



General Information Packet



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;



*is the
National Dissemination Center
for Children with Disabilities.*

*NICHCY
P.O. Box 1492
Washington, DC 20013
1.800.695.0285 (Voice / TTY)
202.884.8200 (Voice / TTY)
nichcy@aed.org
www.nichcy.org*



- 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.



Don't Be Shy!

All of our publications and resource lists are online—help yourself! Visit us at:

www.nichcy.org

If you'd like personalized assistance, email or call us:

nichcy@aed.org

**1.800.695.0285
(V/TTY)**

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 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 a 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-

Other Helpful Things to Know

These NICHCY publications talk about topics important to parents of a child with a disability.

Parenting a Child with Special Needs

Your Child's Evaluation

Parent to Parent Support

Questions Often Asked by Parents About Special Education Services

Developing Your Child's IEP

All are available in English and in Spanish—on our Web site or by contacting us.

Research has shown that stimulation during early developmental stages improves a child's chances of developing to his or her fullest potential.

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. (Phone: 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. (Phone: 800.638.3775. Web: www.brookespublishing.com)

Unruh, J.F. (1994). *Down syndrome: Successful parenting of children with Down syndrome*. Eugene, OR: Fern Ridge Press. (Phone: 800.816.5679. Web: www.fernridgepress.com/)

Woodbine House (Phone: 800.843.7323, Web: www.woodbinehouse.com) publishes a series 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*
- *Down syndrome: The first 18 months (DVD or Video)*
- *Early Communication skills in children with Down syndrome: A guide for parents and professionals*
- *Fine motor skills in children with Down syndrome*
- *Gross motor skills in children with Down syndrome*
- *Medical and surgical care for children with Down syndrome: A guide for parents*
- *Teaching reading to children with Down syndrome*

◇ Organizations ◇

National Down Syndrome Congress
1370 Center Drive, Suite 102
Atlanta, GA 30338
770.604.9500; 800.232.6372
info@ndscenter.org
www.ndscenter.org

National Down Syndrome Society
666 Broadway
New York, NY 10012
212.460.9330; 800.221.4602
info@ndss.org
ndss.org

The Arc of the United States
1010 Wayne Avenue, Suite 650
Silver Springs, MD 20910
301.565.3842
info@thearc.org
www.thearc.org

FS4, January 2004



Publication of this document is made possible through Cooperative Agreement #H326N030003 between the Academy for Educational Development and the Office of Special Education Programs of the U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

This publication is copyright free. Readers are encouraged to copy and share it, but please credit NICHCY.



Down Syndrome: Myths and Truths

Myth: Down syndrome is a rare genetic disorder.

Truth: Down syndrome is the most commonly occurring genetic condition. One in every 800 to 1,000 live births is a child with Down syndrome, representing approximately 5,000 births per year in the United States alone. Today, Down syndrome affects more than 350,000 people in the United States.

Myth: Most children with Down syndrome are born to older parents.

Truth: Eighty percent of children born with Down syndrome are born to women younger than 35-years-old. However, the incidence of births of children with Down syndrome increases with the age of the mother.

Myth: People with Down syndrome are severely retarded.

Truth: Most people with Down syndrome have IQs that fall in the mild to moderate range of retardation. Children with Down syndrome are definitely educable and educators and researchers are still discovering the full educational potential of people with Down syndrome.

Myth: Most people with Down syndrome are institutionalized.

Truth: Today people with Down syndrome live at home with their families and are active participants in the educational, vocational, social and recreational activities of the community. They are integrated into the regular education system, and take part in sports, camping, music, art programs and all the other activities of their communities. In addition, they are socializing with people with and without disabilities, and as adults are obtaining employment and living in group homes and other independent housing arrangements.

Myth: Parents will not find community support in bringing up their child with Down syndrome.

Truth: In almost every community of the United States there are parent support groups and other community organizations directly involved in providing services to families of individuals with Down syndrome.

Myth: Children with Down syndrome must be placed in segregated special education programs.

