

## CHAPTER 3



# The Disabilities Context

## PURPOSE

This purpose of this chapter is to help those who work in mentoring programs serving youth with disabilities understand the following disability-related concepts and information:

1. Labels, language, and portrayal.
2. Disability definitions.
3. Accommodations and assistive technology.
4. Legislation relevant to people with disabilities.

People with disabilities face many barriers and, like many minority groups, have fought for equal access “to education, to employment, to public facilities and services, to transportation, to housing, and to other resources needed to more fully realize their rights as citizens” (Tan, 1995, n.p.).

The major barriers to achievement by people with disabilities in our society, however, continue to be attitudinal barriers, stereotypical thinking, and assumptions about what people can and cannot do. Stereotypes flagrantly and incorrectly limit the range of an individual’s ability. The truth is that the range of abilities of persons within any disability group is enormous.

Attitudinal barriers are ideas, fears, and assumptions that impede meaningful communication between people with and without disabilities and prevent people with disabilities from participating fully in society. Most attitudinal barriers are passively learned; unlearning them takes effort and interaction (Miller, n.d., ch. 3).

## LABELS, LANGUAGE, AND PORTRAYAL

Labels and language have long reflected society’s views of disabilities as abnormal. Although this is changing, some people and institutions continue to focus on individuals’ disabilities rather than their abilities and by doing so foster segregation. In the media, people with disabilities have been portrayed as “broken” and treated with pity, scorn, sorrow, or anger. Or, on the other hand, they have been treated as though they had superpowers. Labels have often been

used to define a person’s potential and value .... When we hear a person’s label, we (mistakenly) think we know something important about him, and we give great weight to the label, using it to determine how/where a person will be educated, what type of job he will/won’t have, where/how he’ll live, and more. In effect, a person’s future is

often cast by others, based on the label. (Snow, 2004.)

The notion of People First Language came about as a result of people with intellectual disabilities being offended by being referred to as “the retarded,” as if their condition was the ultimate indicator of who they were as individuals. People First Language emphasizes that people with disabilities are “people first,” rather than being defined primarily by their disability. So, instead of “the blind kid” or “Billy, the ‘retarded’ boy,” someone might speak of “the boy who is blind,” or “Billy, the student with an intellectual disability.”

Utilizing the principle of People First Language and engaging in the use of positive language allows individuals with disabilities to be seen for their own potential and for what they have to contribute to society. At the same time, positive language usage challenges stereotypical thinking associated with negative language, labels, and stigmas of disability. Familiarity and interaction between people with and without disabilities promotes this idea. Using People First Language is part of the larger effort of changing perceptions of people with disabilities; while it takes effort initially, it quickly becomes habit.

## THINGS YOU SHOULD KNOW WHEN WORKING WITH YOUTH WHO HAVE DISABILITIES

- Youth with disabilities are, first and foremost, youth. Like all youth, they face the complexities of adolescence and are deeply affected by people and events around them. Issues related to friendships, sexuality, family, and other relationships are profoundly important.
  - Youth with disabilities know their needs and can usually express them to others.
  - Some youth with disabilities take more time to perform certain activities. Whether an activity involves traveling somewhere, communicating through speaking or writing, performing specific work tasks, reading, or solving a problem, adults who work with youth with disabilities must understand that a youth’s time in responding does not mean that the individual is incompetent or unintelligent, lacks understanding, or is ignoring
- Some youth with disabilities take medication. Some medication may affect how they interact with others, and the effects may vary from day to day or hour to hour. Youth that are supposed to be taking medication may sometimes choose not to take it for a variety of reasons. Self-medicating (using illicit drugs or alcohol) is also common.
  - Some youth with disabilities have more than one disability. Sometimes, a disability may contribute to mental health impairment.
  - Some youth with disabilities have difficulties with testing and assessment. Youth are commonly given tests that are normed for “average” students who do not have disabilities. Students with learning disabilities, attention problems, visual impairments, or other disabilities often cannot access these materials as readily as their peers without disabilities; hence, their scores may not be valid or reliable. Doing poorly on tests is not necessarily a reflection of intelligence.

## PEOPLE FIRST LANGUAGE

People First Language is so important to me because it’s a simple principle: We’re all people, first and foremost. We have a disability; the disability does not have us. We don’t label people, we label inanimate items and jars. We’ll say a car engine is defective...or a toaster is defective. Would we say a person is ‘defective’ and try to replace it? I don’t think so. A good friend of mine uses these categories: the ‘Good, the Bad & the Ugly.’ For instance: Good: ‘He is a person with autism.’ Bad: ‘He’s autistic.’ Ugly: ‘Rain Man, etc.’ Good: ‘He has a learning disability.’ Bad: ‘He’s disabled.’ Ugly: ‘He’s slow.’ You get the picture. The person is what the focus should be on first, and the disability last, if at all; never-ever the other way around.

—J. Paul Chase,  
National Youth Leadership Network Access for All Committee

you. Although you may be able to perform a task for a youth with a disability more efficiently than the young person can complete it, resist the urge to help. If the young person would like your assistance, he or she will ask you for it.

