



Adopting Children With Developmental Disabilities



The estimates of children who are awaiting adoption (legally free) indicate that anywhere between 30 and 50% have a developmental disability. However, these children are not a homogeneous group. Their physical, cognitive and social characteristics may differ considerably. Each child's diagnosis and/or classification are coupled with their individual uniqueness. Children with developmental disabilities, like all children, benefit from the

What's Inside:

- What is a developmental disability?
- Types of disabilities
- Challenges of adopting a child with developmental disabilities
- What parents say
- Sources of support and information



love and stability that come from belonging to permanent families.

Families adopting children with developmental disabilities often have different motivations from those adopting healthy infants. Couples faced with infertility, who choose adoption as an option, are looking for a healthy baby and the opportunity to create their family. However, adoptive parents seeking children with disabilities have different goals and characteristics. These adoptive parents tend to already have large families with many biological children and/or other adopted or foster children. They see themselves as successful parents equipped with the special skills necessary to parent a “challenged” child. These adoptive families also tend to have had previous experience with health care professionals, school systems and administrators that helps them to navigate systems to advocate on behalf of their children. The parents know from their personal experience that every child is different and that all children have at least one difficulty—some are just more serious than others. The motivation shifts for these families from wanting to adopt infants to form a family to providing for the quality of life for additional family members.

Families who have adopted children with developmental disabilities talk about the “incredible joy” the children bring to them. They describe them as having enriched their families in ways they could never have imagined. Parents derive tremendous satisfaction from helping their child make developmental gains and each accomplishment is a cause for celebration. However, parents must also balance the fine line between following their protective instincts and helping their child achieve greater independence.

What Is a Developmental Disability?

According to the Federal Developmental Disabilities Act of 1984, Public Law 98-527, Sec. 102(7), a developmental disability is a severe, chronic disability which:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before age 22;
- is likely to continue indefinitely;
- 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 sufficiency
- reflects the person’s need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

Within each disability there is a range in conditions from mild to severe. Several handicapping conditions are most associated with developmental disabilities—two of which, mental retardation and cerebral

palsy, affect the most children with the greatest severity.

Types of Disabilities

Mental Retardation

Mental retardation is impaired or incomplete mental development. Usually a life-long condition occurring at or near birth, it may be treated through educational techniques, but is not cured. More than 200 specific causes of mental retardation have been identified; together they account for less than half of all cases, underscoring the need for greater knowledge in this field.

There are four classes of mental retardation: mild, moderate, severe, and profound. People who have mild mental retardation and function in the educable range can achieve competitive employment on a semiskilled or unskilled level with minimal support. They may need guidance in crisis situations, but can participate as fully contributing members of society in the mainstream of community life with jobs, independent living, cars and their own families.

People who have moderate mental retardation and function in the trainable range may achieve self-maintenance in unskilled or semiskilled work under sheltered conditions. They need supervision and guidance when under mild social or economic stress and must live in group homes, family situations or assisted living settings.

People who have severe mental retardation may contribute partially to self-maintenance under complete supervision. They can

develop self-protection skills to a minimally useful level in a controlled environment.

People who have profound mental retardation have some motor and speech development. They may achieve limited self-care and need nursing care.

Down Syndrome

Down syndrome is a form of mental retardation in which the child is born with an extra chromosome. It occurs in approximately 1 of every 800 births. There are more than 50 characteristics that identify a child with Down syndrome—the most prominent being slanted eyes, short stature, and poor muscle tone. No child has all 50 characteristics, and, contrary to popular thinking, very few have severe mental retardation.

Children with Down syndrome exhibit a wide range of mental development with most in the mildly to moderately delayed category. They commonly have respiratory infections and congenital heart disease. Fortunately, many heart defects are treatable now; some even can be corrected without surgery.

Current research with computers shows that children with Down syndrome understand more than they verbalize. This may mean that there is a vast, untapped potential that can be explored and nurtured, since it is known that learning in these children continues through adolescence. In addition, there is evidence that as more children with Down syndrome are raised in families where they receive individual attention, they will accomplish more than once thought possible.

Cerebral Palsy

A catch-all term, cerebral palsy refers to a group of conditions resulting from brain damage before, during, or shortly after birth. It is not hereditary and is often attributed to a lack of oxygen to the brain. The most obvious symptom is an inability to coordinate or control muscles; children with cerebral palsy lack muscle control in one or more parts of their bodies. Children whose conditions are more serious may experience other symptoms, such as convulsive disorders, limited general intelligence, and problems in thinking, expressing thoughts, speaking, hearing, and seeing. Some children who have serious limb involvement attend orthopedic schools (part of the public school system) where occupational and physical therapy are part of the curriculum.

