability can be varied, the federal definition of severe disabilities includes amputations, arthritis, cerebral palsy, multiple sclerosis, muscular dystrophy, and spinal cord injuries as examples of physical impairments resulting in extensive support needs.

Characteristics of individuals with physical impairments vary, depending on the specific nature of the disability. Children and adults with cerebral palsy may have difficulties with walking, swallowing, talking, breathing, or using their hands to grasp objects. Individuals with spina bifida may experience lower limb paralysis and incontinence. Traumatic brain injury can result in memory problems, emotional issues, and vision problems (Smith et al., 2020).

Assessment and Identification of Physical Disabilities

The assessment and identification of physical impairments is likely made by medical professionals, occupational therapists, and physical therapists and includes a variety of medical and physical examinations. Table 2.2 provides a description of some of the more common physical disabilities that could result in the need for extensive supports. The impact of each of these

TABLE 2.2 ■ Descriptions of Various Physical Disabilities and Functional Impact

Specific Impairment	Characteristics	Etiology	Functional Impact
Amputation	Partial or total absence of an arm or leg	Unknown birth defect; accident; vascular disease	Mobility, work, independent living
Arthritis	Pain in joints	Inflammation	Mobility, work
Cerebral palsy	A disorder of movement or posture	Brain injury either pre- or postnatal	Mobility, work, communication, independent living
Multiple sclerosis	Inflammatory disease attaching central nervous system	Unknown; believed to be genetic	Mobility, work, communication, independent living
Muscular dystrophy	Group of muscle diseases resulting in muscular dystrophy	Genetic	Mobility, work, communication, independent living
Spinal bifida	Congenital neural tube defect	Unknown	Mobility, work, independent living
Spinal cord injury	Physical damage to spinal cord resulting in degrees of muscle functioning loss	Accidents, disease	Mobility, work, independent living

disabilities varies greatly. For example, an individual might have mild cerebral palsy that minimally impacts functional areas, or it could be severe, resulting in substantial limitations in a number of areas including communication and mobility.

Adult Outcomes for Individuals with Physical Disabilities

Krause (1992) completed a study of adults with paraplegia and quadriplegia and found the following:

- The study sample had a mean of 14.2 years of education.
- 48% were working at the time of the accident leaving them with the physical disability.
- 12% of those working at the time of the accident returned to the same job.
- Individuals with paraplegia were more likely to return to their original jobs than those with quadriplegia.
- Younger individuals had higher employment rates than older persons.
- 95% of all participants who were at least 21 at the age of injury worked some after their injury.

MEDICAL CONDITIONS RESULTING IN EXTENSIVE SUPPORT NEEDS

A variety of **medical conditions** can result in extensive support needs. These medical conditions may be the primary cause resulting in support needs or may be present with other disabilities that result in needing extensive supports. For example, individuals with cerebral palsy may experience a higher than normal rate of seizures, and children with spina bifida may also develop hydrocephalus, which results in fluid buildup in the brain. The federal definition of severe disabilities includes some specific medical issues, including cancer, cystic fibrosis, heart disease, hemiplegia, hemophilia, respiratory or pulmonary dysfunction, neurological disorders (including stroke and epilepsy), sickle cell anemia, and specific end-stage renal disease. These are only listed as examples; any medical condition that results in a substantial limitation of a functional activity could result in an individual having extensive support needs. Medical conditions concomitant with other disabilities can also result in needing extensive supports.

For individuals with medical conditions that result in extensive support needs, educators and adult service providers play a role of supporting medical interventions. While school nurses are often present to manage many of these needs, educators and adult service workers need to understand basic health care supports and interventions, including seizure management, clean intermittent catheterization, monitoring for problems with shunts, awareness of too much or too little insulin for students with diabetes, and G-tube feeding.

FINAL THOUGHTS ON DISABILITIES REQUIRING EXTENSIVE SUPPORTS

Disabilities are generally thought of as specific conditions that limit an individual in numerous ways, including sensorily, cognitively, physically, and emotionally. These include categories such as intellectual disability, autism spectrum disorder, and sensory disorders. The term or category of e*xtensive support needs* implies functionality, not a specific category of disabilities.

All of the definitions of specific disabilities described in this chapter focus on one type of disability. Individuals can have many disabilities that result in mild or minimal impact on daily activities. For example, a person can have an intellectual disability, autism spectrum disorder, physical disabilities, or mental challenges and still experience a high quality of life without extensive or lifelong supports. This is not saying that the experience of having a disability does not impact the individual, but the impact it has on day-to-day functioning can be minimized with minimal supports. Individuals whose daily lives are impacted to the degree that extensive and often lifelong supports are needed in order to achieve an acceptable quality of life require a different support system. These are individuals who simply cannot function without a high level of support.

Preparing adults with extensive support needs for a successful quality of life begins early in a child's education. School personnel and families must ensure that young children with extensive support needs are active participants in the school community and have the necessary supports to minimize the impact of the disability (Horn & Kang, 2014). It is never too early to begin transition planning by taking a future-based perspective on services needed. The end goal for all educational programs for all students, including students with extensive support needs, is to facilitate the successful independence of these individuals as adults. Keeping this at the forefront of planning during the elementary and secondary school years can assist individuals with extensive support needs to become as independent as possible and enjoy a high quality of life.