Truth: Children with Down syndrome have been included in regular academic classrooms in schools across the country. In some instances they are integrated into specific courses, while in other situations students are fully included in the regular classroom for all subjects. The degree of mainstreaming is based in the abilities of the individual; but the trend is for full inclusion in the social and educational life of the community.

Myth: Adults with Down syndrome are unemployable.

Truth: Businesses are seeking young adults with Down syndrome for a variety of positions. They are being employed in small and medium sized offices: by banks, corporations, nursing homes, hotels and restaurants. They work in the music and entertainment industry, in clerical positions and in the computer industry. People with Down syndrome bring to their jobs enthusiasm, reliability and dedication.

Myth: People with Down syndrome are always happy.

Truth: People with Down syndrome have feelings just like everyone else in the population. They respond to positive expressions of friendship and they are hurt and upset by inconsiderate behavior.

Myth: Adults with Down syndrome are unable to form close interpersonal relationships leading to marriage.

Truth: People with Down syndrome date, socialize and form ongoing relationships. Some are beginning to marry. Women with Down syndrome can and do have children, but there is a 50 percent chance that their child will have Down syndrome. Men with Down syndrome are believed to be sterile, with only one documented instance of a male with Down syndrome who has fathered a child.

Myth: Down syndrome can never be cured.

Truth: Research on Down syndrome is making great strides in identifying the genes on chromosome 21 that cause the characteristics of Down syndrome. Scientists now feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.

Reprinted with permission from the National Down Syndrome Society, www.ndss.org.



Questions and Answers About Down Syndrome

Why should we be concerned about Down syndrome?

Chromosomal abnormalities are a widespread medical problem, with Down syndrome being the most common genetic condition. One in every 800 to 1,000 children is born with Down syndrome. More than 50 percent of miscarriages are caused by a chromosomal abnormality. As many as 25 percent of all miscarriages are caused by a trisomy, which is the presence of three copies of a particular chromosome, rather than the normal two.

The most common form of Down syndrome is called Trisomy 21, because it involves an extra copy of the 21st chromosome. Twenty to 25 percent of children conceived with Down syndrome survive past birth.

What impact does Down syndrome have on society?

Individuals with Down syndrome are becoming increasingly integrated into society and community organizations, such as school, health care systems, work forces and social and recreational activities. Individuals with Down syndrome possess varying degrees of mental retardation, from very mild to severe. Most people with Down syndrome have IQs in the mild to moderate range of mental retardation.

Due to advances in medical technology, individuals with Down syndrome are living longer than ever before. In 1910, children with Down syndrome were expected to survive to age nine. With the discovery of antibiotics, the average survival age increased to 19 or 20. Now, with recent advancements in clinical treatment, as many as 80 percent of adults with Down syndrome reach age 55, and many live even longer.

In the United States, approximately 350,000 families are affected by Down syndrome. Approximately 5,000 children with Down syndrome are born each year. As the mortality rate associated with Down syndrome is decreasing, the prevalence of individuals with Down syndrome in our society will increase. Some experts project that the number of people with Down syndrome will double in the next 10 years. More and more Americans will interact with individuals with this genetic condition, increasing the need for widespread public education and acceptance.

Is Down syndrome transmitted from the mother or father?

The additional genetic material which causes Down syndrome can originate from either the father or the mother. Approximately five percent of the cases have been traced to the father.

Who has the highest risk of having a child with Down syndrome?

Down syndrome affects people of all races and economic levels. Women age 35 and older have a significantly increased risk of having a child with Down syndrome. A 35-year-old woman has a one in 400 chance of conceiving a child with Down syndrome and this chance increases gradually to one in 110 by age 40. At age 45 the incidence becomes approximately one in 35.

Since many couples are postponing parenting until later in life, the incidence of Down syndrome conceptions is expected to increase. Therefore, genetic counseling for parents is becoming increasingly important. Still, many physicians are not fully informed about advising their patients about the of incidence of Down syndrome, advancements in diagnosis and the protocols for care and treatment of babies born with Down syndrome.

Why is it important to raise children with Down syndrome at home?

