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Overview: defining developmental disorders

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It was not that long ago when children with developmental disabilities and adults with a range of disorders did not exist. We never saw them in our schools, movies, or communities. President Roosevelt may have had an attack of poliomyelitis, but everyone knew he had no problem standing and walking. At least it all seemed that way.

It took a long time to find out that tens of millions of youngsters and the not so young with a vast range of disabilities were concealed out of sight in institutions or in family homes. Somehow it was disgraceful, shameful, embarrassing, and a reflection on other family members to have a relative with some type of developmental or intellectual disability—except maybe a 95-year-old great-grandmother. Only later did we find out that the press and just about everyone in Washington was involved in the cover-up to ensure that the president of the country did not appear weak during the years of the Depression and World War II.

But that was the middle and the final decades of the twentieth century. In this second decade of the twenty-first century, we have learned that there are more than half a billion people in the world who are disabled as a consequence of mental, physical, and sensory impairment (United Nations 2010). “Disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives” (World Health Organization 2008). In the United States, there are more than fifty million individuals with developmental disabilities,

complex medical problems, significant physical limitations, and a vast array of other conditions under the rubric of “disabilities” who live in local communities; many as a result of deinstitutionalization and mainstreaming them into community housing, education, and employment (U.S. Census Bureau 2010a).

The U.S. Census Bureau reported for 2006, among the total population:

- 5 years and over—6.8% had one disability. 8.3% had two or more disabilities.
- Five–15 years—536,400 had a sensory disability, almost 500,000 had a physical disability, and 2.8 million had an intellectual disability.
- Adults—37 million had a hearing disability, 21 million had a vision disability, and 15 million had a physical functioning disability. Specifically for seniors, 14.6 million had one or more disabilities (U.S. Census Bureau 2010a).

Among the non-institutionalized U.S. population 5 years and older:

- A larger number of females than males had physical, mental, and self-care disabilities—particularly in the older years, reflecting the greater longevity of females.
- A larger number of males than females had sensory disabilities (Table 1.1).

The number of persons with disabilities is projected to increase dramatically as the population 65 years and over reaches 1 in 5 residents during the next 2 decades (U.S. Census Bureau 2010b, 2010c). Media reports abound with references to the increasing numbers of older individuals with disabilities and government efforts to control the potential costs to service their mounting needs. By contrast, attention to the costs for youngsters with disabilities generally is centered on supportive education programs. Health financial issues, particularly during the years when youngsters enter adulthood, tend to be underreported.

It is estimated that the lifetime costs for all people with intellectual disabilities who were born in the United States in 2000 will total \$51.2 billion (in 2003 dollars). These costs include both direct and indirect costs. Direct medical costs, including physician visits, prescription drugs, and inpatient hospital stays, account for 14% of these costs. Direct nonmedical expenses, such as home modifications and special education, make up 10% of the costs. Indirect costs, which include the value of lost wages when a person dies early, cannot work, or is limited in the amount or type of work that can be done, make up 70% of costs. These estimates do not include expenses such as hospital outpatient visits, emergency room visits, residential care, and family out-of-pocket expenses. The actual economic costs of intellectual disabilities are, therefore, even higher (CDC 2010e). Specifically, the average per capita society lifetime cost for individuals with autism through 66 years of age is \$3.1 million (Ganz 2007).

Table 1.1 Non-institutionalized U.S. residents (in thousands) with disabilities by gender and age: 2006 (U.S. Census Bureau 2010a).

	Male	Female
Sensory disabilities:		
5–15 yrs	292	229
16–20	155	126
21–64	2,926	2,215
65–74	1,028	835
75+	1,674	2,347
Total	6,075	5,752
Physical disabilities:		
5–15 yrs	289	218
16–20	172	179
21–64	6,346	7,433
65–74	1,828	2,515
75+	2,346	4,453
Total	10,981	14,798
Mental disabilities:		
5–15 yrs	1,529	758
16–20	626	388
21–64	4,033	4,186
65–74	654	783
75+	1,053	1,915
Total	7,895	8,030
Self-care disabilities:		
5–15 yrs	240	148
16–20	89	66
21–64	1,835	2,197
65–74	455	677
75+	807	1,780
Total	3,426	4,868

TYPES OF DISORDERS

This chapter will describe the more common developmental disorders in the literature today. However, it is important to note that there are literally hundreds that exist and hundreds that are yet to be identified.