## MODELS OF DISABILITY

Throughout history, different models of disability have been used to explain and sometimes justify the treatment (or mistreatment) of people with disabilities. These models were and are frameworks or lenses for how society views and treats people with disabilities. People with disabilities have been viewed as deserving of pity, helpless, and in need of care. Or, sometimes they are seen as “supercrips” — people who are inspirational and super human, achieving the incredible in spite of their disability. These portrayals are perpetuated in the media and pop culture of the time. As times and attitudes have changed, so has the model of disability depicted in the media and accepted in society. With the rise of the Disability Rights movement and the passage of the Americans with Disabilities Act, the perception of disability has shifted from one in which a disability is equated with sinfulness, or where an individual with a disability needs to be “fixed,” to one that includes disability as a part of diversity. As a result, there has been an additional push for society, mainstream culture, and government to ensure the full participation of people with disabilities in everyday life.

As young people with disabilities are developing and struggling with issues of self-esteem, disability disclosure, body image, and other personal issues, it is important for them to understand the perceptions society may have of them.

Table 3, following, illustrates the various models of disability, defines them, and gives examples cited from the media, society, and pop culture. Be aware that although society is moving toward an inclusive view of disability, old views are slow to disappear. On any given day, a youth with a disability may encounter people who perceive him or her through any of the various models below.

For additional information on the shift in disability policy, please refer to *Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy* by Robert Silverstein and the Center for the Study and Advancement of Disability Policy, 85 IOWA L. REV. 1691 (2000). For a more in-depth history of the Disability Rights Movement and Disability Culture, mentors may want to read *No Pity: People with Disabilities Forging a New Civil Rights Movement* by Joseph Shapiro (Three Rivers Press, 1994).

## DISABILITY DEFINITIONS

Many public school students with disabilities receive special education services funded through the Individuals with Disabilities Education Act (IDEA) by the U.S. Department of Education, as amended by the Individuals with Disabilities Education Improvement Act of 2004, Public Law 108-446 (IDEA). As youth prepare to transition to adulthood, additional services may be accessed through an array of federally supported programs such as Vocational Rehabilitation (VR) services, the Workforce Investment Act (WIA), the Developmental Disabilities Assistance and Bill of Rights of 2000 (DD) and Social Security’s Supplemental Security Income (SSI) programs. Each state has offices and staff that provide services to promote employment and independent living for youth and adults who have disabilities. More specific information about each of these federal resources can be found at the end of this chapter.

Eligibility for any of these services may depend on whether or not an individual has been determined to have a disability. Each program above has somewhat different eligibility criteria, and an individual who may qualify for one service or resource may not qualify for another. Because program criteria can be complicated and confusing, parents and youth must be prepared to spend time learning about the particulars of various programs and services that will best meet their needs.

This Guide is intended to familiarize the reader with descriptions and characteristics of common disabilities that older youth may have. It is divided into two sections. The first lists those categories listed in IDEA that define disabilities that determine eligibility for services in public schools. The second describes hidden or non-apparent disabilities: conditions that may or may not be identified, yet can profoundly affect the life of an individual. Neither of the two lists nor any other resource can serve as an adequate substitute for talking to young people with disabilities about their disabilities. As mentioned earlier, many youth with disabilities know their needs and in many cases have had to communicate them for most of their lives. Because of this experience, many young people with disabilities have as much expertise in the area (if not even more knowledge) than the professionals who work with them.

**TABLE III: MODELS OF DISABILITY IN OUR CULTURE**

MODEL	DEFINITION	EXAMPLE(S)
<b>Moral Model</b>	People with disabilities are afflicted by the devil, or their disability is the result of a sin or punishment for wrongdoing by them or their family. In other words, the “external” disability represents a spiritual or internal “defect.”	<ul style="list-style-type: none"> <li>• Captain Hook (<i>Peter Pan</i>)</li> <li>• Quasimodo (<i>The Hunchback of Notre Dame</i>)</li> <li>• Dr. Claw (<i>Inspector Gadget</i>)</li> <li>• King Richard III (<i>Shakespeare’s Richard III</i>)</li> </ul>
<b>Medical Model</b>	People with disabilities are broken and need to be fixed. For example, people who were unable to walk were often forced to wear heavy braces or undergo experiments and radical treatments to make them “whole” or “normal” again.	<ul style="list-style-type: none"> <li>• <i>One Flew Over the Cuckoo’s Nest</i></li> </ul>
<b>Charity Model</b>	People with disabilities are tragic and deserve pity and protection from the demands of society. The term “handicap” came from the image of a person with a disability during the Industrial Revolution, who had a “cap in hand” to beg in the streets.	<ul style="list-style-type: none"> <li>• Laura in <i>The Glass Menagerie</i></li> <li>• <i>Pollyanna</i></li> <li>• Tiny Tim from <i>A Christmas Carol</i></li> <li>• Oompa Loompas from <i>Charlie and the Chocolate Factory</i></li> </ul>
<b>Social/Civil Rights Model (1980-1990s)</b>	Under this model, systems, laws, policies, environments, and relationships that continue to keep people with disabilities isolated from society all need to change. This model promotes “inclusion,” “full participation,” “self-sufficiency,” and “independent living.”	<ul style="list-style-type: none"> <li>• David Rappaport in <i>The Wizard</i> (1980s television show)</li> <li>• Daniel Day Lewis in <i>My Left Foot</i></li> <li>• Paul Wellstone</li> <li>• Ed Roberts</li> </ul>
<b>Cultural Minority Model (1990s-present)</b>	People with disabilities join together and form a separate cultural group similar to those that arise from ethnicity, race, or religion. The cultural minority model emphasizes the need to appreciate the differences that come out of being a person with a disability, as one would appreciate differences in ethnicity, race, or religion. Out of this model came the assertion that people should embrace the idea of a “disability culture” and be “Disabled and Proud!”	<ul style="list-style-type: none"> <li>• Linda from <i>Sesame Street</i></li> <li>• Actor Mitch Longley from <i>Las Vegas</i></li> <li>• Actor Robert David Hall from <i>CSI</i></li> <li>• Christopher Snow, a character in Dean Koontz’s novels</li> </ul>