A greater understanding of Down syndrome and advancements in treatment of Down syndrome-related health problems have allowed people with Down syndrome to enjoy fuller and more active lives. Children raised at home and included in all aspects of community life can best reach their potential and function in society with a greater degree of independence. Parental love, nurturing and support, as well as early intervention programs, educational opportunities and community involvement, have a direct relationship to the degree that a person with Down syndrome is able to achieve his/her potential.

Why are medical researchers following Down syndrome work so closely?

Down syndrome is a developmental disorder. As researchers learn more about the molecular genetics and other aspects of Down syndrome, they also obtain valuable information about human development and can advance the study of many biological processes.

In addition, individuals with Down syndrome have a higher incidence of certain medical problems and the study of Down syndrome may yield important breakthroughs in those areas. Research in Down syndrome provides a way for looking at many important problems:

Heart disease: Up to 50 percent of individuals with Down syndrome are born with congenital heart defects. The majority of heart defects in children with Down syndrome can now be surgically corrected with resulting long-term health improvements. However, scientists continue to search for the cause of this problem and look for means of prevention.

Alzheimer's disease: Estimates vary, but it is reasonable to conclude that 25 percent or more of individuals with Down syndrome over the age of 35 will develop the clinical signs and symptoms of Alzheimer's-type dementia.

Leukemia: Individuals with Down syndrome have a 15 to 20 times greater risk of developing leukemia. The majority of cases are categorized as acute megakaryoblastic leukemia, which tends to occur in the first three years of life, and for which there is a high cure rate. A transient form of leukemia is also seen in newborns with Down syndrome, disappearing spontaneously during the first two to three months of life.

Why hasn't Down syndrome received much attention in the past?

Even though Dr. Jerome Lejeune discovered in 1959 that it was an extra 21st chromosome that caused Down syndrome, it is only in the last few years that a focus has been placed on the study of the 21st chromosome.

In May 2000, researchers completed sequencing the approximately 225 genes on the 21st chromosome - only the second chromosome to be fully sequenced at this time. Although these findings will not have an immediate impact on the Down syndrome community, they will open the door to valuable research on this small set of genes.

Researchers continue to look for the genes related to the development of intelligence and the physical characteristics associated with Down syndrome. Once identified, it is hoped that the biochemical process which causes Down syndrome can be decoded, leading to the development of an intervention and cure. See the Research section of this Web site for more information about sequencing the 21st chromosome.

Reprinted with permission from the National Down Syndrome Society, www.ndss.org.



Down Syndrome

by Siegfried M. Pueschel, M.D., Ph.D., J.D.,
M.P.H.

What is Down syndrome?

Persons with Down syndrome are first and foremost human beings who have recognizable physical characteristics and limited intellectual endowment that are due to the presence of an extra chromosome 21.

The estimated incidence of Down syndrome is between 1 in 800 to 1 in 1,100 live births. Each year approximately 3,000 to 5,000 children are born with this chromosome disorder. It is believed there are about 250,000 families in the United States who are affected by Down syndrome.

How do children with Down syndrome develop?

Children with Down syndrome are usually smaller, and their physical and mental developments are slower, than those who do not have Down syndrome. The majority of children with Down syndrome function in the mild to moderate range of mental retardation. However, some children are not mentally retarded; they may function in the borderline to low average range; and only a few children may be severely mentally retarded. There is a wide variation in mental abilities and developmental progress in children with Down syndrome. Also, their motor development is slow; e.g. instead of walking by 11 to 14 months as other children do, children

with Down syndrome usually learn to walk between 15 to 36 months. Their language development is also markedly delayed.

It is important to note that a caring and enriching home environment, early intervention, and integrated educational efforts will have a positive influence on the child's development.

What are the physical features of a child with Down syndrome?

