

**SPECIALIZED FAMILY CARE
Provider Training**

Category:	Developmental Disability
Title:	Down Syndrome
Materials:	Articles Down Syndrome, National Institute of Health, Eunice Kennedy Shriver, National Institute of Child Health & Human Development
Goal:	Provider is comfortable providing care to an individual with Down syndrome.
Credit Hours:	1 Hour
Date Developed:	October 2011
Developed by:	Donna McCune, MSW, Specialized Family Care Program

This skill-building instruction has been approved for Specialized Family Care Provider training by:

 October, 2011
Specialized Family Care Program Manager Date

Training Objectives:

- Provider knows the cause of Down syndrome
- Provider knows common physical characteristics of an individual with Down syndrome
- Provider knows health risks for an individual with Down syndrome
- Provider knows about the availability of resources for a person with Down syndrome

Training Procedures:

- Provider initiated self-study
- Test completed by Provider
- Review of test responses by Family Based Care Specialist and Provider

I certify that I have completed all the materials associated with this training module. I feel that I have a basic understanding of the material completed.

Specialized Family Care Provider Date

Reviewed by: _____
Family Based Care Specialist Date

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WVDHHR/CED/SFC/DOWN SYNDROME/10/11

Down Syndrome

Article from

**National Institute of Health
Eunice Kennedy Shriver
National Institute of Child Health & Human Development**

Last update 02/23/11

Down syndrome

What is Down syndrome?

Down syndrome is a set of mental and physical symptoms that result from having an extra copy of Chromosome 21.

Normally, a fertilized egg has 23 pairs of chromosomes. In most people with Down syndrome, there is an extra copy of Chromosome 21 (also called trisomy 21 because there are three copies of this chromosome instead of two), which changes the body's and brain's normal development.

What are the signs and symptoms of Down syndrome?

Even though people with Down syndrome may have some physical and mental features in common, symptoms of Down syndrome can range from mild to severe. Usually, mental development and physical development are slower in people with Down syndrome than in those without the condition.

Intellectual and Developmental Disabilities (IDDs) is a disability that causes limits on intellectual abilities and adaptive behaviors (conceptual, social and practical skills people use to function in everyday lives). Most people with Down syndrome have IQs that fall in the mild to moderate range of IDDs. They may have delayed language development and slow motor development.

Some common physical signs of Down syndrome include:

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

There are a variety of other health conditions that are often seen in people who have Down syndrome, including

- Congenital heart disease

- Hearing problems
- Intestinal problems, such as small bowel or esophagus
- Celiac disease
- Eye problems, such as cataracts
- Thyroid dysfunctions
- Skeletal problems
- Dementia – similar to Alzheimer's

What is the treatment of Down syndrome?

Down syndrome is not a condition that can be cured. However, early intervention can help many people with Down syndrome live productive lives well into adulthood.

Children with Down syndrome can often benefit from speech therapy, occupational therapy, and exercises for gross and fine motor skills. They might also be helped by special education and attention at school. Many children can integrate well into regular classes at school. For more information about treatments for Down syndrome, ask your health care provider.

Who is at risk for Down syndrome?

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 gets pregnant at age 25, to about 1 in 100 for a woman who gets pregnant at age 40. But, most babies with Down syndrome are born to women under age 35 because more younger women have babies.

Because the chances of having a baby with Down syndrome increase with the age of the mother, many health care providers recommend that women over age 35 have prenatal testing for the condition. Testing the baby before it is born to see if he or she is likely to have Down syndrome allows parents and families to prepare for the baby's special needs.

Parents who have already had a baby with Down syndrome or who have abnormalities in their own chromosome 21 are also at risk of having a baby with Down syndrome.

Once the baby is born, a blood test can confirm whether the baby has Down syndrome.

Down Syndrome

Down syndrome is the most common occurring genetic condition and a common cause of birth defects. The Down Syndrome Society reports that one in every 691 live births is a child with Down syndrome, representing approximately 6,100 births per year. More than 400,000 people in the United States have Down syndrome. The condition is named after a physician, John Langdon Down, who first identified the syndrome.

The chromosomal error which causes Down syndrome is unpreventable, and no one knows for sure why it occurs. There are some risk factors, however. The risk factors include:

- Advancing maternal age. A woman's eggs have a greater inclination to divide improperly as she ages. By age 35 a woman's risk of conceiving a child with Down syndrome is 1 in 350. This risk increases to 1 in 100 to women who are age 40. By age 45 the risk is 1 in 30. Most children with Down syndrome, however, are actually born to women under age 35 because this age group of women have more babies.
- Mothers who already have one child with Down syndrome. The Mayo Clinic reports that typically a woman who has one child with Down syndrome has about a 1% chance of having another child with Down syndrome.
- Parents who are carriers of the genetic translocation for Down syndrome

While Down syndrome cannot be prevented, it can be detected before a child is born, which allows parents to prepare for the special needs which their child will have.

Diagnosis of Down syndrome is often based on the baby's appearance at birth. A chromosomal test will probably be ordered for a baby who displays some or all of the typical characteristics. Individuals born with Down syndrome can have a range of complications and are closely monitored for medical conditions. Complications can include:

- Heart defects (approximately half of children with Down syndrome are born with some type of heart defect)
- Leukemia (Down syndrome children are more likely than other children to develop this)
- Infectious Diseases (Abnormalities in the immune system make those with Down syndrome more susceptible to diseases)
- Dementia (Signs and symptoms of Down syndrome may appear before age 40)
- Other problems (Gastrointestinal blockage, thyroid problems, hearing loss and poor vision)

Initially, parents of a child with Down syndrome may feel overwhelmed. Feelings of guilt, loss and fear are normal. Support services are available including linkage with other parents who have shared or are sharing a similar experience. In general, children with Down syndrome meet developmental milestones, but it may take longer. The IQ of most persons with Down syndrome falls between the mild to moderate range of intellectual ability. It is recommended that infants/ children with Down syndrome be enrolled in early-intervention programs as soon as possible. Physical, occupational, and speech therapists can work with the child to stimulate and encourage development. Behavioral training can help people with Down syndrome deal with any frustrations, anger or compulsive behavior that may occur. Professionals, parents and other caregivers should work together to encourage independence in the individual with Down syndrome.

Most people with Down syndrome reside at home with their families and are integrated into the community, participating in vocational, social and recreational activities. They are integrated into regular school classroom settings in public and private educational programs. Local schools must provide for "a free appropriate education" in the least restrictive environment" through an individualized education plan (IEP). Businesses often employ young adults with Down syndrome to work in a variety of settings.

As individuals with Down syndrome age, they may experience premature aging. The Cleveland Clinic reports that they show physical changes related to aging 20 to 30 years ahead of people of the same age in the general population. Alzheimer's disease is more common in this population as a result of this premature aging. They may be in their mid 40s or early 50s when the symptoms first appear.

Individuals with Down syndrome may reside with their families, in group homes and in independent housing arrangements. They are integrated into the community, participating in vocational, social and recreational activities. They can socialize with people with and without disabilities. In almost every community there are support services available through organizations and agencies.

References:

- KidsHealth.org, Down Syndrome, <http://kidshealth.org>
- Mayo Clinic Website, Down syndrome article, www.mayoclinic.com/down-syndrome
- National Down Syndrome Society, Down Syndrome Fact Sheet, <http://ndss.org>
- National Institute of Health, Eunice Kennedy Shriver, National Institute of Child Health & Development, article, [http://www.nichd.nih.gov/health/topics/Down Syndrome](http://www.nichd.nih.gov/health/topics/Down%20Syndrome)