Autism spectrum disorders

Autism spectrum disorders (ASDs), also known as pervasive developmental disorders, are a group of developmental disorders defined by a significant impairment in social interaction and communication and by the presence of unusual behaviors and interests. Many individuals with ASD have

atypical ways of learning, paying attention, or reacting to different sensations and stimuli. The assessment and learning abilities of youngsters and adults with ASD can vary from gifted to severely challenged. ASDs usually are diagnosed before age 3 and last throughout a person's life. ASDs occur in all racial, ethnic, and socioeconomic groups and are 4 times more likely to occur in boys than girls (CDC 2010a). "If 4 million children are born in the United States every year, approximately 24,000 of these children will eventually be diagnosed with ASD" (CDC 2010b).

The Centers for Disease Control and Prevention (CDC) conducts two nationally representative surveys in which parents are asked whether their child has ever received a diagnosis of autism. Estimates from these studies suggest that, as of 2003–2004, autism had been diagnosed in at least three hundred thousand children aged 4–17 years (CDC 2010d). "CDC estimates 1 in 88 children in United States has been identified as having an autism spectrum disorder" (CDC 2012).

Based upon these national studies and other CDC local studies, it is estimated that up to five hundred thousand individuals between the ages of 0 and 21 years have an autism spectrum disorder (Yeargin-Allsopp et al. 2003; Bertrand et al. 2005) (Table 1.2). A CDC study found that the rate

Table 1.2 Prevalence of parent-reported autism among non-institutionalized children age 4–17 years (per 1,000 children) by selected demographic characteristics 2003–2004 (U.S. Census Bureau 2010a).

	NHIS*	NSCH*
Gender:		
Male	8.8	8.5
Female	2.4	2.3
Age (yrs):		
4–5	4.8	4.4
6–8	7.5	7.6
9–11	7.2	5.8
12–14	4.6	4.3
15–17	4.2	4.1
Race/ethnicity:		
Hispanic	2.9	3.2
White, non-Hispanic	7.0	6.2
Black, non-Hispanic	5.2	5.8
Highest level of education achieved by family member:		
≤ High school grad.	4.0	4.1
> High school grad.	6.6	6.0
Family income:		
< 200% poverty level	5.7	5.6
≥ 200% poverty level		7.1

*NHIS - National Health Interview Survey
NSCH - National Survey of Children's Health

among young children (3–10 years) was lower than the rate for intellectual disabilities but higher than the rates for cerebral palsy, hearing loss, and vision impairment.

More children are being classified as having an autism spectrum disorder, but it is unclear how much of this increase is due to changes in how one identifies and classifies people with ASDs or whether it is a true increase in prevalence (Shieve et al. 2006). By current standards, “the ASDs are the second most common serious developmental disability after mental retardation/intellectual impairment” (CDC 2010c).

The total number of children (3–22 years of age) with ASDs in a state is, to a great extent, a reflection of the variation in state populations. As of 2003, there were almost 25,000 youngsters with ASDs in California, almost 12,000 in Texas, and approximately 9,500 in New York. In addition, there were between 5,000 and more than 7,000 children with ASDs in 9 states, and between 1,000 and more than 4,000 children with ASDs in 21 states (Statemaster.com 2010).

Whether because of (1) better diagnosis, (2) a broader definition of autism, (3) a marked enlargement in the population of a particular state (e.g., Nevada), or (4) an actual increase in the numbers of individuals with ASDs, nationally between 1992 and 2003 there has been about a 2,560% increase in reported cases. These increases range from 23,300% in Ohio, 17,700% in Nevada, 16,200% in Wisconsin, 12,500% in Maryland, and 11,600% in New Hampshire, to between 1,000% and 5,000% in twenty-one states and less than 500% in eight states. There was a 1,086% increase in California (Table 1.3).

Table 1.3 Cumulative growth of autism cases in children (ages 6–22 years) by state: 1992–2003 (Statemaster.com 2010).