Although individuals with Down syndrome usually have distinct physical characteristics, generally, they are more similar to the average person in the community than they are different. The physical features are important to the physician in making the clinical diagnosis, but no emphasis should be put on those characteristics otherwise. Not every child with Down syndrome has all the characteristics; some may only have a few, and others may show most of the signs of Down syndrome. Some of the physical features of children with Down syndrome include flattening of the back of the head, slanting of the eyelids, small skin folds at the inner corner of the eyes, depressed nasal bridge, slightly smaller ears, small mouth with narrow palate, decreased muscle tone, loose ligaments, and small hands and feet. About fifty percent of children with Down syndrome have one line across the palm, and there is often a wide gap between the first and second toes. The physical features observed in children with Down syndrome (and there are many more than described above) usually do not cause any significant disability in the child.

How many chromosome subtypes are observed in Down syndrome?

There are four main types of chromosome abnormalities in Down syndrome:

The vast majority of children with Down syndrome (approximately 95 percent) have an extra 21 chromosome. Instead of the normal number of 46 chromosomes in each cell, the individual with Down syndrome has 47 chromosomes. This condition is called trisomy 21.

The second type is called translocation. Here, the extra 21 chromosome is attached or translocated on to another chromosome, usually on chromosome 14, 21 or 22.

If translocation is found in a child with Down syndrome, it is important to examine the parents' chromosomes, since in at least one-third of the cases, a parent may be a carrier of the translocation. This form of chromosome error is found in 3 to 4 percent of individuals with Down syndrome.

Another chromosome problem, called mosaicism, is noted in about 1 percent of persons with Down syndrome. In this case, some cells have 47 chromosomes and others have 46 chromosomes. Mosaicism is thought to be the result of an error in one of the cell divisions after conception. Children with mosaicism Down syndrome usually have fewer physical characteristics and function better intellectually than those with trisomy 21 and translocation Down syndrome.

A very rare chromosome abnormality in persons with Down syndrome is called partial trisomy 21. Here, part of an extra chromosome 21 is usually attached to another chromosome.

What is the cause of Down syndrome?

Although many theories have been proposed, at the present time it is not known what actually causes Down syndrome. Some professionals believe that hormonal

abnormalities, X-rays, viral infections, immunologic problems, or genetic predisposition may be the cause of the improper cell division resulting in Down syndrome, but there is no evidence that any of these conditions causes Down syndrome.

It has been known for a long time that the risk of having a child with Down syndrome increases with advancing age of the mother; i.e., the older the mother, the greater the possibility that she may give birth to a child with Down syndrome. However, most babies with Down syndrome (more than 85 percent) are born to mothers younger than 35 years of age. Recent studies revealed that if the mother has only one ovary, she also has an increased risk of having a child with Down syndrome.

The extra chromosome in trisomy 21 could either originate in the mother or the father. Most often, however, the extra chromosome comes from the mother.

What kind of information can be provided through genetic counseling?

Parents who have a child with Down syndrome have an increased risk of having another child with Down syndrome in future pregnancies. It is estimated that the risk of having another child with Down syndrome is about one in 100 in trisomy 21 and probably also in mosaicism. If, however, the child has translocation Down syndrome and if one of the parents is found to be a translocation carrier, then the risk of recurrence increases markedly. The actual risk depends on the type of translocation and whether the translocation is carried by the father or the mother.

What health concerns are often observed in people with Down syndrome?

Generally, the child with Down syndrome is in need of the same kind of optimal medical care as any other child. The pediatrician or family physician should offer support and counseling to the family, provide general health maintenance, immunizations, and attend to medical problems. There are, however, situations when children with Down syndrome need special attention.

Sixty to eighty percent of children with Down syndrome have hearing deficits. Therefore, audiologic assessments at an early age and follow-up hearing tests are indicated. If there is a significant hearing loss, the child should be seen by an ear, nose and throat specialist.

Forty to fifty percent of children with Down syndrome have congenital heart disease. Many of these children will have to undergo cardiac surgery and often will need long term care by a pediatric cardiologist. Persons with Down syndrome beyond adolescence often have mitral valve prolapse which is thought to be a benign condition.

