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## Chapter 1

### The Nature of Developmental Disabilities

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#### Learning Objectives

Readers will be able to:

1. Define developmental disabilities
2. Describe several types of developmental disabilities
3. Describe the changes in our understanding of developmental disabilities over the past 200 years

#### First, A Focus On Language:

The fact that language is powerful in shaping how we think and feel is well known. However, this is a critical fact to bear in mind when studying the history of services for persons who have what we now call developmental disabilities. If you think back to your days in elementary school, playing in the school yard at recess, you will recall people being called “retarded” by their peers in a spirit of taunting. This inappropriate and hurtful use of a clinical term is the fate that has tended to befall most terms used to describe persons who have intellectual disabilities. For this reason, and for reasons of improved accuracy, the labels used to describe people who have these chal-

lenges tend to be changed on a fairly regular basis. In the mid 20<sup>th</sup> century, terms such as “mental deficiency, feeble-mindedness, mental subnormality, mental handicap, and oligophrenia” (Scheerenberger, 1983, p. 217) were all used to label people. These labels send chills through us as we stand at the dawn of the 21<sup>st</sup> century. However, just as these terms developed negative meaning through misapplication and careless use, so it is likely the same will happen for the terms we use today. In Canada, we tend to use the term developmental disabilities; whereas, in the United States and in Europe, the term mental retardation is more common, and in the United Kingdom, the term learning disabilities is common.

Labels, regardless of what they may be, tend to change the way people interact with the person who has the label. For this reason, the Canadian Association for Community Living abandoned its former name (Canadian Association for the Mentally Retarded) in response to feedback from people with intellectual disabilities who resented the term “mental retardation” (CACL, 2000). The Association is committed to the use of inclusive language, and has identified preferred terms to include “...people who have an intellectual disability, people who have a mental handicap, and people who have a developmental disability” (CACL, 2000).

In 1982, Bogdan and Taylor wrote a powerful biography of two people who had been labeled “mentally handicapped.” One of these people, Ed Murphy, spoke eloquently about the challenges he faced: “The problem is getting labeled as being something. After that, you’re not really a person. It’s like a sty in your eye – it’s noticeable” (p. 33). Think for a moment about all the labels with which you live, and how each of those labels changes how those around you react to you. Think also about the expectations that people have of you as a result of

each label. For example, what social expectations are attached to the labels “student” or “professor”? Consider also how social expectations others have for you change as you move from being a student to being a worker. We all live with other labels as well. We may be sons or daughters, mothers or fathers, aunts or uncles, husbands or wives, friends and neighbours. Each of these labels carries with it both privileges and responsibilities that are socially determined. People who have been labeled as having a developmental disability may have many of these labels, but because of the power of language, their one label tends to override all the others, and colours the expectations and perceptions others have of them.

### **What is Developmental Disability?**

This is far from a straightforward question. The definition of developmental disability has undergone many changes, some driven by medical and other research advances, and others driven by advocacy and policy revision. As Landesman and Ramey (1989) point out, “changes in the definition reflect shifting professional consensus (usually by a select group charged with establishing diagnostic criteria), as well as fluctuating political and social agendas (e.g., limiting how many are eligible for services, avoiding over-representation of certain subpopulations, and including a new group of special needs children)” (p. 409).

While many organizations around the world address issues related to developmental disabilities, in terms of definitions, we in North America tend to look to the American Association on Mental Retardation (AAMR) for leadership. On their website (<http://www.aamr.org/Policies/faqmentalretardation.html>), AAMR identifies mental retardation as “a particular state of

functioning that begins in childhood and is characterized by limitation in both intelligence and adaptive skills.” Evidence of limitations in adaptive functioning must occur in two or more of the following: “communication, home living, community use, health and safety, leisure, self-care, social skills, self-direction, functional academics, work.” AAMR emphasizes that the definition includes the ‘fit’ between the capabilities of individuals and the structure and expectations of their environment. This contextual focus is clarified in the DSM – IV (Diagnostic and Statistical Manual– 4th Edition) where impairments in adaptive functioning are identified as “the person’s effectiveness in meeting the standards expected for his or her age by his or her cultural group” (American Psychiatric Association, 1994, p. 50).

