

DOWN SYNDROME

INFORMATION PACKET

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- “Early Intervention” by the National Down Syndrome Society
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- “Visual Supports for Children with Down Syndrome” by the Down Syndrome Centre
- “Speech and Language Practical Activities” by Down’s Syndrome Association UK
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SUPPORT FOR FAMILIES
OF CHILDREN WITH DISABILITIES

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National Dissemination Center for Children with Disabilities (NICHCY)*

Center for Parent Information and Resources
35 Halsey St., Fourth Floor, Newark, NJ 07102
973-642-8100, www.parentcenterhub.org

National Down Syndrome Congress (NDSC)

30 Mansell Court, Suite 108, Roswell, GA 30076
800-232- 6372, www.ndsccenter.org

Libby Kumin and Jessica Pearsall

National Down Syndrome Society

666 Broadway, 8th Floor, New York, New York, 10012
800-221-4602, www.ndss.org

Family Center on Technology and Disability

1825 Connecticut Ave, NW 7th Floor Washington, DC 20009
202-884-8068, www.fctd.info

Down Syndrome Centre

Unit 1, 88/89 Furze Road, Sandyford Dublin 18
www.downsyndromecentre.ie

Down's Syndrome Association UK

Langdon Down Centre, 2a Langdon Park
Teddington, Middlesex, TW11 9PS, United Kingdom
www.downs-syndrome.org.uk

DeAnna Horstmeier & Woodbine House

6510 Bells Mill Road, Bethesda, MD 20817
800-843-7323, www.woodbinehouse.com

The American Academy of Pediatrics

141 Northwest Point Boulevard Elk Grove Village, IL 60007
800-433-9016, www.aap.org

**NICHCY lost funding in 2014, but the Center for Parent Information and Resources has obtained and will continue to update many of NICHCY'S legacy publications.*

Disclaimer: While many people have reviewed this packet for accuracy, policies, procedures and information such as websites, agency names, mailing addresses and phone numbers can change at any time. It is always a good idea to request copies of current policies and rules from the agencies with whom you are working.

Additional Packets Available

Additional disability information packets and guides are available. Many are also available in Spanish and Chinese.

They include:

- ADHD
- Autism
- Behavior
- Cerebral Palsy
- Learning Disabilities
- Mental Health
- Medical Home
- Transition from Early Intervention to Preschool

To request another packet or for more information please contact:

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Section 1: Fact Sheets and Diagnosis

General Information



Down Syndrome

A legacy disability fact sheet from NICHCY
Links updated, May 2014

Definition

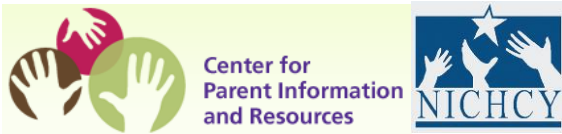
Down syndrome is the most common and readily identifiable chromosomal condition associated with intellectual disabilities. It is caused by a chromosomal abnormality: for some unknown reason, an accident in cell development results in 47 instead of the usual 46 chromosomes. This extra chromosome changes 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.



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 intellectual disability may range from mild to severe, with the majority functioning in the mild to moderate range.

Because children with Down syndrome differ in ability, it's important that families and members of the intervention team place few limitations on potential capabilities and possible achievements. Each child with Down syndrome has his or her own talents and unique capacities, and it's important to recognize these and reinforce them. As the Family Doctor website states:

In many important ways, children who have Down syndrome are very much the same as other children. They have the same moods and emotions, and they like to learn new things, to play and enjoy life. You can help your child by providing as many chances as possible for him or her to do these things. Read to your child and play with him or her, just as you would any other child. Help your child to have positive experiences with new people and places. (1)



Incidence of Down Syndrome

Nearly 6,000 babies are born with Down syndrome in the United States each year. (2) This means that 1 in every 691 babies is born with this condition. (3) Although parents of any age may have a child with Down syndrome, 80% are born to women under the age of 35. (4)

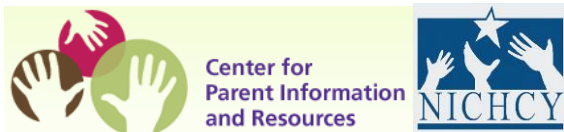
Down syndrome is not a disease, nor is it contagious. Its most common forms usually do not occur more than once in a family.