Intestinal abnormalities also occur at a higher frequency in children with Down syndrome. For example, a blockage of the food pipe (esophagus), small bowel (duodenum), and at the anus (anal atresia) are not uncommon in infants with Down syndrome. These may need to be surgically corrected at once in order to have a normal functioning gastro-intestinal tract.

Celiac disease which is due to an intolerance to a particular part of protein in flour (gluten) is also more often observed in persons with Down syndrome.

Children with Down syndrome have more eye problems than other children who do not

have this chromosome disorder. For example, 3 percent of newborn infants with Down syndrome have cataracts that need to be removed surgically. Other eye problems such as cross-eyedness (strabismus), near-sightedness, far-sightedness and other eye conditions are frequently observed in children with Down syndrome. Therefore, regular ophthalmological examinations are recommended.

Another concern relates to nutritional aspects. Some children with Down syndrome, in particular those with severe congenital heart disease, often fail to thrive in infancy. On the other hand, obesity is frequently noted during adolescence and early adulthood. These conditions can be prevented by providing appropriate nutritional counseling and dietary guidance.

Thyroid dysfunctions are more common in children with Down syndrome than in normal children. Between 15 and 20 per cent of children with Down syndrome have hypothyroidism. A few children may have hyperthyroidism. It is important to identify individuals with Down syndrome who have thyroid disorders and institute appropriate treatment, since it may compromise central nervous system functioning.

Skeletal problems have also been noted at a higher frequency in children with Down syndrome, including kneecap subluxation, hip dislocation, and atlantoaxial instability. The latter condition occurs when the first two neck bones are not well aligned because of the presence of loose ligaments.

Approximately 15 percent of people with Down syndrome have atlantoaxial instability. Most of these individuals, however, do not have any symptoms, and only 1 to 2 percent of individuals with Down syndrome have a serious

neck problem (symptomatic atlantoaxial instability) that requires surgical intervention.

Other important medical aspects in Down syndrome, including immunologic concerns, leukemia, seizure disorders, sleep apnea, skin disorders, zinc deficiency, and Alzheimer disease may require the attention of specialists in their respective fields.

Can Down syndrome be medically treated?

Although many medications and various therapies including nutritional supplements have been touted as treatment for people with Down syndrome, there is no effective medical treatment available at the present time. However, recent advances in molecular biology make it feasible now to examine the genetic basis for Down syndrome. In the spring of 2000 nearly all genes on chromosome 21 were identified and their DNA was sequenced. However, at the present time we do not know how the triple genetic dose interferes with normal developmental sequences. Once we have more knowledge of the genes' function and how to counteract these genes, a rational approach to medical therapy could emerge.

What educational services and vocational opportunities are available for people with Down syndrome?

Today early intervention programs, pre-school nurseries, and integrated/inclusive special education strategies have demonstrated that youngsters with Down syndrome can participate in many learning experiences that will positively influence their overall functioning. Research has shown that early intervention, environmental enrichment, and assistance to the families will result in marked progress that is

usually not achieved by those infants who have not had such educational and stimulating experiences.

Children with Down syndrome, like other children, can benefit from sensory and cognitive stimulation, specific exercises involving gross and fine motor activities, and speech therapy. Also, preschool nurseries play an important role in the young child's life since exploring the environment beyond the home enables the child to participate in a broader world.

Later, the school can give the child a foundation for life through the development of academic skills and physical as well as social abilities. School should provide an opportunity for the child to engage in sharing relationships with others and help to prepare the child to become a productive citizen. Contrary to some views, all children can learn, and they will benefit from placement in a normalized setting with support as needed.

During adolescence, youngsters with Down syndrome should be exposed to prevocational training in order to learn good work habits and to engage in proper relationships with co-workers. Appropriate vocational counseling and job training will result in meaningful employment, and this, in turn, should lead to a feeling of self-worth and of making a contribution to society. In addition, post-secondary school educational opportunities should be made available for young people with Down syndrome.

What attitude should society have?

It is important that society develop attitudes that will permit people with Down syndrome to participate in community life and to be accepted. They should be offered a status that

observes their rights and privileges as citizens, and in a real sense preserves their human dignity. When accorded their rights and treated with dignity, people with Down syndrome will, in turn, provide society with a most valuable humanizing influence.