While cerebral palsy is a permanent disability that cannot be cured, many people with the condition experience no limitation to their abilities to achieve. Many have risen high in the fields of medicine, law, education, and writing. Some people with cerebral palsy have completed the New York Marathon race. These are cases in which mental function has not been impaired.

Autism

Autism is a distinct developmental brain disorder with both physical and behavioral components. It affects the brain areas controlling language, social interaction and abstract thought. About one in every one thousand people are autistic. The symptoms vary greatly, but usually become apparent by two or three years of age and affect males more often than females. People with autism share a common problem of having

difficulty expressing what they mean or sometimes cannot speak. Emotional problems and mental retardation can also be present. Individuals with autism are usually very sensitive to sensory stimuli and are often overwhelmed by ordinary sounds, sights, smells and touch.

The cause of autism is still unclear, although the most widely accepted explanation is a combination of genetic factors and damage affecting the part of the brain that processes and interprets information. Autistic youngsters are often described as being “in a shell” or “living in a world all their own.”

While autism is considered a life-long condition, good educational training and programs reduce the severity of its symptoms. Occupational therapy, speech and language therapy, and medication are sometimes helpful. In the cases where retardation is accompanied by normal or superior skills (as in arithmetic, music, or memory), these skills can be expanded.

Epilepsy

There are many definitions of epilepsy. Generally, the term, which comes from the Greek word for “seizures,” is applied to a number of disorders of the nervous system centered in the brain. Seizures of one kind or another are the primary characteristics or symptoms of all forms of epilepsy. Not all seizures, however, are epileptic in nature. Seizures are characterized by one or more of these symptoms: convulsions of the body’s muscles, partial or total loss of consciousness, mental confusion, or disturbances of bodily functions which are usually controlled automatically by the brain and nervous system.

There is no known cause of epilepsy. Scientists generally agree that epilepsy can result from defects in the brain; brain injury before, during, or after birth; head wounds, chemical imbalance, poor nutrition, childhood fevers, some infectious diseases, brain tumors, and some poisons. But sometimes the cause cannot be found.

Strictly speaking, epilepsy is not curable, but it is highly treatable. It can be controlled in varying degrees by careful use of medicines (up to 50% of those affected can achieve complete control, and 30% partial control of their seizures).

In most cases, people with epilepsy have the same general range of intelligence as other people. Only occasionally do uncontrolled seizures during childhood affect mental capacity. A brain injury or disorder of the central nervous system, which caused epilepsy, may also cause other conditions that affect mental development, for example, mental retardation or cerebral palsy.

Spina Bifida

Spina bifida is a birth defect involving the nervous system. It occurs when the vertebral bony units that cover and protect the spinal cord do not develop fully. The spinal cord fails to form a tube and send out enough nerve fibers to the muscles below. As a result, the lower extremities and the lower part of the tube are affected in various ways. A child may not be able to move his legs, may not feel heat, touch, or pain, and may not be able to achieve bowel and bladder control. Many children, however, are able to walk unaided. Others require braces and crutches; still others are restricted to wheel-

chairs. The bowel and bladder function, but are commonly susceptible to infection.

Frequently, a problem called hydrocephalus accompanies spina bifida, which is an abnormally rapid and excessive enlargement of the head caused by fluid backup. Immediate treatment calls for insertion of a shunt or tube to drain fluid off the brain. Once a shunt has been properly inserted, the hydrocephalus seldom causes further problems. Shunting has also proven effective in preventing hydrocephalus. This procedure is critical – not only for cosmetic purposes, but also to prevent brain damage which often is a result of the increased pressure. Early damage can result in mild or even severe retardation. Many children with spina bifida are of average or higher intelligence.

Acquired Immune Deficiency Syndrome (AIDS)

Acquired Immune Deficiency Syndrome (AIDS) is a disorder that slowly destroys the body's immune system, leaving it incapable of fighting off disease. It is caused by the Human Immunodeficiency Virus (HIV). Both children and adults can contract the virus from blood transfusions. AIDS is not transmitted by casual contact. Because there is no cure yet, AIDS is the most serious disease a child can acquire. Because of new drug treatments, however, children who are HIV positive can live for a number of years.