In the United States, the Developmentally Disabled Assistance and Bill of Rights Act of 1994 (PL 104-183) offers a definition of the term **developmentally disabled**:

The term “developmental disability” means a severe, chronic disability of an individual 5 years of age or older that:

1. is attributable to a mental or physical impairment or combination of mental and physical impairment;
2. is manifested before the individual attains age 22;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in three or more of the following areas of major life activity:
  - self-care
  - receptive and expressive language
  - learning
  - mobility
  - self-direction

- capacity for independent living;  
economic self-sufficiency
5. reflects the individual's need for a combination and sequence of special, interdisciplinary, or genetic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

The CACL (2000) defines an intellectual disability as "... an impaired ability to learn. It sometimes causes difficulty in coping with the demands of daily life. It is a condition which is usually present from birth, and it is not the same as mental or psychiatric illness."

### *Intellectual Functioning*

The definition of developmental disability describes the limitations in the area of intellectual functioning of the individual. Subaverage intellectual functioning is usually translated as an IQ score below 70-75 on standardized intelligence tests. However, the central role of the intelligence test in identifying developmental disability has been reduced over the years, since research has shown that I.Q. tests have overidentified people who lived in poverty, whose parents are identified as having a developmental disability, and those who are members of certain racial and cultural minority groups (Scheerenberger, 1983). Nevertheless, the IQ is used to differentiate among levels of mental retardation.

Level of Mental Retardation	IQ Level
Mild	50-55 to approximately 70
Moderate	35-40 to 50-55
Severe	20-25 to 35-40
Profound	Below 20 or 25

(American Psychiatric Association, 1994).

### Adaptive Skills

As mentioned earlier, to be identified as having a developmental disability, a person must have identifiable deficits in adaptive functioning as well as intellectual potential. The adaptive skill areas that are assessed include:

- *Communication* includes expressive and receptive language skills as well as interpreting the “body language” of others.
- *Self-care* includes activities of daily living such as grooming, toileting, appropriate eating skills, dressing and personal hygiene.
- *Home living skills* include areas related to housekeeping, general maintenance, food preparation, shopping and home safety.
- *Social skills* include appropriate skills such as making and keeping friends, demonstrating personal restraint in public places, smiling, and showing signs of appreciation. Inappropriate skills include lewdness, obscene words or gestures, inappropriately approaching others, bawdy behaviours, and tantrums.
- *Community use* includes the appropriate use of and access to community resources such as restaurants, transportation, shopping areas, and places of worship.
- *Self-direction* refers to the ability to make appropriate life decisions related to scheduling and personal endeavors.

- *Health and safety* issues include the ability to maintain an appropriate diet, basic preservation and health issues, and following directions.
  - *Functional academics* include the basic academic information learned in school needed for the “world of work.”
  - *Leisure* includes activities such as games, sports, recreational activities and appropriate behaviors at those functions.
  - *Work* includes the skills needed to maintain a job.
- (AAMR, 1992)

### **Individual Differences**

Beyond the definitions of developmental disability that are generally accepted, as with any other diagnosis, every person who has a developmental disability is an individual with unique talents, personality, and interests. As mentioned earlier in this chapter, it is important that people who have developmental disabilities not be seen simply in terms of this one label but, rather, as people who are multifaceted. In some cases, the talents and skills exhibited by people who have developmental disabilities may be quite remarkable. For example, the phenomenon known as Savant Syndrome is evident when a person has specific skills that are at a level that is inconsistent with his/her general intellectual functioning. The presence of these special talents has been documented for more than 200 years. Evidence of Savant Syndrome includes people with developmental disabilities who have outstanding abilities in music, number derivation, arithmetic, mechanical tasks, language, art and sensory sensitivity.

Regardless of the label used to identify these special skills and talents, it is important for everyone who associates with people

who have developmental disabilities to be aware of not only their challenges, but more importantly their strengths, interests, gifts and talents.

### **Statistics**

In Canada, the CACL (2000) reports that there are 899,000 people who have been identified as having an intellectual disability. In the United States, 5.6 million children (12.43% of the general population) have a disability (U.S. Department of Education). In Britain, Mencap, “the largest charity working on behalf of people with learning disabilities and their families” (What is Mencap? [Http://www.gmp.police.uk/mencap/whatis.html](http://www.gmp.police.uk/mencap/whatis.html)) reports that 1.2 million people have been identified with learning disability.