Characteristics of Down Syndrome

There are over 50 clinical signs of Down syndrome, but it is rare to find all or even most of them in one person. Every child with Down syndrome is different. **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; and
- Short neck and 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.



Help for Babies and Toddlers

When a baby is born with Down syndrome, his or her parents should know that there's a lot of help available—and immediately. Shortly after the diagnosis of Down syndrome is confirmed, parents will want to get in touch with the early intervention system in their community.

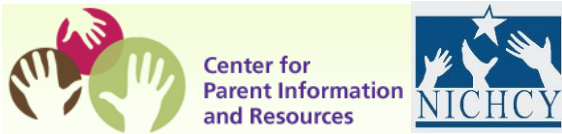
Early intervention (www.parentcenterhub.org/repository/ei-overview/) is a system of services designed to help infants and toddlers with disabilities (before their 3rd birthday) and their families. It's mandated by federal law—the Individuals with Disabilities Education Act (IDEA), the nation's special education law. Staff work with the child's family to develop what is known as an Individualized Family Services Plan, or IFSP. The IFSP will describe the child's unique needs as well as the services he or she will receive to address those needs. The IFSP will also emphasize the unique needs of the family, so that parents and other family members will know how to help their young child with Down syndrome. Early intervention services may be provided on a sliding-fee basis, meaning that the costs to the family will depend upon their income.

To identify the EI program in your neighborhood:

- Ask your child's pediatrician for a referral.
- Call the local hospital's maternity ward or pediatric ward, and ask for the contact information of the local early intervention program.

Help for School-Aged Children

Just as IDEA requires that early intervention be made available to babies and toddlers with disabilities, it requires that **special education and related services** (www.parentcenterhub.org/repository/steps/) be made available free of charge to every eligible child with a disability, including preschoolers (ages 3-21). These services are specially designed to address the child's individual needs associated with the disability—in this case, Down syndrome.



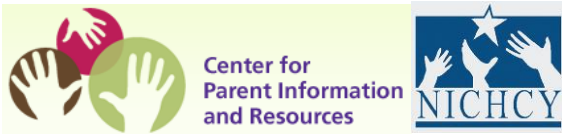
There is a lot to know about the special education process, much of which you can learn at here at the Center for Parent Information and Resources, which offers a wide range of publications on the topic. To begin, however, and access special education services for a school-aged child in your area, **get in touch with your local public school system**. Calling the elementary school in your neighborhood is an excellent place to start.

Health Considerations

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 common 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.



Educating Children with Down Syndrome

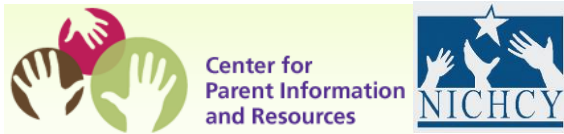
When a child with Down syndrome reaches school age (after the 3rd birthday), the public school system becomes responsible for educating the child and for addressing the child's unique needs related to his or her disability. Parents and school personnel will work together to develop what is known as an Individualized Education Program (IEP) (www.parentcenterhub.org/schoolage/iep/) for the child.

The IEP is similar to an IFSP in that it describes the child's unique needs and the services that will be provided to meet those needs. The IEP will include annual goals for learning and much more. CPIR offers a great deal of information about the process for developing an IEP—especially the parent's guide called Developing Your Child's IEP (www.parentcenterhub.org/repository/pa12)—all of which can help parents learn how to participate effectively in their child's education.

Much information is also available for teachers to learn more about effective teaching practices for children with Down syndrome. It's important for teachers to take into consideration the degree of intellectual disability involved, the child's talents and interests, and the supports and services he or she needs, as specified in the IEP. Generally speaking, teachers will find it more effective to emphasize concrete concepts with a student who has Down syndrome, instead of abstract ideas. Teaching skills in a step-by-step fashion with frequent reinforcement and consistent feedback has proven successful. Other suggestions for teachers are given toward the end of this fact sheet.

