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UNDERSTANDING DISABLING CONDITIONS

Causes of Disabling Conditions
Disabling Conditions
Fact Sheets about Disabling Conditions

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UNDERSTANDING DISABLING CONDITIONS

As a Direct Support Provider (DSP) you may be responsible for individuals who have disabling and/or medical conditions. Some of these conditions require that the DSP have specific

information in order to provide appropriate support. This is particularly important if a condition causes the individual to have medical or health issues. Understanding particular aspects of some conditions will enable the DSP to build upon the individual's strengths while being mindful of restrictions the person may have. In this section you will learn about:

- ◆ Causes of Disabling Conditions
- ◆ Particular Disabling Conditions

Having a son or daughter with a disability or other type of difficulty can be challenging at times for families. However, with effective supports from DSPs, other professionals, and the community, most families continue to thrive.

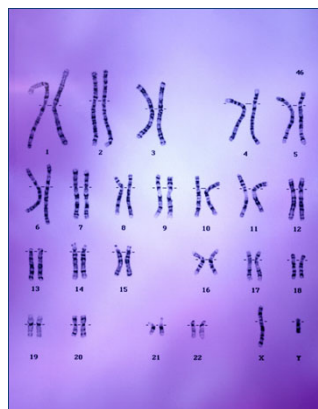
CAUSES OF DISABLING CONDITIONS

There are a variety of disabling conditions that can be related to a specific cause. Some of these may include genetic disorders; others may be related to a trauma or injury occurring **before, during, or after birth**. Because of the complexity of the human body, there are no easy answers to the question of what causes disability.

Before Birth

Genetic Factors

Genetics is the science that studies the means by which traits are passed from parents to their children. Through this science, a number of specific disorders have been identified as being genetically caused. In humans, there are 46 chromosomes in each cell. Each parent provides twenty-three. Within the genes of each of these chromosomes is the "blueprint" for how we will look, sound, grow, and behave.



When there are errors in genetic composition or structure, often the affected individual will develop a disabling condition or disease.

Sometimes the conditions that develop as a result of genetic errors are referred to as syndromes. Two of the many genetic conditions that cause disability are Down syndrome and Fragile X syndrome.

*For more information on these syndromes see the **Fact Sheets** at the end of this section.*

Exposure to Infections or Illness

Although the placenta acts as a barrier to some harmful substances, it does not always prevent the passing of drugs or infections from the mother to the baby. Infections can cause problems for the developing baby. Some examples of these are syphilis (a sexually transmitted infection), toxoplasmosis (a parasitic infection sometimes found in cat feces), varicella (chicken pox) and rubella (German measles). Diabetes and other illnesses of the mother may also cause difficulties.

Exposure to Drugs and Alcohol

The use of illegal drugs as well as the abuse of prescription drugs can result in serious developmental problems in the baby. Drugs such as cocaine, heroin, and methadone have been associated with various short and long-term negative effects. The negative outcomes of cigarette smoking include an increased risk of miscarriage and low birth weight.

Alcohol use during pregnancy is a leading cause of preventable birth defects and developmental delays. Fetal Alcohol Spectrum Disorder (FASD) refers to the full range of these problems.

*For more information on FASD see the **Fact Sheet** at the end of this section.*

During Birth Process

The possibility of being born with a disabling condition can be caused by other factors unrelated to genetics, exposure to infections, or drugs. During the birth itself, complications can arise that may deprive the baby of oxygen. This deprivation can cause brain damage resulting in intellectual disability as well as other disabling conditions such as cerebral palsy.

*For more information on Cerebral Palsy see the **Fact Sheet** at the end of this section.*

Other birth complications include:

- ◆ Problems with the placenta
- ◆ Untreated pregnancy-induced high blood pressure
- ◆ Premature membrane rupture (woman's “water breaks” too soon)
- ◆ Breech (backside first) delivery

After Birth

Prematurity and Low Birth Weight

Immediately following birth, some babies are considered “at risk” due to prematurity and low birth weight. If they are not provided with the specialized care necessary, they may experience long term brain and nervous system damage.