	% increase
Ohio	23,291
Nevada	17,720
Wisconsin	16,195
Maryland	12,529
New Hampshire	11,600
Between 1,000% and 5,000% increase (in decreasing order):	
Colorado, Arkansas, Minnesota, Illinois, Mississippi, Vermont, Nebraska, Montana, Kentucky, New Mexico, Idaho, Connecticut, Rhode Island, Alaska, Georgia, California, Oklahoma, Iowa, North Dakota, Guam, Maine, Kansas	
Between 500% and 980% increase (in decreasing order):	
Wyoming, New Jersey, Utah, South Dakota, Arizona, Pennsylvania, Missouri, Texas, Alabama, South Carolina, Florida, Oregon, Hawaii, District of Columbia, Massachusetts, Virginia, Indiana	
Between 40% and 472% increase (in decreasing order):	
Washington, Michigan, West Virginia, American Samoa, Northern Mariana Islands, North Carolina, Louisiana, Puerto Rico, Tennessee, New York, Delaware, U.S. Virgin Islands	
National average = 2,560% increase	

The number of children ages 3–22 with ASDs per 10,000 population in Oregon and Minnesota is about 4–5 times greater than the proportions in West Virginia, Montana, Oklahoma, Mississippi, New Mexico, and Colorado, as well as the Northern Mariana Islands, Puerto Rico, the U.S. Virgin Islands, and American Samoa (Statemaster.com 2010).

Types of autism spectrum disorders

1. Asperger syndrome: characterized by a greater or lesser degree of impairment in language and communication skills, as well as repetitive or restrictive patterns of thought and behavior. The most distinguishing symptom of Asperger syndrome is a child's obsessive interest in a single object or topic to the exclusion of any other. Unlike children with other types of autism, children with Asperger syndrome retain their early language skills (National Institute of Neurological Disorders and Stroke 2010c).
2. Rett syndrome: characterized by normal early development followed by loss of purposeful use of the hands, distinctive body movements, slowed brain and head growth, gait abnormalities, seizures, and intellectual disabilities. It affects females almost exclusively (National Institute of Neurological Disorders and Stroke 2010b).
3. Pervasive developmental disorder, not otherwise specified (PDD-NOS): encompasses cases where there is marked impairment of social interaction, communication, and/or stereotyped behavior patterns or interest (Yale Developmental Disabilities Clinic 2010b).
4. Childhood disintegrative disorder: a rare condition that resembles autism but only after a relatively prolonged period (usually 2–4 years) of clearly normal development. Typically language, interest in the social environment, and often toileting and self-care abilities are lost, and there may be a general loss of interest in the environment (Yale Developmental Disabilities Clinic 2010a).
5. Fragile X syndrome: a genetic condition involved in changes in part of the X chromosome. It is the most common form of inherited intellectual disability in males and a significant cause of intellectual disability in females. Fragile X syndrome is caused by a change in the FMR1 gene. A small section of the gene code (three letters only—CGG) is repeated on the fragile bottom area of the X chromosome. (The name "fragile X" was derived from the appearance of the X chromosome in a specialized tissue culture, because it looked like the end of the chromosome was broken.) The more repeats in the gene code, the more likely there is to be a problem. Normally, the FMR1 gene makes a protein needed for normal brain development. As a result of a defect in this gene, too little or none at all of the protein is produced. A male and female can both be affected, but because males have only one X chromosome, a fragile X is likely to affect them more severely (MedlinePlus 2010). Men pass the mutation only to their daughters. Their sons receive a Y chromosome, which

does not include the FMR1 gene. Fragile X syndrome occurs in approximately 1 in 4,000 males and 1 in 8,000 females (Genetics Home Reference 2010).

When the gene shuts down in people with fragile X syndrome, the result is that brain cells do not communicate normally and cause a form of hyperactive brain activity, a form common in many autism spectrum disorders. Compounds exist that dampen these effects. Studies are under way using lithium to intervene with autism and fragile X syndrome symptoms (Fraxa Research Foundation 2010).

6. Savant syndrome: not a recognized medical diagnosis. It is a rare condition in which people with developmental disorders have one or more areas of expertise, ability, or brilliance that are in contrast with the individual's overall limitations. About half of persons with savant syndrome have autistic disorder, while the others have another developmental disability, intellectual disability, brain injury, or disease. Savant syndrome is 6 times more frequent in males than females (Savant syndrome 2010).