Today, the majority of children with Down syndrome are educated in the regular classroom, alongside their peers without disabilities. This is in keeping with the inclusion movement of the last decade and the requirements of IDEA, which states that each school system must ensure that:

Special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. (5)



Equally clear is this requirement of IDEA:

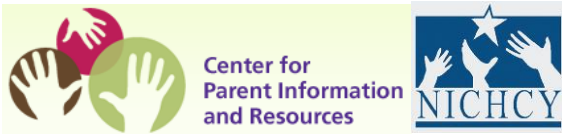
A child with a disability [may not be] removed from education in age-appropriate regular classrooms solely because of needed modifications in the general education curriculum.

(6)

For High School Students with Down Syndrome

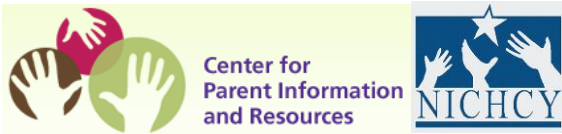
While the student is still in secondary school, parents, the IEP team, and the student himself (or herself!) will need to **plan for the future and the student's life as an adult**. This involves considering, for example, issues such as employment (with or without supports), independent living and self-care skills, the possibility of higher education or vocational training, and how to connect with adult service systems. Under IDEA, the process of planning for transition to adulthood should begin **no later than the student's 16th birthday**. (7) For adolescents with Down syndrome, it's usually important to begin earlier than that.

Adult life for individuals with Down syndrome has changed noticeably from just two decades ago. Opportunities to live and work independently in the community have greatly expanded for those with Down syndrome. This owes much to the more inclusive and comprehensive education IDEA promotes and to improved public attitudes towards disability. Today, there's a nationwide network of independent living centers, as well as apartments that are group-shared and supervised for those who need this level of support. Training, education, and assistance are also available to eligible adults with Down syndrome through service systems such as Vocational Rehabilitation and Social Security. Adult life holds many opportunities for those with Down syndrome, so it's important to plan ahead with optimism and vigor.



Tips for Parents

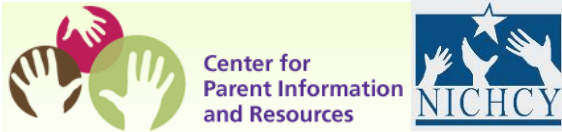
- ✓ **Learn about Down syndrome.** The more you know, the more you can help yourself and your child. See the list of organizations below.
- ✓ **Love and play with your child.** Treat your son or daughter as you would a child without disabilities. Take your child places, read together, have fun.
- ✓ **Encourage your child to be independent.** For example, help your son or daughter learn self-care skills such as getting dressed, grooming, and doing laundry.
- ✓ **Give your child chores.** Keep in mind his or her age, mental capacity, attention span, and abilities. Divide tasks into small steps. Explain what your child is supposed to do, step by step, until the chore is done. Demonstrate. Offer help when it's needed and praise when things go well.
- ✓ **Work with the professionals who are working with your child.** Participate in team meetings where your child's education or program is being planned, share your unique knowledge of who your son or daughter is, advocate that the program address your child's needs.
- ✓ **Find out what your child is learning at school.** Look for ways to apply it at home. For example, if the teacher is reviewing concepts of money, take your child to the supermarket with you to help keep track of what money you're spending.
- ✓ **Look for social opportunities in the community** (such as Scouts) or activities offered through the department of sports and leisure. Joining in and taking part will help your child develop social skills and have fun.
- ✓ **Talk with other parents whose children have Down syndrome.** They can be a fountain of practical advice and emotional support. Visit the websites of the organizations listed below to see if they have a parent group nearby.



- ✓ **Be patient, be hopeful.** Your child, like every child, has a whole lifetime to learn and grow.