#### **The Case of Jack**

*Jack Crane’s mother suspected that he was not developing in the way his older brother and sister had. He was slow to reach milestones such as holding his head up, rolling over and pulling himself to stand. He was a happy baby who seemed content wherever he was. Marg Crane talked to her family physician about her concerns, but after examining Jack briefly, he told her the baby was healthy, and reminded her that each child develops at his or her own rate. Marg tried to pacify herself with this reassurance, but by the time Jack was two years of age and he still had not said an intelligible word, she was very concerned. She revisited her family physician.*

*To this point, Jack’s story is not particularly unusual. It is not unusual for parents to report that they suspected their child had a developmental concern before professionals recognized the difficulty. However, the next part of the story would vary sig-*



*nificantly depending on the time period in which Jack was born. If he had been born in the 1940s, chances are that as Jack's developmental delay became more obvious, the family physician would have suggested that he be institutionalized "for his own good and that of the family." If Jack had been born in the 1960s, he would probably have stayed at home as a preschooler, and then would have been enrolled in a special, segregated school for children who had developmental disabilities. If he had been born in the 1990s, it is likely that he would have been referred to a developmental pediatrician for assessment, an infant development program for in-home parent education, and he would have attended an integrated preschool program. He would then have gone on to attend the local elementary school where he would have been enrolled in a class with other children his age, and would have participated in classes modified to meet his needs.*

*While the level of support available in community services (such as preschools and in-home consultation programs), and in school systems varies from one jurisdiction to another, there is an increasing commitment to inclusion of persons with developmental disabilities in community and school programs. Over the past half century, the evolution of services to support people who have developmental disabilities has been dramatic, as is evident from the variations in Jack's life story. As you will see from the following brief history, Jack's circumstances would have been even more challenging if he had been born in the 19th century or even earlier.*

### **A Very Brief Early History of Developmental Disabilities**

Historically, people with developmental disabilities have been protected in some civilizations, reviled, taunted, abused and rejected in others. They were protected by the powerful Egyp-

tian god Osiris in ancient times, but they faced rejection and even death in ancient Greece (Scheerenberger, 1983). In ancient Rome, unwanted children were left at Columna Lactaria where people employed by the state were assigned to rescue them. However, many of these rescued children faced a terrible fate. It was common that they would be physically mutilated to increase their potential earning power as beggars. Nevertheless, as the medical sciences developed in Rome, people such as Asclepiades of Prusa and Soranus advocated for more humane treatment of persons who had various kinds of mental disorders (Scheerenberger, 1983).

The advent of Christianity helped to stem the tide of infanticide and child slavery in Rome. Other religions and religious leaders, notably Zoroaster, Buddha, Confucius and Mohammed, also preached concern, caring and respect for all people, including those who had special needs. From ancient times to the Enlightenment (476-1799 A.D./C.E.), there was some increase in the understanding of developmental disabilities. However, religious prohibitions against medical research limited investigations that might have led to more significant developments (Scheerenberger, 1983). Despite the fact that infanticide was less common in this period than it had been in ancient Greece and Rome, thousands of children suffered from abandonment, were sold into slavery, or were left to die. There is evidence to suggest that during the Inquisition, some people with developmental disabilities were even put to death as witches. The earlier practice of mutilating children to increase their value as beggars was also revisited in the 17th century. Many died when they could no longer beg effectively, prompting Vincent de Paul to start his eleemosynary programmes. He believed that mental disease was not different from physical disease, and that Christians were called to address both needs.

The programmes Vincent de Paul started in the 17th century were the precursors to the work of the reformers, Philippe Pinel and William Tuke (Scheerenberger, 1983).

Some encouraging medical progress was made during the 17th and 18th centuries. Walter Harris suggested the importance of examining heredity, and related children's ingestion of alcohol to their reduced intellectual functioning. Also during this period, Wolfgang Hoefler provided the first detailed description of cretinism, Phillippus Jacobus Duttel published a monograph on birth defects, and Robert Whytt described hydrocephalus. In 1801, Philippe Pinel wrote his influential A Treatise on Insanity in which he attempted to differentiate between dementia and idiocy, saying that "the latter condition involved the loss of both intellect and behavior" (Pinel, 1806 in Scheerenberger, 1983, p. 40). Pinel fought for the removal of restraints from patients, and instituted moral treatment of patients, including the provision of music, conversation, books and employment opportunities. By today's standards, these concepts are not novel, but at the time they were truly revolutionary.