Down syndrome

Down syndrome is a set of mental and physical symptoms that result from having an extra copy of chromosome 21 (called trisomy 21), which affects brain and body development. While individuals with Down syndrome may have some physical and mental features in common, the signs can range from mild to severe. Usually mental and physical developments are slower than in those individuals without the condition. IQs range in the mild to profound range of intellectual disability. Language and physical motor development may be delayed or slow. Common physical signs include:

- Flat face with an upward slant to the eyes, short neck, and abnormally shaped ears.
- Deep crease in the palm of the hand.
- White spots on the iris of the eye.
- Poor muscle tone, loose ligaments.
- Small hands and feet.

There are a variety of other health conditions that often are seen, including:

- Congenital heart disease—30–50% have heart defects at birth.
- Hearing loss and eye problems (mostly due to cataracts). These changes tend to occur 20–30 years before other persons in the general population.
- Intestinal problems, such as blocked small bowel or esophagus—8–12% have gastrointestinal tract abnormalities at birth.
- Celiac disease.
- Thyroid dysfunction.

- Skeletal problems.
- Dementia—similar to Alzheimer’s disease (National Institute of Child Health and Human Development 2010; National Down Syndrome Congress 2010).

Down syndrome is the most commonly inherited form of learning disability. In developed countries it accounts for 12–15% of the population with learning disabilities (Bittles & Glasson 2004). The chance of having a baby with Down syndrome increases as a woman gets older—from about 1 in 1,250 for a woman who becomes pregnant at age 25, to about 1 in 100 for a woman who becomes pregnant at age 40. But most babies with Down syndrome are born to women under 35 years because of the fact that younger women have more babies. Parents who already have a child with Down syndrome or who have abnormalities in their own chromosome 21 are also at higher risk for having a baby with Down syndrome (National Institute of Child Health and Human Development 2010). Approximately 5,000 children with Down syndrome are born each year in this country. The condition is not related to race, nationality, religion, or socio-economic status (National Down Syndrome Congress 2010). There are presently more than 350,000 people in the United States with this genetic condition (National Down Syndrome Society 2010). Advances in medical treatments have greatly improved the life expectancy of people with Down syndrome, with the majority living past age 55 (Harvard Medical School Consumer Health Information 2010).

Attention deficit hyperactivity disorder

Attention deficit hyperactivity disorder (ADHD) is a neurobehavioral developmental disorder that affects about 3–5% of the world’s population. It is thought to be caused by problems in the regulation of two neurotransmitters, dopamine and norepinephrine, which are believed to play an important role in the ability to focus and pay attention to tasks. “Genetic research strongly suggests that ADHD tends to run in families and that 55% of diagnosed adults have one or more children with ADHD” (Dodson 2008). It usually presents itself during childhood and is characterized by a persistent pattern of impulsiveness and inattention, with or without a component of hyperactivity (Attention-deficit hyperactivity disorder 2010).

In 2006, an estimated 4.5 million school-age children (5–17 years of age) had been diagnosed with ADHD and 4.6 million children with learning disorder (LD). Past estimates of the prevalence of ADHD and LD have varied, in part, because of differences in the criteria used for identifying these conditions and the variations in the population that were selected for study (Pastor & Reuben 2008). A recent national survey of special education students showed that youngsters with ADHD are a rapidly growing group of students within special education programs (Schnoes et al. 2006). Though previously regarded as a childhood diagnosis, studies have shown that

ADHD may continue through adulthood, though generally with a reduction in hyperactivity that may adversely affect day-to-day vocational, social, and family functioning (Attention-deficit hyperactivity disorder 2010). Between 10% and 60% of individuals diagnosed in childhood with ADHD continue to meet the diagnostic criteria in adulthood. As they mature, adolescents and adults with ADHD are likely to develop coping mechanisms to compensate for their impairment (Elia et al. 1999; Gentile et al. 2006; Therapeutics letter 2008).

Tic disorder

Tic disorder is a problem in which a part of the body moves repeatedly, quickly, suddenly, and uncontrollably. Tics can occur in any body part, such as the face, shoulders, hands, or legs. They can be stopped voluntarily for brief periods. Sounds that are made involuntarily (such as throat clearing) are called vocal tics. Most tics are mild and hardly noticeable. However, in some cases they are frequent and severe, and they can affect many areas of a child's life.