Selected Resources

Organizations:

National Down Syndrome Congress
1370 Center Drive, Suite 102
Atlanta, Georgia 30338
Toll-free: 800-232-6372
Local: 770-604-9500
E-mail: info@ndsccenter.org
<http://www.ndsccenter.org>

National Down Syndrome Society
666 Broadway, 8th Floor
New York, New York 10012-2317
Toll-free: 800-221-4602
Local: 212-460-9330
E-mail: info@ndss.org
<http://www.ndss.org>

Web sites with information and resources for families:

Family Village
<http://www.familyvillage.wisc.edu>

Down Syndrome WWW Page
<http://www.nas.com/downsyn/>

Down Syndrome on the Internet
<http://downsyndrome.com/>

Down Syndrome: Health Issues –
<http://www.ds-health.com/>

Publishers:

Woodbine House
6510 Bells Mill Road
Bethesda, Maryland 20817

National Headquarters, 1010 Wayne Ave., Suite 650, Silver Spring, MD 20910, (301) 565-3842, (301) 565-3843 FAX
Web site: www.thearc.org

Toll-free: 800-843-7323

Local: 301-897-3570

E-mail: info@woodbinehouse.com

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

Publishes *The Special-Needs Collection* that includes books on Down syndrome.

Brookes Publishing

P.O. Box 10624

Baltimore, Maryland 21285-0624

Toll-free: 800-638-3775

E-mail: webmaster@brookespublishing.com

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

Publishes a number of books on Down syndrome including *A Parent's Guide to Down Syndrome*, *Toward a Brighter Future* (revised 2001) by Dr. Pueschel.

About the author: Dr. Pueschel, Professor of Pediatrics, Brown University School of Medicine, Providence, RI was awarded The Arc's 1990 Distinguished Research Award.

Revised September 2001

Language Guidelines

Language is a reflection of how people see each other. We believe that when referring to an individual with Down syndrome it is important to use language which is both accurate and respectful of the individual.



People with Down syndrome should always be referred to as people first. Instead of “a Down syndrome child,” the correct wording is “a child with Down syndrome.” This is known as Person-First language. It places the individual before the disability. Placing the person before the disability emphasizes the person first and the disability second. Person First language emphasizes respect

for the individual.

Avoid using the term “Down’s child” or describing the condition as “Down’s,” as in, “He has Down’s.” A baby born with Down syndrome is not a “Down’s baby” or a “baby with Downs.” He/she is a baby with Down syndrome.

Down syndrome is named for the English physician Dr. John Langdon Down, who characterized the condition, but did not have it. We use the preferred spelling, Down syndrome, rather than Down’s syndrome as is common in England and other parts of Europe. While Down syndrome is listed in many dictionaries with both popular spellings (with or without an apostrophe s), the preferred usage in the United States is Down syndrome. This is because an “apostrophe s” connotes ownership or possession. The AP Stylebook recommends using “Down syndrome” as well.



It is also important to use correct terminology. People “have” Down syndrome, they do not “suffer from” it nor are they “afflicted by” it. It is not a disease. Down syndrome is a chromosomal condition resulting from an extra copy of the 21st chromosome. Similarly,

when referring to peers, the correct term is “typical” peers as opposed to “normal.” Although it is acceptable to use the term, “mental retardation,” it is more acceptable to use the term “intellectual or cognitive disability.”

People with Down syndrome are sometimes portrayed as being happy and loving all the time or frequently as angels. However, avoid casting every person with Down syndrome as a superhuman model of humanity. They are unique individuals with unique personalities just like everyone else.

You can help others use responsible language which reflects the dignity of people with Down syndrome. Words can create barriers and reinforce stereotypes. Therefore, the DSAGC strongly believes in the importance of ensuring that correct language is used. A child is much more than a label. Help to educate others about the preferred way to refer to individuals with Down syndrome.

This statement was adapted from the Down Syndrome Society of Rhode Island.