During the same period, in England, William Tuke also advocated for and provided humane treatment for people who had a variety of mental health and developmental difficulties. Still, the distinction between mental illness and developmental disabilities was vague. Perhaps the most significant contributions to the field of developmental disabilities during this time period were made by philosophers such as Alexander Pope, Francis Bacon, René Descartes, John Locke, and Jean Jacques Rousseau. Rousseau argued for the basic goodness of human beings, which flew in the face of earlier church teachings, and further advocated for the education of children through self-directed exploration and sensory training, ideas that had an impact on later educators including Maria Montessori

(Scheerenberger, 1983).

The 19th century was a time of enormous progress in Europe as in North America. There was a rapid expansion in medical understanding, including the identification of clinical forms of developmental disabilities. General understanding of developmental disabilities and their treatment was greatly increased during this period. The century began with the work of Jean Marc Itard who worked with Victor, the so-called “wild boy of Aveyron.” Itard worked with Victor for five years, and despite a prognosis of “irreversible mentality,” was able to teach him letter and object recognition, some sensory discrimination and social skills. Throughout the first half of the 19th century, advocacy movements in support of people who had developmental disabilities grew, along with similar movements in support of other disadvantaged groups, including people who had other kinds of disabling conditions, as well as for prisoners and slaves. Building on the work of Itard and others, Johann Jacob Guggenbuhl built a new kind of facility in Switzerland for people who had developmental disabilities. “Guggenbuhl tried to ‘awaken the souls’ of his patients through ‘habituation to regular routine, memory exercises, and speech training.’ He even introduced into the group two children of normal intelligence who ‘brought life into the institution’ ” (National Institute on Mental Retardation, 1981, p. 5). However, a cure for developmental disability was, of course, not found, and the fortunes of Guggenbuhl’s Abendberg centre declined.

Undeterred by the prevailing belief that there was little hope for remediation of people who had developmental disabilities, Edouard Onesimus Seguin made great strides working with several children at a Paris hospital. He was able to help these children to learn some writing and counting skills, to improve

their memory, and to make more effective use of their senses. The Paris Academy of Sciences declared in 1844 that he had “solved the problem of ‘idiot education’” (National Institute on Mental Retardation, 1981, p. 5). Seguin’s fame spread with his publication of a textbook on mental retardation. Political upheaval prompted him to move to the United States where in 1876, he was elected the first president of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons which later became the American Association on Mental Retardation.

### **Growth in Services for People with Developmental Disabilities in Ontario**

The 19th century view that persons with developmental disabilities were in some way a threat to society and needed custody persisted in Ontario into the 1960s (Williston, 1971). At the turn of the 20th century, as Edouard Seguin’s legacy was leaving an impact on education for people who were then described as “feeble minded” in the United States, similar work was being undertaken in Ontario under the leadership of Alexander Beaton and Helen McMurchy. The result of their work was the Special Classes Act passed in 1911 which provided for the establishment of educational classes for children who had tested IQs over 50 (Anglin & Braaten, 1978).

Residential services in Ontario began with the 1859 conversion of an Orillia hotel. What was later known as Huronia Regional Centre, started life as a branch of the “provincial lunatic asylum” (National Institute on Mental Retardation, 1981, p. 7). Within a few years, it was closed due to disrepair, but as the demand for services increased, the facility was reopened in 1876 as the “Orillia Hospital for Idiots and Imbe-

ciles” (National Institute on Mental Retardation, 1981, p. 7). At its peak, this residential facility housed 2400 people (National Institute on Mental Retardation, 1981). Complaints about poor living conditions at the Orillia facility began as early as 1913 yet, changes were not made. Instead, another facility was built, the Ontario Hospital School in Smiths Falls, which opened in 1951. Parents and others concerned about the welfare of persons with developmental disabilities were unhappy with this focus on “the prevailing one-solution of a lifetime institutional care for retarded people” (Anglin & Braaten, 1978, p. 3). More people tried to keep their children out of institutions and at home, but there were few classes for them to attend until the Parents’ Council for Retarded Children was formed in 1948. This lobby group subsequently joined with other similar groups to form the Ontario Association for Retarded Children (OARC), which later became the Ontario Association for Community Living. The lobbying efforts of the Parents’ Council lead to the formation of school classes and integrated recreational programmes by the early 1950s.