The HIV virus can be transmitted to the infant from the mother during pregnancy, birth or breastfeeding. About 20 - 25% of infants born to HIV infected mothers run the risk of contracting the virus. Mothers can reduce the risk of infection by: using

AZT or other antiviral drugs during the last six months of pregnancy; keeping the delivery time short (the possibility of a cesarean section (C-section) birth); and not breast feeding the baby. When AZT is used during pregnancy, the risk of transmitting HIV drops from 25% to 8%. Recent evidence also suggests that the newborn be given AZT for six weeks after birth. Even if the mother does not take AZT during the pregnancy, the risk of transmission is less if the baby is given AZT within two days of birth. Most babies born to infected mothers test positive for HIV at birth. However, testing positive means the HIV antibodies are found in the blood. Babies get HIV antibodies from their mother even if they are not infected with the virus. If babies are infected with HIV, their own immune systems will start to make antibodies and they will continue to test positive. If they are not infected, the mother's antibodies will gradually disappear and the babies will test negative after about 6 to 12 months (New Mexico AIDS InfoNet). Even though an infant has two or more negative HIV antibody tests, the National Pediatric HIV Resource Center recommends a final HIV antibody test at 24 months of age for the HIV-exposed infant (American Academy of Pediatrics).

Fetal Alcohol Syndrome/ Fetal Alcohol Effect

Fetal Alcohol Syndrome (FAS) refers to a set of physical and mental birth defects found in babies whose mothers drank alcohol regularly and heavily during their pregnancy. Fetal Alcohol Effect (FAE) is a milder version of birth defects found in some babies of women who drank less during pregnancy. Some effects of alcohol in pregnancy are small size/low birth weight, brain damage,

mental retardation, behavioral problems, facial abnormalities, and heart, lung and kidney defects.

A great deal of neurological development occurs after birth, and if child care, nutrition, and environment are adequate, it is likely that FAS/FAE children can make considerable progress. However, FAS/FAE related neurological damage is not curable. Early intervention, education, training and treatment from family members, community organizations and professionals can increase later success. But, adoptive parents need to be prepared, educated and supported through services before, during, and after the placement in order to overcome the special challenges that these children will face as they age.

Challenges of Adopting a Child with Developmental Disabilities

Those who have adopted children with disabilities feel that they receive more from the experience than they give. Adoptive parents need a special awareness to understand that parenting children with developmental disabilities can require a different kind of lifetime commitment in terms of the amount of continued care and support the child may need as an adult. The challenges don't go away, rather they shift at different developmental ages and stages. Nonetheless, it takes a person with specific abilities and an optimistic attitude to help a child with developmental disabilities reach his or her full potential.

Joan and Bernard McNamara, authors of *The Special Child Handbook*, are the parents of six children, five of whom have special needs. Of these, four are adopted. The McNamaras suggest that some combination of the following qualities is helpful in parenting a child with developmental disabilities:

- You like children and enjoy the challenge of raising a family. If you are not a parent already, you may have had other kinds of exposure to children, through volunteer work, teaching, or your own extended family, that have given you an insight into the daily realities of parenting.
- You are a flexible person. You usually deal with frustration with patience and are open to changes in your expectations and lifestyle.
- You are able to view people for what they can accomplish, not what they cannot, and you value them according to their own potentials.
- You have had contact with people who have disabilities.

The task of finding resources in terms of services and support is added to the challenge of finding out who you are and who the child is. Adoptive parent groups assist with all of these issues. They provide a unique setting to help parents share, understand, and manage the complexities they face. The groups offer educational, social, and support services, sometimes including respite care. They can refer to other information systems in the community, such as specialized organizations like the National Down Syndrome Congress or the United Cerebral Palsy Association. In addition, more adoption agencies and adoptive parent groups

are providing post-adoption and counseling services.

Financial assistance is available to most families who adopt children who have disabilities and can include monthly cash payments, medical costs, some specialized services, and adoption-related expenses. This assistance is available through State Departments of Public Welfare and is usually arranged before the adoption occurs. More information is available in the Child Welfare Information Gateway publication “Adoption Assistance for Children Adopted from Foster Care: A Factsheet for Families” or via North American Council on Adoptable Children’s NAATRIN program. The National Adoption Assistance Training, Resource, and Information Network (NAATRIN) offers support and information without charge to adoptive and foster parents, adoption professionals, and other child advocates who have questions about Title IV-E Adoption Assistance. NAATRIN can be contacted by telephone toll-free at (800) 470-6665, email to adoption.assistance@nacac.org, or online at www.nacac.org/adoptionssubsidy.html.

What Parents Say

The McNamaras sum up this special type of parenting when they say, “...most parents who have adopted children with special needs agree that the positive growth of their whole family through adoption has been a cherished opportunity and one they would enthusiastically repeat. Adopting children with special needs means opening yourself to a loving challenge and to the gifts they bring.”

Sources of Support and Information

A complete resource listing of national organizations and information and referral sources entitled “Children with Disabilities/Special Needs” is available from Child Welfare Information Gateway.

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