Final Thoughts on Caitlin

It appears from the opening vignette that Caitlin is experiencing a high quality of life as a young adult with Down syndrome. She lives semi-independently, has a job, enjoys friends, and even has a boyfriend with a possibility of getting married in the future. Caitlin was diagnosed with Down syndrome when she was 1 week old, and her parents were engaged in preschool and school-age educational programs for her entire childhood. They have also supported her involvement in the community as an adult and continue to be her strong advocates.

Although diagnosed with an intellectual disability, Caitlin has persevered to become an independent adult. Had her parents and school personnel allowed the diagnosis of intellectual disability to determine her life trajectory, she may not have been able to enjoy the opportunities in school and as an adult that have resulted in her current high quality of life. While labels can be helpful in understanding an individual, too much emphasis on them can result in lowered expectations or self-fulfilling prophecy. The term *extensive support needs* should not result in an automatic response of low expectations; it simply implies that the individual will need extensive supports, and when those supports are provided, the individual can achieve a high quality of life.

SUMMARY

Understanding the Concept of Extensive Support Needs

- Most individuals with disabilities have mild disabilities.
- There are several definitions of severe disabilities, which primarily focus on the impact of a disability on major life activities, such as language, mobility, and learning.

- IDEA does not define severe disabilities or individual with extensive support needs.
- Up to 1% of students can take alternate assessments.
- An individual is determined to have extensive support needs based on the impact of a disability, not a specific disability category.
- Determining an individual has extensive support needs is a professional judgment.

Autism Spectrum Disorder

- Autism spectrum disorder is a relatively new disability, first identified in 1943.
- The DSM collapsed several specific disabilities, including autism and Asperger's syndrome, into the diagnostic category of autism spectrum disorder.
- Autism spectrum disorder is characterized by persistent deficits in social interactions, communication, and restricted patterns of behavior, interests, or activities.
- The prevalence of autism spectrum disorder has increased exponentially over the past 20 years.
- Most individuals with autism spectrum disorder exhibit mild disabilities while a smaller percentage are classified as having extensive support needs.
- Adults with autism spectrum disorder may have extreme difficulties in the areas of independent living, employment, and social interactions.

Intellectual Disabilities

- Previously, the term mental retardation was used to describe individuals currently identified as having intellectual disabilities.
- The AAIDD and APA are the primary sources for defining intellectual disabilities.
- Definitions of intellectual disabilities include three componentsintellectual functioning, adaptive behavior, and developmental period.
- Most individuals with intellectual disabilities are classified as having mild disabilities.
- Adults with severe intellectual disabilities experience major difficulties in independence, employment, and social interactions.

Multiple Disabilities

- The term multiple disabilities applies to individuals who exhibit more than one specific disability.
- The presence of more than one disability exacerbates characteristics of only one disability.
- The causes and characteristics of individuals with multiple disabilities are dependent on the specific disabilities exhibited.
- Adults with multiple disabilities experience major difficulties in independence, employment, and social interactions.

Emotional/Behavioral Disorders and Serious Mental Health Issues

- IDEA includes serious emotional disturbance as a category but not serious mental health issues; the APA describes different mental health issues but does not include a category called serious emotional disturbance.

- Different labels and different definitions create confusion among agencies that provide services to individuals with these disorders.
- Vague definitions and subjective assessment procedures result in wide differences in estimated prevalence rates.
- While the majority of individuals with mental health problems experience mild disabilities, approximately 5.2% of adults in the United States experience serious mental health issues.
- Adults with serious mental health issues experience major difficulties in independence, employment, and social interactions.

Physical Disabilities

- A broad array of physical disabilities impacts the quality of life of children and adults.
- Paraplegia, the partial or total loss of the lower extremities, and quadriplegia, the partial or total loss of all extremities, can have a strong negative impact on functional skills.
- Causes and characteristics of individuals with physical disabilities are dependent on the specific physical disability.
- Assessment and diagnosis of physical disabilities is usually made by physicians or occupational and physical therapists.

Medical Conditions Resulting in Extensive Support Needs

- Medical conditions can result in extensive support needs, or their presence with another disability can exacerbate the outcomes for that disability.
- Medical conditions resulting in extensive support needs are diagnosed by medical professionals.

REVIEW QUESTIONS

1. How does the definition of "extensive support needs" differ from definitions of specific disabilities?
2. What factors influence the quality of life of individuals with extensive support needs?
3. What influenced change in how individuals with extensive support needs are treated?
4. What are some common characteristics of individuals with extensive support needs?

CRITICAL THINKING QUESTIONS

1. What can schools do to mitigate the impact of extensive support needs?
2. When and how should schools plan for the transition of students with extensive support needs?
3. Why should individuals be classified as having mild or extensive support needs?

4. How does the presence of a disability that results in extensive support needs impact the level of services for individuals?
5. Should adults with extensive support needs live as independently as they can, or should services be centralized to provide more efficiency in their delivery?

KEY TERMS

adaptive behavior
American Association on Intellectual and Developmental Disabilities (AAIDD)
American Psychiatric Association (APA)
Asperger's syndrome
autism spectrum disorder
borderline, educable, trainable
deaf-blindness
developmental disability
Diagnostic and Statistical Manual of Mental Disorders (DSM)
emotional/behavioral disorders
emotional disturbance
etiology
idiot, moron, and imbecile
independent living
intellectual disability
IQ
IQ score
IQ tests
measles, mumps, and rubella (MMR) vaccines
medical conditions
mental health issues
mental retardation
mild, moderate, severe, and profound
mobility
multiple disabilities
orthopedic impairment
physical disabilities
supported employment