Despite the push for community-based services, the large institutions were still thriving. However, the momentum of the deinstitutionalization movement was helped with Pierre Berton’s scathing column describing the conditions at Orillia in 1959. This was followed by a film, commissioned by the Ontario Minister of Health, Dr. Matthew Dymond. The film, “One on Every Street” remains a tribute to a courageous elected representative who dared to encourage the public to demand change” (Anglin & Braaten, 1978, p. 34).

The commitment toward the development of community services and the de-population of the traditional large institutions persisted through the 1960s. This process was given legitimacy

with the 1967 passing of Dr. Dymond's "Bluebook" which advocated the support of children in their homes with the assistance of a coordinated system of community supports (Anglin & Braaten, 1978). A series of legislative reforms through the 1970s, 1980s and 1990s continued the process of deinstitutionalization in Ontario and the building of community support services.

The Ontario Association for Community Living (OACL) has continued to pursue the ideals of its founders. With a current membership of approximately 12 000, and over 100 affiliated associations across the province, the OACL's goal continues to focus on advocacy. "OACL's goal is 'that all persons live in a state of dignity, share in all elements of living in the community, and have the opportunity to participate effectively'" (OACL, 2000). Its local member associations provide a wide variety of services across Ontario. The OACL provides information and resources for its member associations, and advocates with government to shape policy for Ontarians who have developmental disabilities (OACL, 2000).

In recent years a number of organizations have been formed to advocate and provide services for persons with developmental disabilities. These organizations, including the Habilitative Mental Health Resource Network, focus on a variety of issues of special interest to persons with disabilities, their families, and caregivers.

### **Biological Factors in Developmental Disabilities**

In the case of Jack mentioned earlier, there were no obvious physical features that identified him as a person who had a developmental disability. This is the case with many people.

However, there are some conditions associated with developmental disability that include a variety of physical characteristics that make them identifiable. Every human being has approximately 100, 000 genes comprising a very complex jigsaw for researchers to piece together. However, with the formation of the international Human Genome Project (HGP) in 1988, the rate of genetic research has exploded. Every year, enormous strides are made toward the HGP's "goal of sequencing the entire human genome" (Hagerman, 1996, p. 416). The congenital origins of various forms of developmental disability have been uncovered; however, we have a long way to go before the biological roots of all disabilities will be known (Mehes & Kosztolanyi, 1998). In fact, in 30% to 50% of cases, it is not possible for physicians to determine the cause of developmental disability even after undertaking a complete evaluation (Daily, Ardinger & Holmes, 2000).

### Chromosomal Abnormalities

Human genetic abnormalities are common, involving as many as 50% of humans conceived. Most genetic abnormalities result in spontaneous abortion; therefore, we do not see the result in the regular population. Although there are more than 100 genetic disorders, the most common are: Down syndrome, Phenylketonuria, and fragile x syndrome (Plomin, DeFries, & McClearn, 1980).

### Down Syndrome

Down syndrome is a genetic disorder that accounts for about 10% of individuals labelled with moderate to severe retardation. Those with Down syndrome are easily recognized by their short stature, rounded face and almond eyes. Individuals with Down syndrome may also exhibit low muscle tone



(hypotonia), short, broad hands with a single simian crease, hyperflexibility of the joints, and a small oral cavity which causes tongue protrusion. In addition, they may have accompanying physical complications such as heart, eye, respiratory, or ear problems.

As individuals who have Down Syndrome mature, they appear to have an increased disposition to depression, dementia, and Alzheimer's Disease as well as obesity (Loveland & Tunali-Kotoski in Burack, Hodapp, & Zigler, 1998).

### Phenylketonuria

Phenylketonuria (PKU) is an unusual disorder that inhibits the production and performance of enzymes. The absence of a specific enzyme in the liver leads to a buildup of the amino acid *phenylalanine*. PKU can be treated using a specific diet. This diet puts stress on the family due to its requirements. PKU is detected at birth so the nutritional treatment can begin immediately. Mental retardation results if the diet is not begun soon enough or not adhered to (Smith, Polloway, Patton & Dowdy, 1998).