Childhood Illnesses and Injuries

Complications from illnesses such as pertussis (whooping cough), chicken pox, measles, meningitis, and encephalitis can damage the brain. Also accidents such as falls from bikes while not wearing a helmet or near drowning incidents can cause trauma to the brain. Substances such as lead and mercury can cause irreparable damage to the brain and nervous system.



Abuse and Neglect

Abuse can be of a physical, emotional, or sexual nature. When abuse occurs, a child is at risk for physical, psychological, and emotional harm. These may interfere with learning, normal development, and overall health and well being.

Neglect refers to allowing something to happen that is likely to cause serious physical or psychological harm to an individual. Harm occurs when individuals are exposed to disease producing conditions, inadequate medical care, malnutrition, and environmental health hazards. Neglect may also affect children's mental, emotional, and physical development if they are deprived of common cultural and daily experiences such as playing with other children and having appropriate toys and activities.

PARTICULAR DISABLING CONDITIONS

These include:

1 Mental Disability

This means that the individual has:

- ▶ Significant difficulties learning
- ▶ Problems functioning in a number of skill areas. e.g. communication, self-care, and learning

This condition can also be called **intellectual disability** or **developmental delay**.

A mental disability can be caused by a number of things, including, atypical development in utero, a genetic disorder (e. g. Down Syndrome), or acquired brain damage due to a head injury (e. g. a motor vehicle collision).

2 Physical Disability

Some of the individuals that you work with may have **physical disabilities**. This usually refers to individuals who may have conditions that interfere with their ability to move around easily on their own. Still others may have conditions that affect their vision or hearing.

3 Mental Illness

Mental illness may also be a concern for some of the individuals and families that you support. These may include conditions such as depression, anxiety, schizophrenia, and bipolar disorder.

*For more information on Mental Illnesses consult the **Fact Sheet** at the end of this section.*

So . . .

Some of the individuals you support may have a combination of various medical or disabling conditions. While it is important to be as informed as possible about these conditions, it is more important to recognize that each individual is a unique human being. Focus on the gifts, talents, skills, and strengths of each person.

Resources

Batshaw, M. (Ed.). (2001). **When Your Child Has a Disability-Revised Edition**. Baltimore, Maryland: Paul H. Brooks Publishing

The ARC of the United States website
www.thearc.org

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Conditions

Resources

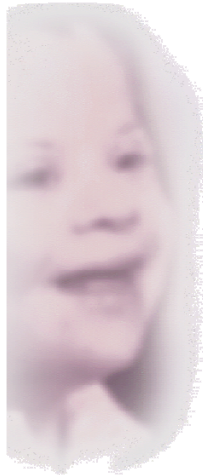
FACT SHEETS ABOUT DISABLING CONDITIONS

For information about each of the following conditions please refer to the FACT SHEETS.

Understanding
Disabling
Conditions

- Down syndrome
- Fragile X syndrome
- Fetal Alcohol Spectrum Disorder
- Seizure Disorders
- Cerebral Palsy
- Autism Spectrum Disorders
- Attention Deficit Hyperactivity Disorder
- Learning Disabilities
- Mental Illness

Down Syndrome Fact Sheet



What is it?

Down syndrome is a common genetic cause of intellectual disability which usually results in delays in physical, cognitive and language development.

For unclear reasons, an error in cell development results in 47 instead of the usual 46 chromosomes. This extra chromosome changes the orderly development of the body and brain. Down syndrome occurs in approximately 1 in 800 -1000 births.

Key Points

- ◆ There is wide variation in intellectual abilities, behavior and physical development in individuals with Down syndrome. Each individual has his or her own unique personality, capabilities and talents.
- ◆ Individuals with Down syndrome benefit from loving homes, early intervention, inclusive education, appropriate medical care and positive public attitudes.
- ◆ In adulthood, many persons with Down syndrome hold jobs, live independently, and enjoy recreational opportunities in their communities.