Film references used in the above table come from <<http://www.disabilityfilms.co.uk>>.

## IDEA Disability Categories

- 1. Autism:** A developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, which adversely affects [an individual's] educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if [an individual's] educational performance is adversely affected primarily because the child has a serious emotional disturbance as defined below.
- 2. Deafness:** A hearing impairment so severe that the [individual] cannot understand what is being said even with a hearing aid.
- 3. Deaf-blindness:** A combination of hearing and visual impairments causing such severe communication, developmental, and educational problems that the [individual] cannot be accommodated in either a program specifically for the deaf or a program specifically for the blind.
- 4. Hearing impairment:** An impairment in hearing, whether permanent or fluctuating, that adversely affects [an individual's] educational performance but that is not included under the definition of deafness as listed above.
- 5. Mental retardation:** Significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior, manifested during the developmental period, which adversely affects [an individual's] educational performance.
- 6. Multiple disabilities:** A combination of impairments that causes such severe educational problems that the [individual] cannot be accommodated in a special education program solely for one of the impairments. The term does not include deaf-blindness.
- 7. Orthopedic impairment:** A severe orthopedic impairment that adversely affects educational performance. The term includes impairments such as amputation, absence of a limb, cerebral palsy, poliomyelitis, and bone tuberculosis.
- 8. Other health impairment:** A condition of limited strength, vitality, or alertness due to chronic or acute health problems such as a heart condition, rheumatic fever, asthma, hemophilia, and leukemia, which adversely affects educational performance.
- 9. Emotional Disturbance (also known as Serious Emotional Disturbance [SED]):** A condition characterized by one or more of the following, displayed over a long period of time and to a marked degree, that adversely affects [an individual's] educational performance:
  - An inability to learn that cannot be explained by intellectual, sensory, or health factors.
  - An inability to build or maintain satisfactory interpersonal relationships with peers or teachers.
  - Inappropriate types of behavior or feelings under normal circumstances.
  - A general pervasive mood of unhappiness or depression.
  - A tendency to develop physical symptoms or fears associated with personal or school problems.
  - SED includes schizophrenia, but does not include students who are socially maladjusted, unless they have a serious emotional disturbance. (See below for more information.)
- 10. Specific Learning Disability (SLD):** A disorder in one or more of the basic psychological processes involved in understanding or using language, spoken or written, that may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. This term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. This term does not include [individuals] who have learning problems that are primarily the result of visual, hearing, or motor disabilities; mental retardation; or environmental, cultural, or economic disadvantage. (See below for more information.)
- 11. Speech or language impairment:** A communication disorder such as stuttering, impaired articulation, language impairment, or a voice impairment that adversely affects [an individual's] educational performance.

12. **Traumatic Brain Injury (TBI):** An acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects [an individual's] educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma. (See below for more information.)

13. **Visual impairment, including blindness:** An impairment in vision that, even with correction, adversely affects [an individual's] educational performance. The term includes both partial sight and blindness.

In most states, eligibility for special education services continues to age 21, but services will cease if the youth graduates or otherwise leaves the public school system. Beginning around age 16, individuals may seek to include services through VR or WIA to assist with issues related to employment, job training, or postsecondary education.

## HIDDEN OR NON-APPARENT DISABILITIES

Up to 75% of youth with disabilities have what are called hidden or non-apparent disabilities. These include mental health or emotional disorders; specific learning disabilities; attention deficit hyperactivity and attention deficit disorders; acquired and traumatic brain injuries; and other chronic health conditions. Hidden disabilities are not readily apparent when observing a young person; in fact, many of these conditions have not been diagnosed or have not been recognized or acknowledged by the individual or his or her parents.

Unfortunately, the frustrations and functional limitations caused by hidden disabilities can lead to harmful, unsafe, or illegal behavior. Unemployment or underemployment, teen pregnancy, drug or alcohol

abuse, and involvement with the juvenile or adult justice system are common outcomes for youth with hidden disabilities. Diagnosing or treating the disability is usually necessary to optimize educational and vocational outcomes.

Because so many youth with disabilities have learning disabilities, mental health disorders, or other hidden disabilities, it is important for workforce development programs, including mentoring programs, to learn how to serve these individuals effectively. Teachers, WIA staff, and vocational rehabilitation counselors can provide assistance and specific resources to help this population. What follows are general descriptions of hidden disabilities that can guide the work of youth service practitioners.