Tips for Teachers

- ✓ **Learn as much as possible about Down syndrome.** The organizations mentioned in this fact sheet can help you identify techniques and specific strategies to support the student's learning. We've included some additional suggestions below.
- ✓ This may seem obvious, but sometimes the appearance of Down syndrome can give the mistaken impression that the child cannot learn. **Focus on the individual child and learn firsthand what needs and capabilities he or she has.**
- ✓ **Realize that you can make a big difference in this student's life!** Use the student's abilities and interests to involve and motivate. Give lots of opportunities for the student to be successful.
- ✓ **Talk candidly with your student's parents.** They're experts and can tell you a great deal about their daughter's or son's special needs and abilities.
- ✓ **Work with the student's parents and other school personnel** to develop and implement a special educational plan (IEP) that addresses the individual needs of the student. Share information on a regular basis with parents about how things are going for the student at home and in school.
- ✓ If you're not part of the student's IEP team, **ask for a copy of this important document.** The student's educational goals will be listed there, as will the services and accommodations that he or she is supposed to receive, including in your class.



- ✓ **Talk to specialists in your school** (for example, special educators), as necessary. They can help you identify methods that are effective for teaching a student with disabilities, ways to adapt the curriculum, and how to address the student's IEP goals in the classroom.
- ✓ **Be as concrete as possible with the student.** Demonstrate what you want to see happen instead of giving only verbal instructions. When you share concrete information verbally, also show a photograph. Give the student practical materials and experiences and the opportunity to touch and examine objects.
- ✓ **Divide new tasks and large tasks into smaller steps.** Demonstrate the steps. Have the student do the steps, one by one. Offer help when necessary.
- ✓ **Give the student immediate, concrete feedback.**

Organizations

National Down Syndrome Society

1.800.221.4602 | www.ndss.org/ (English)

<http://www.ndss.org/Resources/NDSS-en-Espanol/> (Spanish)

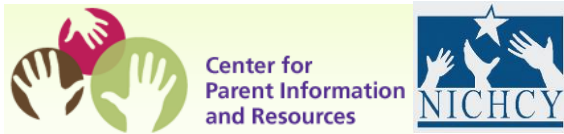
NDSS offers authoritative information about Down syndrome, including a new parent video, *A Promising Future Together: A Guide for New Parents of Children with Down Syndrome*.

National Down Syndrome Congress

1.800.232.6372 | www.ndsccenter.org (English)

<http://www.ndsccenter.org/en-espanol/> (Spanish)

NDSC is also an authoritative source of information on Down syndrome, offering such resources as its *New Parent Package*, a collection of materials refined over years to provide new and expectant parents with an initial understanding of the challenges— and joys—of raising a child with Down syndrome.



Resource of Special Note

Woodbine House publishes an impressive collection of low-cost books and DVDs on Down syndrome, including a Parent's Guide (in English and Spanish) and materials for teachers. Call 1.800.843.7323 or visit: www.woodbinehouse.com/Down-Syndrome.29.0.0.2.htm

References

1 Family Doctor. (2005). *Down syndrome: How to know if your child has Down syndrome*. This article is no longer available, but you can read the new article on Down syndrome, at: <http://familydoctor.org/familydoctor/en/diseases-conditions/down-syndrome.html>

2 National Down Syndrome Society. (n.d.). *What is Down syndrome?* Available online at: <http://www.ndss.org/Down-Syndrome/What-Is-Down-Syndrome>

3 Ibid.

4 National Down Syndrome Congress. (n.d.). *Facts about Down syndrome*. Available online at: <http://www.ndsccenter.org/resources/general-information/facts-about-down-syndrome/>

5 Section 300.114(a)(2)(ii) of IDEA.

6 Section 300.116(e) of IDEA.

7 Section 300.320(b) of IDEA, Transition services.



Language Guidelines

Public Awareness Guidelines

- The correct name of this diagnosis is Down syndrome. There is no apostrophe (Down). The “s” in syndrome is not capitalized (syndrome).
- An individual with Down syndrome is an individual first and foremost. The emphasis should be on the person, not the disability. A person with Down syndrome has many other qualities and attributes that can be used to describe them.
- Encourage people to use people-first language. “The person with Down syndrome”, not “the Down syndrome person.” A person with Down syndrome is not “a Downs”.
- Words can create barriers. Recognize that a child is “a child with Down syndrome,” or that an adult is “an adult with Down syndrome.” Children with Down syndrome grow into adults with Down syndrome; they do not remain eternal children. Adults enjoy activities and companionship with other adults.
- It is important to use the correct terminology. A person “has” Down syndrome, rather than “suffers from,” “is a victim of,” “is diseased with” or “afflicted by.”
- Each person has his/her own unique strengths, capabilities and talents. Try not to use the clichés that are so common when describing an individual with Down syndrome. To assume all people have the same characteristics or abilities is demeaning. Also, it reinforces the stereotype that “all people with Down syndrome are the same.”

