

Chapter 1

Overview of the Special Needs Market

You know someone who has a disability. More likely, you know several people who have disabilities. Those individuals may be children or adults of any sex and race. The disabilities may be obvious or obscure to casual observation and may manifest in various ways. It is clear that a wheelchair user with leg braces has a disability, yet not apparent that a person has deafness or serious mental illness. The effects of a disability may be slight for the individual and family or devastating to all concerned, depending on the type and severity of the disability. These individuals—and their family members—often face a seemingly overwhelming forest of medical, caregiving, financial, and public benefits issues. These folks are looking for help understanding the medical and caregiving systems available and gaining access to financial and public assistance resources to help maintain an independent, secure life. In law school, we were told that the only reason a person comes to see a lawyer is because that person has a problem they need help solving. When persons with disabilities and those important persons around them learn that a lawyer has understanding and expertise in these disability-related matters, they will seek out that lawyer. They will become your clients.

DEMOGRAPHICS OF DISABILITY

The population of persons with disabilities (PWD) in the United States is large and growing.¹ According to the *2016 Disability Statistics Annual Report*, the percentage of people with disabilities in the U.S. population

¹ Outdated laws, regulations, and terminology often referred to people with disabilities as “retarded,” “insane,” “incompetent,” or the like. Today, the broad-based disability community and many states by statute use “people first” terminology such as a “person with a mental illness” or “person with cerebral palsy” to acknowledge that they are, first, people like any others, and that the disability is not their primary characteristic.

rose from 11.9 percent in 2010 to 12.6 percent in 2013, 2014, and 2015.² That survey also found that rates of disability increase with age. In the United States in 2015, less than 1.0 percent of the population under 5 years old had a disability. For those ages 5 to 17, the rate was 5.4 percent. For ages 18 to 64, the rate was 10.5 percent. For people ages 65 and older, 35.4 percent had a disability. More than half (51.1 percent) of people with disabilities were in the working ages of 18 to 64, while 41.2 percent were 65 and older. In 2015, 34.9 percent of people with disabilities in the United States ages 18 to 64 living in the community were employed compared to 76.0 percent for people without disabilities—a gap that widened steadily over the previous eight years, from 38.8 to 41.1 percentage points.³

The July 2015 Centers for Disease Control and Prevention (CDC) report entitled “Prevalence of Disability and Disability Type Among Adults—United States, 2013” states that, based on a survey, 22.2 percent of U.S. adults (53,316,677 persons) reported having a disability (including vision, mobility, self-care, and independent living).⁴ Therefore, approximately one in five adults in the United States has one or more disabilities, with mobility (13 percent) and cognition (10.6 percent) problems being the most frequently reported types. According to the CDC study, women reported a higher prevalence of any disability (24.4 percent) than did men (19.8 percent), and also reported higher prevalence of each disability type. In addition, nearly 50 percent of adults with a household income of less than \$15,000 and 40 percent of adults who did not graduate from high school had a disability compared with only 10.8 percent of adults with a household income of \$50,000 or more and 11.8 percent of college graduates. Prevalence of any disability among unemployed adults was more than twice as high as it was among those who were employed (33.5 percent versus 12.6 percent).⁵

The CDC media release that accompanied publication of the report noted that the researchers found that the highest percentages of people with disabilities are generally in Southern states, for example, Alabama

² Lewis Kraus, Lewis. (2017). *2016 Disability Statistics Annual Report* (2017), https://disability.compendium.org/sites/default/files/user-uploads/2016_AnnualReport.pdf.

³ *Id.*

⁴ Elizabeth A. Courtney-Long et al., *Prevalence of Disability and Disability Type Among Adults—United States, 2013*. *MMWR MORB MORTAL WKLY REP*, 64, 777–83 (2015).

⁵ *Id.*

(31.5 percent), Mississippi (31.4 percent), and Tennessee (31.4 percent).⁶ The report did not determine why differences occur by state, but noted that states in the South tend to have some of the higher rates of chronic diseases, such as heart disease and diabetes, which may also be associated with disability. The *2016 Disability Statistics Annual Report* found that the reported prevalence of mobility disabilities was 18 percent or higher in Alabama, Arkansas, Kentucky, Mississippi, Tennessee, and West Virginia, whereas it was lower than 10 percent in Colorado, Connecticut, Hawaii, Idaho, Minnesota, New Hampshire, and Vermont.

Although it is not clear that age, income status, sex, race, employment, or place of residence cause or contribute to the development of disabilities, it is helpful for the special needs attorney to understand the demographics of this “client market” as they relate to persons with disabilities. Such an understanding may equip the attorney to advocate (and join with clients in advocating) in support of health and policy initiatives that address those issues that more significantly affect the state or local population.