### Fragile X Syndrome

“Fragile x syndrome is the single most common inherited cause of mental impairment. Recent studies suggest that fragile x affects 1 in 2000 males, and 1 in 4000 females of all races and ethnic groups” (How prevalent is fragile x in the general population? 1997-2000). There is evidence that 1 in 259 women is a carrier of fragile x and, as such, has the capacity to pass it to her children. Men have been found to be carriers at a rate of 1 in 800. The vast majority of people who have fragile x syndrome have not been diagnosed (How prevalent is fragile

x in the general population? 1997-2000). In 1992, a DNA based test was developed that identifies the presence of fragile x (Is there a way to test for fragile x? 1997-2000). The symptoms of fragile x include a wide range of intellectual disability including learning disabilities and intellectual disabilities, attention problems, anxiety, autistic-like behaviors, and physical features that include “long face, large ears, flat feet, and hyper-extensible joints, especially fingers” (What are the common symptoms, 1997-2000). Behavioral and emotional difficulties tend to be present in both genders (What are the common symptoms, 1997-2000). However, boys tend to be more severely impacted than girls in terms of intellectual functioning. In fact, some girls have normal IQ levels, while approximately 80% of boys who have fragile x syndrome have a developmental challenge or disability, ranging from low-average intelligence to severe developmental disability (What are the common symptoms, 1997-2000; Hagerman, 1994).

### *Autism*

Autism is a condition with lifelong implications. It is a Pervasive Developmental Disorder that is characterized by stereotypical, perseverative behaviors, resistance to environmental changes or change in routine, and unusual sensory experiences (Kirk, Gallagher, & Anastasiow, 2000). The expression of autism is variable with the symptoms ranging from close to normal to very severe symptoms. As a developmental diagnosis, the symptomatology varies with age. Diagnosis relies on the evaluation of a detailed developmental history, and it is important to note that autism can co-exist with other conditions. People who have autism function in a fairly wide intellectual range. By age five or six, 50% demonstrate significant delay in both non-verbal and verbal skills; 25% show delays in verbal

skills but have normal nonverbal skills, while 25% function in the normal range in both verbal and nonverbal skills. Of even more importance is the assessment of adaptive functioning since this is a particularly problematic area for people who have autism (Freeman, [http://www.autism-society.org/packages/getstart\\_diagnosis.html](http://www.autism-society.org/packages/getstart_diagnosis.html)).

### Prader-Willi Syndrome

Prader-Willi Syndrome (PWS) is a complex genetic disorder that is typically characterized by low muscle tone, short stature, incomplete sexual development, cognitive deficits, behavior problems, and a chronic feeling of hunger that can lead to excessive eating and life-threatening obesity. Most cases of PWS are attributed to a spontaneous genetic error that occurs at or near the time of conception for unknown reasons. In a very small percentage of cases (two percent or less), a genetic mutation that does not affect the parent is passed on to the child, and in these families more than one child may be affected. A PWS-like disorder can also be acquired after birth if the hypothalamus portion of the brain is damaged through injury or surgery (Frequently Asked Questions – Prader-Willi Syndrome, 1999).

It is estimated that one in 12,000 to 15,000 people has PWS. Although considered a "rare" disorder, Prader-Willi syndrome is one of the most common genetic causes of obesity that has been identified. PWS is found in people of both sexes and all races (Frequently Asked Questions – Prader-Willi Syndrome, 1999).

In addition to their involuntary focus on food, people with PWS tend to have obsessive/compulsive behaviors that are not related to food, such as repetitive thoughts and verbalizations,

collecting and hoarding of possessions, picking at skin irritations, and a strong need for routine and predictability. Frustration or changes in plans can easily set off a loss of emotional control in someone with PWS, ranging from tears to temper tantrums to physical aggression. While psychotropic medications can help some individuals, the essential strategies for minimizing difficult behaviours in PWS are careful structuring of the person's environment, and consistent use of positive behavior management and supports (Frequently Asked Questions – Prader-Willi Syndrome, 1999).

Although in the past many people with PWS died in adolescence or young adulthood, prevention of obesity can enable those with the syndrome to live a normal lifespan. New medications, including psychotropic drugs and synthetic growth hormone, are already improving the quality of life for some people with PWS. Ongoing research offers the hope of new discoveries that will enable people affected by this unusual condition to live more independent lives (Frequently Asked Questions – Prader-Willi Syndrome, 1999).

### Cerebral Palsy

Cerebral Palsy (CP) is a group of disorders whose major feature is brain damage. Damage to the brain occurs before, during, or shortly after birth, and can be due to a variety of causes. Cerebral Palsy can result from a brain injury that may occur due to a fall down stairs, or a car accident. However, this is more commonly called Traumatic Brain Injury if the event occurs after the age of 3 (Types of Cerebral Palsy, 2000).