The most common tic disorder is called "transient tic disorder" and may affect up to 10% of children during the early school years. Teachers or others may notice the tics and wonder if the child is under stress or "nervous." Transient tics go away by themselves. Some may get worse with anxiety, tiredness, and some medications. Some tics do not go away. Tics that last 1 year or more are called "chronic tics." Chronic tics affect less than 1% of children and may be related to a special, more unusual tic disorder called Tourette's disorder.

Children with Tourette's disorder have both body and vocal tics (throat clearing). Some tics disappear by early adulthood and some continue. Children with Tourette's disorder may also have problems with attention and learning disabilities. They may act impulsively and/or develop obsessions and compulsions. Sometimes people with Tourette's disorder may blurt out obscene words, insult others, or make obscene gestures or movements. They cannot control these sounds and movements and should not be blamed for them. Punishment by parents, teasing by classmates, and scolding by teachers will not help the child to control the tics but will hurt the child's self-esteem and increase his or her distress (American Academy of Child and Adolescent Psychiatry 2010).

Dyspraxia

Dyspraxia is a neurological disorder of motor coordination usually apparent in childhood that manifests as difficulty in thinking out, planning out, and executing planned movements or tasks. Dyspraxia is a variable condition; it manifests in different ways at different ages. It may impair physical, intellectual, emotional, social, language, and/or sensory development. Dyspraxia is often subdivided into two types: developmental

dyspraxia and verbal dyspraxia. Symptoms of the dyspraxia typically appear in childhood, anywhere from infancy to adolescence, and can persist into adult years. Other disorders such as dyslexia, learning disabilities, and attention deficit disorder often co-occur in children with dyspraxia. Estimates of the prevalence of developmental coordination disorder are approximately 6% in children aged 5–11. Some reports indicate a higher prevalence in the 10–20% range. Males are 4 times more likely than females to have dyspraxia. In some cases, the disorder may be familial (Answers.com 2010b).

Cerebral palsy

Cerebral palsy refers to any one of a number of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination but don't worsen over time. Even though cerebral palsy affects muscle movement, it isn't caused by problems in the muscles or nerves. It is caused by abnormalities in parts of the brain that control muscle movements. The majority of children with cerebral palsy are born with it, although it may not be detected until months or years later. The early signs of cerebral palsy usually appear before a child reaches 3 years of age. The most common are a lack of muscle coordination when performing voluntary movements (ataxia); stiff or tight muscles and exaggerated reflexes (spasticity); walking with one foot or leg dragging; walking on the toes, a crouched gait, or a "scissored" gait; and muscle tone that is either too stiff or too flaccid. A small number of children have cerebral palsy as the result of brain damage in the first few months or years of life, brain infections such as bacterial meningitis or viral encephalitis, or head injury from a motor vehicle accident, a fall, or child abuse. It is estimated that about 764,000 children and adults in the United States have one or more of the symptoms of cerebral palsy. Currently, about 8,000 babies and infants are diagnosed with the condition each year. In addition, some 1,200–1,500 preschool-age children are recognized each year to have cerebral palsy (National Institute of Neurological Disorders and Stroke 2010; United Cerebral Palsy 2010).

Intellectual disabilities

An intellectual disability (ID) 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. ID is the most common developmental disorder. Approximately 350 million people throughout the world are affected by ID. (Intellectual disability is sometimes referred to as a cognitive disability or mental retardation.)

ID occurs in 2.5–3% of the general population. About 6–7.5 million individuals with ID live in the United States. ID begins in childhood or

adolescence before the age of 18. In most cases, it persists throughout adulthood. Specifically, a diagnosis of ID is made if an individual has an intellectual functioning level well below average and significant limitations in two or more adaptive skill areas. Intellectual functioning level is defined by standardized tests that measure the ability to reason in terms of mental age (intelligence quotient or IQ). Intellectual disability is defined as IQ score below 70–75. Adaptive skills are the skills needed for daily life. Such skills include the ability to produce and understand language (communication); home-living skills; use of community resources; health, safety, leisure, self-care, and social skills; self-direction; functional academic skills (reading, writing, and arithmetic); and work skills.