GIVE YOURSELF A DISABILITY-SPECIFIC EDUCATION

If the prospective client identifies a diagnosis that you are unfamiliar with, you would be well-served to learn something about it before the initial conference with the client. According to the Social Security Administration Supplement to the 2014 Panel of the Survey of Income and Program Participation, of the approximately 85.3 million U.S. citizens with disabilities in 2014, approximately 17.6 percent, or 55.2 million people, have a severe disability.⁷

That is a huge number of people fitting under a broad label of “disability.” Within that enormous group, there is great variation in the nature, scope, and severity of disability conditions. Of course, disabilities are not alike. They are unique in their effects on each person—as well as their effects on the family members of the person with a disability. However, there are some general characteristics of certain types of disabilities. We will call these types developmental disabilities (DD),

⁶ <https://www.cdc.gov/media/releases/2015/p0730-us-disability.html>.

⁷ Danielle M. Taylor, *Americans With Disabilities: 2014 Household Economic Studies—Current Population Reports*, P70-152 (November 2018), <https://www.census.gov/content/dam/Census/library/publications/2018/demo/p70-152.pdf>.

traumatic brain injury–related disabilities (TBI), and serious mental illness (SMI). An understanding of how and when such disabling conditions are generally acquired will enable you, and the client families you counsel, to anticipate a course of needs for the child or adult person with a disability. Once needs are anticipated, a course of solutions is easier to plot and resources are easier to put in place in advance of the need.

Developmental Disabilities

The CDC says of developmental disabilities: “Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person’s lifetime.” About one in six children in the United States has one or more developmental disabilities or other developmental delays.⁸

The CDC classifies developmental disabilities broadly as autism spectrum disorders (ASDs), cerebral palsy, intellectual disabilities, hearing loss, and vision impairment. *Intellectual disability* is characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities. Intellectual disability is sometimes referred to as a cognitive disability or mental retardation. Children with intellectual disability can and do learn new skills, but they develop more slowly than children with average intelligence and adaptive skills. There are different degrees of intellectual disability, ranging from mild to profound. A person’s level of intellectual disability can be defined by their intelligence quotient (IQ), or by the types and amount of support he or she needs.

MedlinePlus defines developmental disabilities as follows:

Developmental disabilities are severe, long-term problems. They may be physical, such as blindness. They may affect mental ability, such as learning disorders. Or the problem can be both

⁸ <https://www.cdc.gov/ncbddd/developmentaldisabilities/features/birthdefects-dd-keyfindings.html>.

physical and mental, such as Down syndrome. The problems are usually life-long, and can affect everyday living. There are many causes of developmental disabilities, including:

- Genetic or chromosome abnormalities. These cause conditions such as Down syndrome and Rett syndrome.
- Prenatal exposure to substances. Drinking alcohol when pregnant can cause fetal alcohol spectrum disorders.
- Certain viral infections during pregnancy.
- Preterm birth.

Often there is no cure, but treatment can help the symptoms. Treatments include physical, speech, and occupational therapy. Special education classes and psychological counseling can also help.⁹

In November 2017 the CDC released a finding that between 2014 and 2016, the prevalence of developmental disabilities among children ages 3 to 17 increased from 5.76 percent to 6.99 percent.¹⁰

Clients dealing with disabilities often are under significant financial strain. According to research published in 2004 by the CDC, the average lifetime cost for one person with intellectual disability was estimated to be \$1,014,000 (in 2003 dollars). Total direct costs (medical, nonmedical, special education) amounted to approximately \$12.3 billion for persons with intellectual disabilities, and indirect costs from factors such as inability to work and premature mortality accounted for a majority of total costs for persons with developmental disabilities.¹¹

A study published in the April 2007 edition of the *Archives of Pediatrics and Adolescent Medicine* estimated that the average lifetime cost for each individual with autism is \$3.2 million.¹² The \$3.2 million lifetime cost estimate includes more than \$300,000 in lifetime direct medical costs, almost \$1 million in direct nonmedical costs, and more than \$1.8 million in indirect costs, primarily in lost productivity over the lifetimes of both the parents and the individual with autism.

⁹ <https://medlineplus.gov/developmentaldisabilities.html>.

¹⁰ <https://www.disabilityscoop.com/2017/11/29/cdc-disabilities-rise/24468>.

¹¹ Centers for Disease Control and Prevention, *Economic Costs Associated with Mental Retardation, Cerebral Palsy, Hearing Loss, and Vision Impairment—United States, 2003*, MMWR MORB MORTAL WKLY REP, 53, 57–9 (2004), <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5303a4.htm>.