## MENTAL HEALTH OR EMOTIONAL DISORDERS

The most common mental health problems faced by youth involve depression, anxiety, and maladaptive behaviors. Other more serious mental health problems, such as schizophrenia, psychosis, and bi-polar disorder, are less common but may be present in youth who would clearly benefit from mentoring services and exposure to career preparation activities.

**Depressive Disorders:** Young people with clinical depression (defined as depression lasting more than a few weeks) often have multiple symptoms, including a depressed mood or irritability, difficulty enjoying normally pleasurable activities, overeating or lack of appetite, difficulty sleeping at night or wanting to sleep during the daytime, low energy, physical slowness or agitation, low self-esteem, difficulty concentrating, and recurrent thoughts of death or suicide. Like many mental health problems, untreated depression can make education or career planning difficult. Fortunately, depression is one of the most treatable of all medical illnesses.

**Anxiety Disorders:** There are a number of anxiety disorders that interfere with school performance or attendance and with job training or work. Generalized Anxiety Disorder (GAD) is characterized by six months or more of chronic, exaggerated worry and tension that is unfounded or much more severe than the normal anxiety most people experience. People

with GAD are often pessimistic and worry excessively even though there may be no specific signs of trouble. These anxieties may translate into physical symptoms including insomnia, eating problems, and headaches. Young people with GAD may have social anxieties about speaking in public or working in public areas.

**Conduct Disorders:** Conduct disorders are a complicated group of behavioral and emotional problems in youth manifested by a difficulty following rules and behaving in a socially acceptable way.

Youth with conduct disorders may exhibit some of the following behaviors: aggression to people and animals, destruction of property, deceitfulness, lying, stealing, or other serious violations of rules. They are often viewed by other youth, adults, and social agencies as bad or delinquent, rather than mentally ill.

Many youth with conduct disorders have other conditions affecting mental health, and self-medication (through illicit drugs and alcohol) is common. Early and comprehensive treatment is usually necessary to avoid ongoing problems that impede academic growth or vocational planning. Without treatment, many youngsters with conduct disorder are unable to adapt to the demands of adulthood and continue to have problems with relationships and holding a job. They often break laws or behave in an antisocial manner.

**Chemical Dependency:** Although not always considered a disability, chemical dependency is relatively common among youth with hidden disabilities, and can cause serious problems. Chemical dependency is defined as “the continued use of alcohol or drugs which causes disturbance in important areas of functioning where use continues despite adverse consequences” (Mental Health Association of Central Virginia, n.d.). This term includes alcoholism, drug dependency, or both. Youth who use alcohol or drugs while undergoing assessment often end up with poor or invalid results.

## SPECIFIC LEARNING DISABILITIES

Specific Learning Disabilities (SLD) affect an individual’s ability to interpret what he or she sees and hears or to link information from different parts of the brain. These differences can show up as specific

difficulties with spoken and written language, coordination, self-control, or attention. SLDs may include developmental speech and language disorders, academic skills disorders, motor skill disorders, and other specific developmental disorders. It is important to note that not all learning problems are necessarily SLDs; some youth simply take longer in developing certain skills.

Such difficulties may impact a youth’s ability to learn to read, write, or do math. In some individuals, many overlapping learning disabilities may be present. Others may have a single, isolated learning problem that has little impact on other areas of their lives. *It is important to note that having an SLD does not indicate deficits in intelligence. Many people with SLDs have very high IQs.*

SLD is a broad term that covers a pool of possible causes, symptoms, treatments, and outcomes. Partly because learning disabilities can show up in so many forms, it is difficult to diagnose or to pinpoint the causes.

## Helping Young People with Specific Learning Disabilities

Because SLDs are often hidden, screening, testing, and identifying youth with SLDs takes insight and persistence. Collaborating with professionals who specialize in SLDs is valuable. The collaboration should include a process for youth service practitioners to screen for possible SLDs that may lead to referral for further services. Specialists may include psychologists and others who are licensed to make disability determinations. Keep in mind that all persons with SLDs can learn; efforts must be made to find methods of teaching that work for each individual.

## OTHER HIDDEN DISABILITIES

**Attention Deficit/Hyperactivity and Attention Deficit Disorder:** Attention Deficit/Hyperactivity Disorder (AD/HD) refers to a family of related chronic neurobiological disorders that interfere with an individual’s capacity to regulate activity level (hyperactivity), inhibit behavior (impulsivity), and attend to tasks (inattention) in developmentally appropriate ways. The core symptoms of AD/HD

include an inability to sustain attention and concentration, and developmentally inappropriate levels of activity, distractibility, and impulsivity.

Attention Deficit Disorder (ADD) is another type of attention deficit, minus the hyperactivity component. Generally, individuals with ADD may experience problems paying attention to details, staying focused, and organizing and finishing tasks.

**Acquired and Traumatic Brain Injuries (TBI):**

The Brain Injury Association distinguishes between acquired and traumatic brain injuries. A traumatic brain injury is an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force. Long-term effects of brain injuries, depending upon severity, can include mild, moderate, or severe impairments in one or more areas, including cognition; speech-language communication; memory; attention and concentration; reasoning; abstract thinking; physical function; psychosocial behavior; and information processing.

