



Down Syndrome

◆ Definition ◆

Down syndrome is the most common and readily identifiable chromosomal condition associated with mental retardation. It is caused by a chromosomal abnormality: for some unexplained reason, an accident in cell development results in 47 instead of the usual 46 chromosomes. This extra chromosome changes the orderly development of the body and brain. In most cases, the diagnosis of Down syndrome is made according to results from a chromosome test administered shortly after birth.

◆ Incidence ◆

Approximately 4,000 children with Down syndrome are born in the U.S. each year, or about 1 in every 800 to 1,000 live births. Although parents of any age may have a child with Down syndrome, the incidence is higher for women over 35. Most common forms of the syndrome do not usually occur more than once in a family.

◆ Characteristics ◆

There are over 50 clinical signs of Down syndrome, but it is rare to find all or even most of them in one person. Some common characteristics include:

- Poor muscle tone;
- Slanting eyes with folds of skin at the inner corners (called epicanthal folds);
- Hyperflexibility (excessive ability to extend the joints);
- Short, broad hands with a single crease across the palm on one or both hands;
- Broad feet with short toes;
- Flat bridge of the nose;
- Short, low-set ears;

- Short neck;
- Small head;
- Small oral cavity; and/or
- Short, high-pitched cries in infancy.

Individuals with Down syndrome are usually smaller than their nondisabled peers, and their physical as well as intellectual development is slower.

Besides having a distinct physical appearance, children with Down syndrome frequently have specific health-related problems. A lowered resistance to infection makes these children more prone to respiratory problems. Visual problems such as crossed eyes and far- or nearsightedness are higher in individuals with Down syndrome, as are mild to moderate hearing loss and speech difficulty.

Approximately one third of babies born with Down syndrome have heart defects, most of which are now successfully correctable. Some individuals are born with gastrointestinal tract problems that can be surgically corrected.

Some people with Down syndrome also may have a condition known as Atlantoaxial Instability, a misalignment of the top two vertebrae of the neck. This condition makes these individuals more prone to injury if they participate in activities which overextend or flex the neck. Parents are urged to have their child examined by a physician to determine whether or not their child should be restricted from sports and activities which place stress on the neck. Although this misalignment is a potentially serious condition, proper diagnosis can help prevent serious injury.

Children with Down syndrome may have a tendency to become obese 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.

◆ Educational and Employment Implications ◆

Shortly after a diagnosis of Down syndrome is confirmed, parents should be encouraged to enroll their child in an infant development/early intervention program. These programs offer parents special instruction in teaching their child language, cognitive, self-help, and social skills, and specific exercises for gross and fine motor development. Research has shown that stimulation during early developmental stages improves the child's chances of developing to his or her fullest potential. Continuing education, positive public attitudes, and a stimulating home environment have also been found to promote the child's overall development.

Just as in the normal population, there is a wide variation in mental abilities, behavior, and developmental progress in individuals with Down syndrome. Their level of retardation may range from mild to severe, with the majority functioning in the mild to moderate range. Due to these individual differences, it is impossible to predict future achievements of children with Down syndrome.

Because of the range of ability in children with Down syndrome, it is important for families and all members of the school's education team to place few limitations on potential capabilities. It may be effective to emphasize concrete concepts rather than abstract ideas. Teaching tasks in a step-by-step manner with frequent reinforcement and consistent feedback has proven successful. Improved public acceptance of persons with disabilities, along with increased opportunities for adults with disabilities to live and work independently in the community, have expanded goals for individuals with Down syndrome. Independent Living Centers, group-shared and supervised apartments, and support services in the community have proven to be important resources for persons with disabilities.

◆ Resources ◆

Cunningham, C. (1999). *Understanding Down syndrome: An introduction for parents* (2nd ed.). Cambridge, MA: Brookline. (Telephone: 800-666-2665. Web: www.brooklinebooks.com)

Pueschel, S.M. (Ed.). (2001). *A parent's guide to Down syndrome: Toward a brighter future* (2nd ed.). Baltimore, MD: Paul H. Brookes. (Telephone: 800-638-3775. Web: www.brookespublishing.com)

Uhrh, J.F. (1994). *Down syndrome: Successful parenting of children with Down syndrome*. Eugene, OR: Fern Ridge Press. (Telephone: 800-816-5679. Web: www.fernridgepress.com/)

Woodbine House (Telephone: 800-843-7323, Web: www.woodbinehouse.com) publishes a series of books on Down syndrome, including:

- *Babies with Down syndrome: A new parent's guide*
- *Differences in common: Straight talk about mental retardation, Down syndrome, and life*
- *Communication skills in children with Down syndrome: A guide for parents*
- *Medical and surgical care for children with Down syndrome: A guide for parents*
- *Teaching reading to children with Down syndrome*
- *Gross motor skills in children with Down syndrome*
- *Fine motor skills in children with Down syndrome*

◆ Organizations ◆

National Down Syndrome Congress
1370 Center Drive, Suite 102, Atlanta, GA 30338
770-604-9500; 800-232-6372
E-mail: info@ndscenter.org
Web: www.ndscenter.org

National Down Syndrome Society
666 Broadway, 8th Floor, New York, NY 10012-2317
212-460-9330; 800-221-4602
E-mail: info@ndss.org Web: ndss.org

The Arc of the United States
1010 Wayne Avenue, Suite 650,
Silver Springs, MD 20910
301-565-3842
E-mail: info@thearc.org Web: www.thearc.org
For publications: www.TheArcPub.com

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