Unfortunately, many people automatically associate a physical disability with intellectual disability. If Jack, in the case de-

scribed above, had had a mobility problem or unclear speech, it is likely that people would have assumed he had a developmental disability before it had been diagnosed. Because he was able to walk but did so at a slower rate than other children, his developmental disability was not obvious. On the other hand, many people who have mobility problems or other physical difficulties do not have an intellectual difficulty. The following description of the various types of Cerebral Palsy will help you to develop a more realistic view of the specific challenges associated with each.

There are four types of Cerebral Palsy: spastic, athetoid, ataxic, and mixed. Spastic or hypertonic Cerebral Palsy is characterized by tight muscles. Involuntary movements are present in athetoid (dyskinetic, hypotonic, dystonia) Cerebral Palsy. Ataxic Cerebral Palsy occurs when the cerebellum has been damaged, thus causing lack of coordination and jerky movements. Mixed is a combination of any of the above (Types of Cerebral Palsy, 2000).

Spastic Cerebral Palsy is the most common type of Cerebral Palsy, and it is present in about 50% of people with Cerebral Palsy. Spastic Cerebral Palsy may also be called hypertonic Cerebral Palsy since there is an over-abundance of muscle tone resulting in tightened muscles. It is common for individuals with spastic Cerebral Palsy to have learning disabilities or developmental disabilities. However, developmental disability is the exception, not the rule, and it is found in approximately 50% of those with spastic Cerebral Palsy, and 35-40% of the total population of people who have Cerebral Palsy (Types of Cerebral Palsy, 2000).

Among people who have athetoid or dyskinetic Cerebral Palsy,

unintentional or uncontrolled movements will often be seen. This is due to an ever-changing level of muscle tone. This type of Cerebral Palsy accounts for up to 30% of all persons with cerebral palsy (Types of Cerebral Palsy, 2000).

*Some Other Terms for Cerebral Palsy*

- Traumatic Brain Injury
- Little's Disease
- Infantile Cerebral Paralysis
- Dyskinetic Cerebral Palsy or Dystonia (Athetoid Cerebral Palsy)

**Did You Know...**

United Cerebral Palsy Association (UCPA) estimates that between one and three of every 1,000 births will have Cerebral Palsy (Types of Cerebral Palsy, 2000).

**Family Stress and Advocacy**

Families that include a member who has a developmental disability face many special challenges. Parents must grapple with the loss of the child they anticipated, and with the challenges presented by their child's special needs. "When a child has a disability, the mismatch between child and parental expectations and behavior may be high; feelings of grief, denial, and profound disappointment are often experienced by the parents as they mourn the loss of the healthy baby they had hoped for" (Singer & Powers, 1993, p. 26). Siblings may be embarrassed by their brother or sister who has a disability. They may be asked to be their sibling's protector, or may be expected to take on extra responsibilities within the family (Powell & Gal-

lagher, 1993).

On the other hand, some families who have a member with a disability grow stronger and closer. Key factors that contribute to the successful adaptation of families include their ability to mobilize personal, family, extended family and community resources, and the interpretation they give to the challenges they face. Those families who are able to mobilize their available resources successfully are more likely to adjust to the challenges associated with supporting a member who has a disability (Gladding, 1998).

These two opposing views, the family disruption approach versus the family resilience approach, have characterized the literature on families which include a member who has a disability. However, some researchers have suggested a middle ground: that families can be both disrupted in the face of challenges presented by a member with a developmental disability, but they can also exhibit resilience such as supportive emotional tone and interpersonal connectedness (Costigan, Floyd, Harter & McClintock, 1997). In the case discussed earlier in the chapter, Jack's mother certainly experienced stress as she sought answers to her concerns about her son's development. However, she was able to access the appropriate resources that could help him to develop, and could support her family. From the advent of the Parents for Retarded Children in Ontario, this need to find services for family members who have a developmental disability has been a driving force in the development of advocacy groups that have prompted service development and service evolution. Increasingly, people who have developmental disabilities have been actively involved in advocacy. Currently, six self-advocates hold positions on the Board of Directors of the Canadian Association for Community Living

(Canadian Association for Community Living, 2000).