**Chronic health conditions:** Many youth have chronic health problems that may not be considered disabilities per se but can still have an immense impact on an individual’s life. Professionals and volunteers who work with youth should be aware of diseases like diabetes, asthma, epilepsy, or AIDS and how they can affect an individual’s day to day life.

**ACCOMMODATIONS AND ASSISTIVE TECHNOLOGIES**

**Providing Accommodations** Accommodations are modifications or alterations made to a classroom, a workplace, or another environment that allow access to people with disabilities. Accommodations should be individualized and may include, for example,

allowing a student with a learning disability extra time to complete an assignment or a test,

providing amplification equipment for a student with a hearing impairment in a classroom, or providing a special keyboard in a workplace for someone with dexterity problems. Federal laws require that accommodations be provided to people with disabilities who need them in the classroom, at work sites, and in most public places. (Timmons, Podmostko, Bremer, Lavin, & Wills, 2004, chap. 2, pg. 9)

TABLE IV: COMMON ACCOMMODATIONS IN CLASSROOMS, ASSESSMENT SETTINGS, AND WORKPLACES	
<b>Presentation Accommodations</b>	Information read aloud
	Sign language
	Braille
	Large print
	Directions clarified
	Assistance from another person
<b>Presentation Equipment Accommodations</b>	Magnification
	Amplification
	Noise buffer
	Templates
	Audio/video cassettes
	Lighting/acoustics
	Computer or other machinery
<b>Response Accommodations</b>	Communication device (symbol boards, talking boards)
	Computer or other machinery
	Spell checker
	Braille
	Tape recorder
	Calculator
<b>Scheduling Accommodations</b>	Extended time
	Extra breaks
	Multiple sessions
	Time beneficial to individual (such as around medication schedule)
<b>Setting Accommodations</b>	Number (individual may work better alone or in small groups)
	Place (individual may work better at home or at an off-site setting)
	Proximity (individual may need to be closer to instructor, black-board, restrooms, etc.)
<i>Adapted from Thurlow, House, Boys, Scott, and Ysseldyke (2000).</i>	

There are federal laws that address the legal aspects of accommodations; these include the Americans with Disabilities Act, IDEA, Section 188 of the Workforce Investment Act, and Section 504 of the Rehabilitation Act. Within many communities, teachers and rehabilitation professionals have expertise in developing accommodations for individuals with disabilities, and all states have assistive technology centers (discussed below).

The Job Accommodation Network (JAN) is a service of the Office of Disability Employment Policy (ODEP) of the U.S. Department of Labor. JAN's mission is to facilitate the employment and retention of workers with disabilities by providing employers, employment providers, people with disabilities, their family members, and other interested parties with information on job accommodations, self-employment, and small business opportunities and related subjects. JAN represents the most comprehensive resource for job accommodations available. For more information, refer to (<http://www.jan.wvu.edu>).

## ASSISTIVE TECHNOLOGY

Assistive technology is a specific type of accommodation. As defined by the Assistive Technology Act of 2004, assistive technology refers to “any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities.” The range of support can include computer screen readers and magnifiers, closed captioning, alternative keyboards, and other special software and equipment that makes information devices more accessible. It can also include mobility devices and other independent living equipment that is specially designed to increase an individual's ability to perform daily living or work related skills. There are dozens of non-profit and for-profit organizations that manufacture or sell assistive technology equipment and nearly all of them have web sites. Each state has an organization responsible for promoting and supporting the use of assistive technologies: a listing of state contacts can be found at <http://www.resna.org/taproject/at/statecontacts.htm>.

## FEDERAL LEGISLATION AND PEOPLE WITH DISABILITIES

Federal laws define disabilities in different ways, depending on a person's age or situation or the purpose of the particular piece of legislation. According to the Americans with Disabilities Act (1990), a person has a disability if she or he has a physical or mental impairment that substantially limits one or more of the major life activities — work, independent living, and mobility are major life activities. A specific physical or mental “skill” (like visually identifying objects or solving math problems) can be measured and compared to others and typically (sometimes arbitrarily) a person is considered to have a disability based on such a measurement.

Eligibility for certain services may be dependent on which definition of disability is used. It is clear, however, that effective and individualized education and training can go far to allow access to people with disabilities and promote independence. Moreover, individuals who cannot perform certain tasks one way may be able to perform them in another way through the right accommodations and assistive technology. In many cases, barriers preventing access to a building, a book, a program, a mode of transportation, or a piece of equipment can be easily removed. And, because 20% of the American population has some form of disability (U.S. Census Bureau, 2002), providing access, accommodations, and assistive technology is a good investment for society as a whole to make.

**Federal Law and Transition-Aged Youth** Transition is the period of time that a youth spends moving from secondary school to postsecondary school, vocational training, or the work world. During this time, youth with disabilities may be protected by or accorded services through several federal laws. The Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act of 1973, the Individuals with Disabilities Education Act (IDEA), the Vocational Rehabilitation Act (VR), and the Workforce Investment Act (WIA) are five of the most important laws passed in order to guarantee the rights of young people with disabilities to participate fully in education, work, and society in general. These federal laws have increased access, led to greater understanding of accommodations, and made assistive technology much more common.