Intellectual disability varies in severity:

- Mild—approximately 85% of the population with ID is in the mild category. Their IQ score ranges from 50 to 75, and they can often acquire academic skills up to the 6th-grade level. They can become fairly self-sufficient and in some cases live independently, with community and social support.
- Moderate—about 10% of the population with ID is considered moderately retarded. These individuals have IQ scores ranging from 35 to 55. They can carry out work and self-care tasks with moderate supervision. They typically acquire communication skills in childhood and are able to live and function successfully within the community in a supervised environment such as a group home.
- Severe—about 3–4% of the population with ID is severely affected. These individuals have IQ scores of 20–40. They may master very basic self-care skills and some communication skills. Many affected individuals are able to live in a group home.
- Profound—only 1–2% of the population with ID is profoundly affected. These individuals have IQ scores under 20–25. They may be able to develop basic self-care and communication skills with appropriate support and training. Their condition is often caused by an accompanying neurological disorder. The profoundly affected need a high level of structure, supervision, and care.

It is estimated that among children 6–21 years in the United States, one-half million have some level of intellectual disability and are served in school under the Individuals with Disabilities Education Act (CDC 2010f; International Association for the Scientific Study of Intellectual Disabilities 2010; U.S. Department of Education 2010; Answers.com 2010a).

Visual, hearing, and speech disabilities

Among individuals 15 years and older, 6 million have some sight difficulties, 6.8 million have hearing difficulties, and 2.1 million have speech difficulties. The prevalence of each of these disabilities increases with age. Similarly,

Table 1.4 Prevalence of sight, hearing, and speech disabilities among individuals 15 years and older: 2005 (numbers in millions; Brault 2010).

	15 yrs+		65 yrs+	
	#	%	#	%
Sight:				
Some difficulty	6.0	2.6	2.5	7.3%
Severe	1.8	0.8	1.0	2.8
Hearing:				
Some difficulty	6.8	3.0	3.4	9.7
Severe	1.0	0.4	0.5	1.5
Speech:				
Some difficulty	2.1	0.9	0.6	1.8
Severe	0.4	0.2	0.1*	0.3

*Limitation on confidence of number.

Note: Numbers have been rounded to nearest hundred thousand.

the prevalence of severe disabilities for vision, hearing, and speech increases with age (Table 1.4).

Learning disabilities

It is believed that learning disabilities affecting 4.6 million children are caused by a difficulty with the nervous system that affects receiving, processing, or communicating information. They may also run in families. Some children with learning disabilities are also hyperactive; they are unable to sit still, easily distracted, and have a short attention span. Signs of LD may include:

- Difficulty understanding and following instructions.
- Trouble remembering what someone just told him or her.
- Fails to master reading, spelling, writing, and/or math skills.
- Difficulty distinguishing right from left; difficulty identifying words or a tendency to reverse letters, words, or numbers (e.g., confusing 25 with 52, “b” with “d,” or “on” with “no”). The “right-left complexity” is referred to as dyslexia, a language-based learning disability that results in people having difficulties with specific language skills, particularly reading.
- Lacking coordination in walking, sports, or small activities such as holding a pencil or tying a shoelace.
- Easily loses or misplaces homework, schoolbooks, or other items.
- Cannot understand the concept of time; is confused by “yesterday, today and tomorrow” (American Academy of Child and Adolescent Psychiatry 2010).

There are a variety of learning disorders. Some cause problems or difficulties with language (both written and spoken), reading, writing, math, attention, and control. Learning disabilities are not due to mental or emotional problems. Learning disabilities are also not associated with someone having less of an economic or social advantage than someone else. At least 10% of the population has one or more learning disabilities. In special education classrooms, almost 40% of the students have a learning disability. Many more are probably affected throughout the world but have not been diagnosed yet (University of Phoenix 2010).

Psychiatric disorders

There are over three hundred different psychiatric disorders listed in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV), including generalized anxiety, depression, bipolar disorder, schizophrenia, mood, sleep, and a seeming endless array of personal disorders. With continued research, more are named every year and some disorders are removed or recategorized. An estimated almost 16 million non-institutionalized U.S. residents 5 years and older have some form of mental disability (All Psych Online 2010) (Table 1.1).

Cleft lip and palate

Cleft lip and palate is the nonfusion of the body's natural structures that form before birth. One in 700 children born have a cleft lip and/or a palate. Craniofacial defects such as cleft lip and cleft palate are among the most common of all birth defects. The average annual number of cleft palate cases is 2,567; cleft lip with or without cleft palate cases is 4,209. They can occur as an isolated condition or may be one component of an inherited disease or syndrome. A cleft lip or palate can be surgically treated soon after birth. The lifetime cost of treating the children born each year with cleft lip or cleft palate is estimated to be \$697 million (National Institute of Dental and Craniofacial Research 2010).