¹² Michael L. Ganz, *The Lifetime Distribution of the Incremental Societal Costs of Autism*, ARCHIVES PEDIATRICS ADOLESCENT MED, 161, 343–49 (2007).

In 2014, a panel of Harvard researchers published a report on the economic costs of ASDs in *Pediatrics*, the journal of the American Academy of Pediatrics.¹³ They found that “the additional costs of caring for a child with parent-reported ASD, including health care, education, ASD-related therapy, family-coordinated services, and caregiver time, totaled \$17,081 per year.” The largest chunk of additional costs was for school-based special education services—an average of \$8,610 per child per year. Next came an additional \$3,020 in annual medical costs per child with autism. According to the CDC, the total costs per year for children with Autism Spectrum Disorders in the United States in 2014 were estimated to be between \$11.5 billion and \$60.9 billion (2011 U.S. dollars), representing a variety of direct and in-direct costs, from medical care to special education to lost parental productivity. The CDC found that children and adolescents with ASD had average medical expenditures that exceeded those without ASD by \$4,110 to \$6,200 per year. On average, medical expenditures for children and adolescents with ASD were 4.1 to 6.2 times greater than for those without ASD.¹⁴ A 2012 study, funded by Autism Speaks and conducted by health services researchers David Mandell, Sc.D., of the University of Pennsylvania, and Martin Knapp, Ph.D., of the London School of Economics, estimated autism’s lifetime costs for one individual to be more than \$2.3 million for a person with ASD and intellectual disability and \$1.4 million for a person with ASD and no intellectual disability. Intellectual disabilities affect about 40 percent of those with autism.¹⁵

Just as any attorney should keep research files (whether electronic, paper, or both) of the different legal issues they encounter in their legal practices, an attorney should consider developing and maintaining research files of the different disabilities that clients have. The Internet is a powerful tool making it easy to obtain huge amounts of information on just about any topic you can think of, including disabilities. Good sources of general information about a particular disability are the CDC and PubMed Health, which is a service provided by the National Center for Biotechnology Information at the U.S. National Library of Medicine, which is part of the National Institutes of Health (NIH). Additionally,

¹³ Tara A. Lavelle et al., *Economic Burden of Childhood Autism Spectrum Disorders* PEDIATRICS, 133 e520 (2014), DOI: 10.1542/peds.2013-0763, originally published online February 10, 2014.

¹⁴ <https://www.cdc.gov/ncbddd/autism/data.html>.

¹⁵ <https://www.autismspeaks.org/press-release/new-research-finds-annual-cost-autism-has-more-tripled-126-billion-us-and-reached>.

many disabilities have local, national, and international support and advocacy groups that are also great sources of information. A word of caution about those—there are often differing views held by different organizations about causes, therapies, cures, or whether cures are desirable.

The special needs planning attorney needs to be an expert attorney, not an expert about every type of disability. That said, an attorney seeking to represent persons with disabilities or their family members will find it helpful to have a general understanding of the disability that the clients have identified before the clients arrive at your office. The following is a listing of some of the disabilities, with basic descriptions of each.

Angelman Syndrome. The Angelman Syndrome Foundation's *Facts About Angelman Syndrome*, 7th Edition (2009) states that Angelman Syndrome (AS) is a neuro-genetic disorder that is estimated to occur in one in 15,000 live births. AS is generally diagnosed between ages two and five and may be misdiagnosed as cerebral palsy or autism. Characteristics of AS include developmental delay, lack of speech, seizures, and walking and balance disorders. Individuals with Angelman Syndrome will require life-long care."¹⁶

Autism Spectrum Disorders (Autism, Asperger's Syndrome, Childhood Disintegrative Disorder, Rett's Disorder, Pervasive Development Disorder-Not Otherwise Specified [PDD-NOS]). Autism spectrum disorders (ASDs) are a group of developmental disabilities that can cause significant social, communication and behavioral challenges. There has been a dramatic increase in the diagnosis of ASDs over the past two decades. The CDC estimated in a 2012 study that one in every 68 children born in the United States has ASD, with boys being diagnosed at a rate of four to one over girls.¹⁷ However, the 2014 National Health Interview Survey of parents conducted by the National Center for Health Statistics put this number at one in every 45 children.¹⁸ According to the Autism Society of America, the prevalence of ASD in 2018 had risen to 1 in every 59 births in the

¹⁶ https://www.angelman.org/wp-content/uploads/2015/11/facts_about_as_2009_3-19-10.pdf.

¹⁷ <https://www.cdc.gov/ncbddd/autism/data.html>.

¹⁸ <https://www.autismspeaks.org/science/science-news/new-government-survey-pegs-autism-prevalence-1-45>.