The ADA and Section 504 are general laws designed for all people with disabilities, not just youth. Section 504 specifically prohibits discrimination on the basis of disabilities in federally funded programs. The ADA, passed in 1990, goes farther and prohibits discrimination by all public and most private entities regardless of whether they receive public funds. States and local communities have a wide range of educational and vocational programs for youth that are designed to help them become independent adults. Schools, local workforce development organizations, and state vocational rehabilitation agencies have substantial discretion in how they support transition services, so it is helpful to have an understanding of the systems that support youth with disabilities.

One important point about the information that will be discussed below is that several federal programs require that services provided to a recipient be based upon individualized plans. The initials abound — IEP (Individual Education Program), ISS (Individual Service Strategy), and IPE (Individualized Plan for Employment) are three — but they all share three common characteristics.

1. These plans dictate the commitment of an agency or organization to provide fiscal or other forms of support for a specific service.
2. The individualized plans must reflect the needs of the individual young person.
3. Each plan details allowable activities that, in whole or in part, support the Guideposts and the Youth Development and Youth Leadership Competencies (see Chapter 2).

The information contained in these plans may be useful to mentoring programs both in matching mentors and mentees and in identifying the youth's individual needs. Thus, mentoring programs need to establish linkages with the organizations responsible for developing these various plans. Doing so will allow mentoring programs to serve youth better and may additionally provide access to a potential funding stream to support the program. Information included in these plans is considered confidential and cannot be viewed by others without a signed release of information.

**IDEA and Transition.** IDEA is the basis for all special education services provided in public schools. IDEA requires that eligible youth with disabilities receive a free, appropriate public education that includes preparing them for further education, employment, and independent living. Special education is not a place. It is a set of instructional techniques and services tailored to meet the individual needs of each student eligible for services. Special education can occur in a variety of settings, and IDEA mandates that students receiving special education services should be fully integrated into the general education curriculum to the extent possible.

Specific language within IDEA makes it clear that educators, parents, and students must consider adult outcomes as they plan for students' school experiences. "Transition services" is the term used in IDEA to describe a coordinated set of activities for [an individual] with a disability. This coordinated set of activities

1. focuses on improving the academic and functional achievement of the youth with a disability to facilitate the [student's] movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;
2. is based on the individual youth's needs, taking into account the youth's strengths, preferences, and interests; and,
3. includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation.

**VR and Transition.** Vocational rehabilitation services can provide education and other training services to youth and adults with disabilities when the disabilities substantially limit life activities. Vocational rehabilitation services can also support independent living, personal assistance, the purchase of assistive technologies, and medical care — as impacted by the disability. Priority for funding services goes to individuals with the most significant disabilities, a

practice sometimes referred to as “order of selection.” Youth with disabilities who are not eligible for VR services should consider WIA services (see below).

**WIA and Transition.** WIA programs provide workforce services for youth and adults. WIA programs are coordinated statewide but provided in local areas supported by community organizations that can provide a wide variety of employment services.

WIA youth services provide year-round services for enrolled youth, and may include the following: tutoring and study skills training; dropout prevention; leadership development opportunities; community service opportunities; adult mentoring; and comprehensive guidance and counseling leading to employment outcomes that make the best use of the individual’s skills and abilities. Not all of these services need to be provided by a single agency. To prevent overlap and duplication of services, mentoring programs need to be fully informed about which WIA agency provides which type of youth service, including other mentoring activities in their local community.

**Developmental Disabilities and Transition.** Youth with developmental disabilities may be eligible for services covered by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). The DD Act established eight areas of emphasis for programs: Employment, Education, Child Care, Health, Housing, Transportation, Recreation, and Quality Assurance. The primary responsibility to provide local services is based on plans developed by State Councils on Developmental Disabilities and Protection and Advocacy Agencies. Currently, youth leadership is a high national priority and mentoring is recognized as a key component of leadership development services. There are several nationally funded projects promoting youth leadership, and local mentoring programs should contact the State Developmental Disabilities Councils to determine the best ways to collaborate with these programs.

**Social Security and Transition.** Some youth with disabilities may be eligible for services and resources from the Social Security Administration, including income supplements, work incentives, medical supports, and resources for education and training

services. There are several national demonstration programs in the latter category, some of which are specifically focused on youth.

Applying for Social Security benefits or services is an involved process and should not generally be viewed as a mentoring activity for mentoring programs. However, a mentoring program can help connect youth with others who have the relevant expertise. One possibility is holding a group activity session, possibly including parents, and inviting a Benefits Planning expert in to help young people learn about how Social Security resources can be used to promote self-sufficiency and independence. WIA-funded workforce offices, also called One-Stops, and Social Security offices can provide resources for this kind of activity. Some states also have specialized staff called Disability Program Navigators, who are experts in issues related to disability and Social Security.

In some relationships, a mentor may be able to assist an individual in exploring how to use some Social Security programs as a tool for maximizing self-sufficiency. These include the Student-Earned Income Exclusion, which supports the ability of transition-aged youth to work and keep income supplements; the Plan for Achieving Self Support (PASS), which allows a person with a disability to set aside income and resources for a specified period of time to achieve a work goal; and the Ticket to Work and Self-Sufficiency Program, designed to remove many of the barriers that previously influenced people’s decisions about going to work because of concerns over losing health care coverage. For more information about these programs, go to the Social Security Administration’s website at (<http://www.ssa.gov/work>).