Spina bifida

Spina bifida is among the most common permanently disabling birth defect in the United States. It occurs when the spine of a baby fails to close during the first month of pregnancy. Some vertebrae overlying the spinal cord are not fully formed and remain unfused and open. Spina bifida can be surgically closed after birth, but this does not restore normal function to the affected part of the spinal cord. If the opening is large enough, this allows a portion of the spinal cord to protrude through the opening in the bones. The incidence of spina bifida can be decreased by up to 75% when daily folic acid supplements are taken prior to conception.

The conservative estimate is that there are 166,000 living with spina bifida in the United States. The average total lifetime cost to society for each infant born with spina bifida is approximately \$532,000 per child. This estimate is only an average, and for many children the total cost may be well above \$1 million. Estimated total annual medical care and surgical costs for persons with spina bifida in the United States exceed \$200 million.

Risk factors for neural tube defects (NTDs) include:

- A previous NTD-affected pregnancy increases a woman's chance to have another NTD-affected pregnancy by approximately 20 times.
- Maternal insulin-dependent diabetes.
- Use of certain anti-seizure medication (valproic acid/Depakene, and carbamazepine/Tegretol).
- Medically diagnosed obesity.
- High temperatures in early pregnancy (i.e., prolonged fevers and hot tub use).
- Race/ethnicity NTDs are more common among white women than black women and more common among Hispanic women than non-Hispanic women.
- Lower socio-economic status (Spina Bifida Association 2010).

Fetal alcohol syndrome (fetal alcohol spectrum disorders)

Fetal alcohol spectrum disorders (FASDs) affect an estimated forty thousand infants each year in the United States—more than spina bifida, Down syndrome, and muscular dystrophy combined. Alcohol use during pregnancy is the leading known preventable cause of intellectual disability and birth defects in this country. While there is no cure for FASD, it is 100% preventable. It is believed to be the third most common cause of intellectual disability worldwide. Alcohol causes neurological damage and cell loss in the fetal brain, on which it acts as a toxin.

Defects caused by prenatal exposure to alcohol have been identified in virtually every part of the body, including brain, face, eyes, ears, heart, kidneys, and bones. Alcohol sets in motion many processes at different sites in the developing fetus just a few weeks after conception when many women are unaware that they are pregnant and/or are now aware of consequences to the embryo.

Signs of fetal alcohol syndrome may include:

- Distinctive facial features, including small eyes, an exceptionally thin upper lip, a short, upturned nose, and a smooth skin surface between the nose and upper lip.
- Heart defects.
- Deformities of joints, limbs, and fingers.
- Slow physical growth before and after birth.
- Vision difficulties or hearing problems.

- Small head circumference and brain size.
- Poor coordination.
- Sleep problems.
- Intellectual disability and delayed development.
- Learning disorders.
- Abnormal behavior, such as a short attention span, hyperactivity, poor impulse control, extreme nervousness, and anxiety.

SUMMARY

It is difficult to comprehend the full impact of individuals with disabilities on our individual communities and the efforts required by health and social service providers, educational institutions, and the families of individuals with developmental disorders when we are confronted with the facts that:

- There are more than fifty million individuals with disabilities in our nation.
- 12.8% of the adult U.S. population (21–64 years) and 40.6% of the population 65 years and over have a seemingly infinite series of disabilities.

Nationwide data actually mask the reality of the wide variations in different areas and communities of the country. For example, the proportion of the adult population (21–64 years) with a disability ranges from 9.3% in New Jersey to 22.4% in West Virginia (Henry J. Kaiser Family Foundation 2010; U.S. Census Bureau 2010d) (Table 1.5).

ABUSE AND NEGLECT OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

Since this chapter serves as an overview of the category of developmental disorders, it would not be complete without mentioning the potential pain and suffering that many of these patients may endure in their lifetimes. It is difficult for us to conceive of anyone abusing individuals who already are compromised with developmental disabilities. It seems beyond belief that the literature is replete with studies that indicate that there are substantial increases in the risk of abuse for children and adults with disabilities. We tend to mask the unspeakable when we consider the “dirty secret” of abuse and neglect of children, young adults, and the elderly. The reality, however, is that maltreatment of individuals with (and without) developmental disabilities is all too real, especially for persons with disabilities, and all too often the perpetrator may be a caregiver or family member.