Important information for a DSP to know about this condition

It is important for Direct Support Providers (DSPs) to have a full understanding of Down syndrome facts and access to support in order to best help the individual reach their full potential. Besides having some possible physical characteristics (flat bridge of the nose, small mouth, crease extending across palm, decreased muscle tone) individuals with

Down syndrome may have specific health-related problems of which DSPs need to be aware.

- ◆ 30% - 50% of individuals with Down syndrome have heart defects and 8% - 12% have gastrointestinal tract abnormalities present at birth. Most of these defects are correctable by surgery.
- ◆ A lowered resistance to infection makes these individuals more prone to respiratory problems.
- ◆ Some individuals may have a condition which causes a misalignment of the top two vertebrae of their neck. This makes these individuals more prone to injury if they participate in activities which overextend or flex the neck. Although this misalignment is a potentially serious condition, proper diagnosis can help prevent serious injury.
- ◆ Some individuals with Down syndrome may have a tendency to gain weight as they grow older. Besides having negative social implications, this weight gain threatens these individuals' health and longevity. A supervised diet and exercise program may help reduce this problem.
- ◆ Visual problems such as crossed eyes and far or nearsightedness are higher in those with Down syndrome, as are mild to moderate hearing loss and speech difficulties.

Where can you go for more information?

Manitoba Down Syndrome Society

204-825 Sherbrook St.

Winnipeg, MB. R3A 1MS

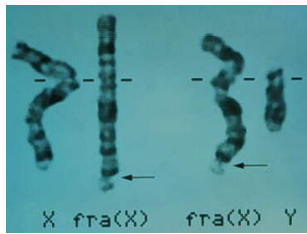
Phone: 992-2731

<http://www.manitobadownsyndromesociety.com/>

mdss@mts.net

Fragile X Fact Sheet

What is it?



Fragile X Fact Sheet

- ◆ Fragile X is the most common *inherited* cause of intellectual disability known.
- ◆ It is a genetic disorder caused by an alteration of a gene on the X chromosome.
- ◆ Boys are typically more severely affected than girls. While most boys have an intellectual disability, only one-third to one-half of girls have significant intellectual impairment; the rest have either normal IQ or learning disabilities.
- ◆ Emotional and behavioral problems are common in both sexes.
- ◆ About 20% of boys with fragile X meet full criteria for autism. Most boys and some girls have some symptoms of autism, but many tend to be very social and interested in other people.
- ◆ While the exact occurrence of fragile x is unknown, 1 in 2,000 males and 1 in 4,000 females have fragile x with intellectual impairment.

Key Points

- ◆ Some individuals will have particular physical characteristics: long face, large ears, flat feet, very flexible joints; especially fingers.
- ◆ There are many areas of support that can improve the lives of those affected and their families.

- ◆ After the seizure, let the person sleep if needed. Suggest that they see a physician.
- ◆ If the person has a second seizure within a few minutes, call a doctor or ambulance.

For Absence Seizures

- ◆ No first aid is required. Reassure the person.

For Simple Partial Seizures

- ◆ No first aid is required. Reassure the person.

For Complex Partial Seizures

- ◆ Do not restrain the person.
- ◆ Protect the person from injury by moving sharp or hot objects away.
- ◆ If wandering occurs, stay with the person and talk quietly.

Do not be frightened if the person appears to stop breathing for a few **seconds**. This is common.

- ◆ If a child or adult that you support has a seizure the parents or caregiver should be notified.
- ◆ Check for medical or emergency identification.

If a seizure lasts longer than five minutes, or repeats without full recovery:

SEEK MEDICAL ASSISTANCE IMMEDIATELY

Although this rarely occurs, status epilepticus is life-threatening.

It is a serious medical emergency.

Where can you go for more information?

Manitoba Epilepsy Association
301-309 Hargrave St.
Winnipeg, MB. R3B 2J8
Phone: 783-0466 Rural: 1-866-374-5377
<http://www.manitobaepilepsy.org>