**Independent Living and Transition.** Many youth and adults with disabilities will benefit from receiving services to foster independent living (IL). Title VII of the Rehabilitation Act provides support to “promote a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society.”

All states have IL centers, usually in major cities. IL centers can provide information and support to mentoring programs through their familiarity with many disability-related resources. These include education, rehabilitation, and Social Security programs; transportation; housing; assistive technology; and disability rights and responsibilities. A growing number of these centers are becoming involved in youth development and youth leadership initiatives.

*For more information contact the following organizations:*

**National Organization on Disability** at

(<http://www.nod.org>)

**Office of Disability Employment Policy** at

(<http://www.dol.gov/odep/pubs/fact/comucate.htm>)

**National Center on Workforce and Disability/Adult**

at (<http://www.onestops.info>)

**Memphis Center for Independent Living** at

(<http://www.mcil.org>)

Table V builds on the alignment between the *Guideposts* and five developmental areas (detailed in Table II on page 2-4). It includes developmental objectives that mentors can consider as they plan mentoring services for all youth, and specific considerations relevant to working with youth with disabilities. An important feature of Table V is the attention to specific mentoring objectives to meet the needs of youth with disabilities. It should be noted that no single mentoring relationship or program is expected to incorporate all activities listed. The activities listed here and elsewhere in this Guide are intended as suggestions and ideas.

**TABLE V: SUPPORT THAT MENTORS PROVIDE TO YOUTH**

	<b>Developmental Area</b>	<b>Mentors can help all youth reach these developmental objectives:</b>	<b>Mentors can help youth with disabilities with specific needs such as the following:</b>
<b>School-Based Preparatory Experiences</b>	<b>Learning</b> is based on positive basic and applied academic attitudes, skills, and behaviors.	<ul style="list-style-type: none"> <li>• Develop improved basic math, reading, and creative expression skills</li> <li>• Improve critical thinking and problem-solving skills</li> <li>• Improve self-assessment of academic skills and areas of need for further education and training</li> </ul>	<ul style="list-style-type: none"> <li>• Learning how to use their individual transition plans to drive their personal instruction, including obtaining extra supports such as tutoring, as necessary; identifying strategies and supports to continue the transition process post-schooling.</li> <li>• Accessing specific and individual learning accommodations while they are in school.</li> <li>• Developing knowledge of reasonable accommodations that they can request and control in educational settings, including assessment accommodations.</li> <li>• Identifying highly qualified transitional support staff, who may or may not be school staff.</li> </ul>
<b>Career Preparation and Work-Based Learning Experience</b>	<b>Working</b> focuses on the positive attitudes, skills, and behaviors necessary to meet expectations in jobs, careers, and vocational development.	<ul style="list-style-type: none"> <li>• Develop an understanding of the world of work</li> <li>• Identify work readiness skills</li> <li>• Identify strategies to complete educational requirements or training</li> <li>• Identify individual strengths and potential opportunities for meaningful work</li> </ul>	<ul style="list-style-type: none"> <li>• Understanding the relationships between appropriate financial and benefits planning and career choices.</li> <li>• Accessing supports and accommodations for work and community living, and learning to request, find, and secure appropriate supports and reasonable accommodations at work, at home, and in the community.</li> <li>• Learning to communicate their support and accommodation needs to prospective employers and service providers.</li> <li>• Accessing multiple opportunities to engage in work-based exploration activities such as site visits, job shadowing, internships, and community service.</li> </ul>
<b>Youth Development and Leadership</b>	<b>Thriving</b> focuses on attitudes, skills, and behaviors that are demonstrated by maintaining optimal physical and emotional well-being.	<ul style="list-style-type: none"> <li>• Demonstrate an ability to articulate personal values</li> <li>• Demonstrate a sense of responsibility to self and others</li> <li>• Demonstrate an ability to assess situations and avoid unduly risky conditions and activities</li> <li>• Demonstrate knowledge and practice of good nutrition, physical exercise, and hygiene</li> <li>• Demonstrate daily living skills</li> </ul>	<ul style="list-style-type: none"> <li>• Participating in mediation and conflict resolution training.</li> <li>• Participating in team dynamics and project management training.</li> <li>• Learning about or improving self-advocacy and conflict resolution skills to fortify leadership skills and self-esteem.</li> <li>• Learning anti-peer pressure strategies.</li> <li>• Learning how to access reliable information sources.</li> </ul>