Table 1.5 Percentage of adult population aged 21–64 years who reported a disability, 2007 (Kaiser Family Foundation 2010).

United States	12.8%
1. New Jersey	9.3%
2. North Dakota	10.1%
3. Illinois	10.3%
4. Minnesota	10.3%
5. Connecticut	10.4%
6. Utah	10.4%
7. Hawaii	10.7%
8. Colorado	10.8%
9. California	10.9%
10. Maryland	10.9%
11. Nebraska	10.9%
12. Virginia	11.1%
13. Nevada	11.2%
14. New Hampshire	11.3%
15. Wisconsin	11.3%
16. Massachusetts	11.4%
17. New York	11.7%
18. District of Columbia	11.8%
19. Arizona	12.0%
20. Kansas	12.0%
21. Florida	12.1%
22. Delaware	12.2%
23. Texas	12.2%
24. Iowa	12.4%
25. Idaho	12.6%
26. Georgia	12.7%
27. South Dakota	12.7%
28. Vermont	13.2%
29. Montana	13.5%
30. Indiana	13.6%
31. Wyoming	13.7%
32. Pennsylvania	13.8%
33. Oregon	13.9%
34. Washington	14.0%
35. Ohio	14.1%
36. Rhode Island	14.2%
37. Michigan	14.4%
38. New Mexico	14.5%
39. North Carolina	14.9%
40. Alaska	15.0%
41. Missouri	15.0%
42. South Carolina	15.1%
43. Louisiana	16.2%
44. Tennessee	16.8%
45. Oklahoma	17.3%

Table 1.5 (cont'd)

46. Maine	18.1%
47. Arkansas	19.0%
48. Alabama	19.3%
49. Kentucky	19.5%
50. Mississippi	19.5%
51. West Virginia	22.4%

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Numbers

Compared to the general population of children, children with disabilities are 3.4 times more likely to be abused or neglected. They are 3.8 times more likely to be neglected, 3.8 times more likely to be physically abused, 3.1 times more likely to be sexually abused, and 3.9 times more likely to be emotionally abused (Sullivan & Knutson 2000).

People with disabilities are abused sexually mostly by caregivers whether it is the family or other disability service providers; specifically, 15–25% of the perpetrators of sexual abuse are natural family members, 15% are acquaintances and neighbors, 30% are disability service providers, and 0–5% are strangers (Wolberg 1994).

Approximately one million elderly Americans are physically abused each year, where the majority of the victims are female (Brunet 2011).

Maltreatment may include:

- Physical abuse—blunt trauma, burns with cigarettes, the use of knives, guns, and/or just about any of a seemingly endless list of objects.
- Sexual abuse—including completed and attempted vaginal, oral, and anal intercourse, cunnilingus, analingus, genital fondling, digital and foreign object penetration.
- Neglect—including physical and medical neglect, abandonment, inadequate supervision, inadequate nurturing/affection, refusal or delay of psychological care.
- Emotional and verbal abuse, lack of supportive and caring environment, and alcohol addictive abuse.

Contributing factors: the individual with a disability may be regarded as a source of embarrassment, and may symbolize “punishment” for the family. The family member with a disability:

- Alters family patterns, roles and routines in particular stressful ways, which may exceed family member’s capacities and result in an abusive reaction.

- May strain housing and employment arrangements and family resources (including financial, socio-economic, and social resources), which in turn may impact on marital and general family relationships.
- May require unexpected and significant support at the time of other needs and wants of the family.
- May need services and support for an extended indeterminate period of time (Waldman et al. 1999).

Perspective of the dental team

The dentist, dental hygienist, and staff members are in a position to recognize instances of physical, emotional, and sexual abuse, failure to thrive, intentional drugging or poisoning, and health (medical and dental) and safety neglect. In the case of children (and adults with diminished intellectual ability), the health professional's legal responsibility requires that even a suspicion of abuse must be reported to the proper authorities. Failure to do so may place the practitioner in legal jeopardy for failure to ensure the safety of the abused individual.

The reality is that health practitioners will be called upon to provide needed services on an individual basis for the hundreds or thousands of individuals with developmental disorders in their communities. It is from this perspective that the following chapters are presented.

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