**Dual Diagnosis:**

The term “dual diagnosis” is used when developmental disabilities are further complicated by mental illness. For many years, practitioners believed that it was not possible for a person to have both a developmental disability and a psychiatric diagnosis. Any behavioral differences were attributed to the developmental disability alone. Fortunately, as attitudes have shifted over the past twenty years, individuals who have both a developmental disability and psychiatric concerns have increasing access to both systems of care, and in some cases, to integrated care plans. Persons with a developmental disability, combined with significant behavioral or psychiatric problems, will require an holistic treatment plan which may include a range of services and supports, including various forms of psychotherapy, psychotropic medication, behavioral counselling, social supports and other individualized services to assist in their inclusion in society. Full inclusion in the community can be hampered by the individual’s limitations in cognitive level, interpersonal skills, and adjustment problems both socially and in the world of work. Later chapters in this book will address diagnostic, therapeutic and social issues facing people who have both a developmental disability and a mental health problem.

**Back to the Case:**

Like many other people who have a developmental disability, the cause of Jack’s delay has not yet been identified. However, as the international work of the Human Genome Project progresses, it is likely that the biological underpinnings of Jack’s



challenges will be uncovered. Whether this will lead to improved medical interventions, or to strategies for preventing future generations from developing similar difficulties remains to be seen. However, just as the quality of Jack's life would have been better had he been born at the end rather than at the beginning of the 20th century, the opportunities for improved treatment and quality of life are increasing as we enter the 21st century. Thanks to the availability of community-based services, Jack could expect to have the opportunity to move into a supported living programme, and to participate in the work force.

### **Summary**

Throughout our history as human beings, we have developed various strategies for either victimizing or supporting those among us who have special needs. Developmental disabilities have been used as justification for pressing people into slavery, or putting them to death as witches. Religious convictions regarding care for the less fortunate helped to increase the resources devoted to support for people with various challenges. With the increase in our understanding of genetics and neurology, there has been an increase in our understanding of the nature of various conditions associated with developmental disabilities. Advances in psychopharmacology, education and therapy have improved the quality of life for people with a variety of challenges related to developmental disability. Of even more importance with regard to life quality have been the advocacy movements and changes in public policy which have resulted in a shift from institutional to community support systems. Full inclusion of persons who have a developmental disability in all aspects of school, work and social life is far from being a reality; however, great strides continue to be made so

that all people may have the opportunity to live the life they choose.

### **Do You Know?**

1. How have attitudes and interventions for people who have developmental disabilities changed over time?
2. What impact has the deinstitutionalization movement had on the quality of life of persons who have developmental disabilities?
3. Why do siblings of individuals who have developmental disabilities tend to experience social and family pressure?
4. What role has an organized advocacy movement played in the development of services for people with developmental disabilities in Ontario?

### **Resources**

Autism Society Ontario. Available:

<http://netrover.com/~southgve/autismso.htm> (This is the home page for the ASO. It describes the organization's mission and includes links to other ASO chapters.)

Autism Society of America. Available: <http://www.autism-society.org> (This site includes a wide variety of material produced and distributed by the Society including conference and research information. The site also has a search engine.)

Canadian Association for Community Living. Available: <http://www.cacl.ca> (This site provides information about National and Provincial programmes that support people in

community settings.)

Centers for Disease Control and Prevention: Division of Birth Defects , Child Development and Disability and Health. Available: <http://www.cdc.gov/nceh/cddh/Default.htm> (This site includes information and links related to the biological bases of child developmental concerns.)

Council for Exceptional Children. Available: <http://www.cec.sped.org> (This is the homepage for CEC which includes links to pages that describe the organization's training events, literature and public policy information.)

Mencap. Available:

<http://www.gmp.police.uk/mencap/index.html> (This site describes the work of the largest charity serving people who have learning disabilities in Britain.)

National Information Center for Children and Youth with Disabilities. Available:

<http://www.kidsource.com/NICHCY/index.html> (This site has links to a wide variety of material of interest to parents and others who are concerned about the needs of children who have various challenges.)

Roeher Institute. Available: <http://www.roeher.ca/roeher> (This site provides information about research, training and publications provided through this major research institute.)

The ARC (1998). Introduction to mental retardation. Available: <http://thearc.org/gaqs/mrqa.html> (This site developed by the ARC in the United States, provides a very basic introduction to mental retardation, its diagnosis, causes and prevention.)

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What are the common symptoms? (1997-2000).

Available:

[http://www.fraxa.org/html/about\\_symptoms.htm](http://www.fraxa.org/html/about_symptoms.htm)

What is Learning Disability? Available:

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