**TABLE V: SUPPORT THAT MENTORS PROVIDE TO YOUTH**

	<b>Developmental Area</b>	<b>Mentors can help all youth reach these developmental objectives:</b>	<b>Mentors can help youth with disabilities with specific needs such as the following:</b>
<b>Youth Development and Leadership</b>	<p><b>Leading</b> is the area of development that centers on positive skills, attitudes, and behaviors around civic involvement and personal goal-setting.</p>	<ul style="list-style-type: none"> <li>• Promote youth leadership development experiences</li> <li>• Promote community volunteerism</li> <li>• Promote youth activities that encourage group participation as well as collaboration with other individuals and groups</li> </ul>	<ul style="list-style-type: none"> <li>• Participating in voter registration and voting in local, state, and federal elections.</li> <li>• Participating in town hall meetings.</li> <li>• Engaging in community volunteerism, such as organizing a park clean-up or building a playground.</li> <li>• Participating in a debate on a local social issue.</li> <li>• Training to become a peer mediator.</li> <li>• Participating in a letter-writing campaign.</li> <li>• Arranging to meet with local and state officials &amp; legislators.</li> <li>• Participating in a youth advisory committee of the city, school board, training center, or other relevant organization.</li> <li>• Participating in learning activities or courses about leadership principles and styles.</li> <li>• Engaging in activities to serve in leadership roles such as club officer, board member, team captain, or coach.</li> <li>• Identifying mentors and role models, including persons with and without disabilities.</li> <li>• Developing an understanding of disability history, culture, and disability public policy issues as well as their rights and responsibilities.</li> </ul>
<b>Connecting Activities</b>	<p><b>Connecting</b> refers to the development of positive social behaviors, skills, and attitudes.</p>	<ul style="list-style-type: none"> <li>• Demonstrate effective interpersonal skills in relating to adults and peers (e.g., conflict resolution and active listening)</li> <li>• Demonstrate a knowledge of key community resources</li> </ul>	<ul style="list-style-type: none"> <li>• Locating the appropriate assistive technologies.</li> <li>• Identifying community orientation and mobility training (e.g., accessible transportation, bus routes, housing, and health clinics).</li> <li>• Gaining exposure to post-program supports such as independent living centers and other consumer-driven community-based support service agencies.</li> <li>• Identifying personal assistance services, including attendants, readers, interpreters, or other such services.</li> <li>• Obtaining benefits-planning counseling, including information regarding the myriad of benefits available and their interrelationships, so that the youth may maximize those benefits in transitioning from public assistance to self-sufficiency.</li> <li>• Locating mentoring activities that connect youth to adult mentors.</li> <li>• Providing tutoring activities that engage youth as tutors or in being tutored.</li> <li>• Engaging in research activities that identify resources in the community to allow youth to practice conversation and investigation skills.</li> <li>• Writing letters to friends, family members, and pen pals.</li> <li>• Attending job and trade fairs to begin building a network of contacts in the youth’s career field of interest.</li> <li>• Participating in mock interviews and role-playing other workplace scenarios.</li> <li>• Providing positive peer and group activities that build camaraderie, teamwork, and a sense of belonging.</li> </ul>

## EXHIBIT 3.1: ETIQUETTE

- When introduced to a person with a disability, it is appropriate to offer to shake hands. People who have limited hand use or who wear an artificial limb can usually shake hands. (Shaking hands with the left hand is an acceptable greeting.)
- Remember that people with disabilities, like all people, are experts on themselves. They know what they like, what they do not like, and what they can and cannot do.
- If you offer assistance, wait until the offer is accepted. Then listen to or ask for instructions. Do not insist or be offended if your offer is not accepted.
- Don't be afraid to ask questions when you're unsure of what to do.
- Usually people with disabilities do not want to make the origin or details of their disability the first topic of conversation.
- Avoid asking personal questions about someone's disability. If you must ask, be sensitive and show respect.
- People with disabilities may be accompanied by a personal assistant or a sign language interpreter. Always direct your communication to the individual with a disability and not to the companion.
- Use a normal speaking tone and style. If someone needs you to speak in a louder voice, he or she will ask you to do so.
- Don't be embarrassed to use common expressions such as "I've got to run now," "See you later," or "Have you heard about" even if the person doesn't run, see, or hear well. People with disabilities use these phrases all the time.
- Be aware that many people can have disabilities that are not apparent. Just because you cannot see a disability does not mean it doesn't exist.
- Be considerate of the extra time it might take a person with a disability to get some things done.
- Give unhurried attention to a person who has difficulty speaking. Don't pretend to understand when you don't; ask the person to repeat what he or she said.
- Speak calmly, slowly, and directly to a person who has a hearing impairment. Don't shout or speak in the person's ear. Your facial expressions, gestures, and body movements help in understanding. If you're not certain that you've been understood, write your message.
- Greet a person who is visually impaired by telling the person your name and where you are. When you offer walking assistance, let the person take your arm and then tell him or her when you are approaching inclines or turning right or left.
- Avoid excessive praise when people with disabilities accomplish normal tasks. Living with a disability is an adjustment, one most people have to make at some point in their lives, and does not require exaggerated compliments.
- Avoid terms that imply that people with disabilities are overly courageous, brave, special, or superhuman.
- Respect all assistive devices (e.g., canes, wheelchairs, crutches, communication boards, service dogs, etc.) as personal property. Unless given specific and explicit permission, do not move, play with, or use them.
- Don't pet a guide or companion dog while it's working.
- Make community events available to everyone. Hold them in wheelchair accessible locations.
- When planning a meeting or other event, try to anticipate specific accommodations a person with a disability might need.
- Relax. Anyone can make mistakes. Offer an apology if you forget some courtesy. Keep a sense of humor and a willingness to communicate.