Here are some basic guidelines for using People First Language:

- Put people first, not their disability
 - A “person with a disability”, not a “disabled person”
 - A “child with autism”, not an “autistic child”
- Use emotionally neutral expressions
 - A person “with” cerebral palsy, not “afflicted with” cerebral palsy
 - An individual who had a stroke, not a stroke “victim”
 - A person “has” Down syndrome, not “suffers from” Down syndrome
- Emphasize abilities, not limitations
 - A person “uses a wheelchair”, not “wheelchair-bound”
 - A child “receives special education services”, not “in special ed”
- Adopt preferred language
 - A “cognitive disability” or “intellectual disability” is preferred over “mentally retarded”
 - “Typically developing” or “typical” is preferred over “normal”
 - “Accessible” parking space or hotel room is preferred over “handicapped”

RESOURCES

- [OVERVIEW](#)
- [GENERAL INFORMATION](#)
- [NEW AND EXPECTANT PARENTS](#)
- [DELIVERING A DIAGNOSIS](#)
- [MORE ALIKE CAMPAIGN](#)
- [HEADQUARTERS](#)
- [SPEECH AND LANGUAGE](#)
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National Down Syndrome Congress

30 Mansell Court, Suite 108
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Toll Free: 800.232.NDSC (6372)

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[NDSC Film Expert on “The Amazing Spider-Man 2”](#)
May 23, 2014

[NDSC Film Expert Reviews “Rio 2”](#)

Recent Tweets

RT @OWNTV: Go on a journey with 5 people who remind us what means to be human. The debut of #TheSpecials airs Sept 7, 2:30/1:30c <http://t.c...> Aug 09, 2014

Section 2: Strategies for Home and School

*Different management approaches for the specific disability
from various sources*





Early Intervention

The first years of life are a critical time in a child's development. All young children go through the most rapid and developmentally significant changes during this time. During these early years, they achieve the basic physical, cognitive, language, social and self-help skills that lay the foundation for future progress, and these abilities are attained according to predictable developmental patterns. Children with Down syndrome typically face delays in certain areas of development, so early intervention is highly recommended. It can begin anytime after birth, but the sooner it starts, the better.

What Is Early Intervention?

Early intervention is a systematic program of therapy, exercises and activities designed to address developmental delays that may be experienced by children with Down syndrome or other disabilities. These services are mandated by a federal law called the Individuals with Disabilities Education Act (IDEA). The law requires that states provide early intervention services for all children who qualify, with the goal of enhancing the development of infants and toddlers and helping families understand and meet the needs of their children. The most common early intervention services for babies with Down syndrome are physical therapy, speech and language therapy, and occupational therapy.

When Should Early Intervention Start?

Early intervention should begin any time shortly after birth, and usually should continue until the child reaches age three. An amendment to IDEA in 2004 allows states to have early intervention programs that may continue until the child enters, or is eligible to enter, kindergarten. The sooner early intervention begins, the better, but it's never too late to start.

How Can Early Intervention Benefit a Baby with Down Syndrome?

Development is a continuous process that begins at conception and proceeds stage by stage in an orderly sequence. There are specific milestones in each of the four areas of development (gross and fine motor abilities, language skills, social development and self-help skills) that serve as prerequisites for the stages that follow. Most children are expected to achieve each milestone at a designated time, also referred to as a "key age," which can be calculated in terms of weeks, months or years. Because of specific challenges associated with Down syndrome, babies will likely experience delays in certain areas of development. However, they will achieve all of the same milestones as other children, just on their own timetable. In monitoring the development of a child with Down syndrome, it is more useful to look at the sequence of milestones achieved, rather than the age at which the milestone is reached.

Milestone	Range for Children with Down Syndrome	Typical Range
GROSS MOTOR		
Sits Alone	6 – 30 Months	5 – 9 Months
Crawls	8 – 22 Months	6 – 12 Months
Stands	1 – 3.25 Years	8 – 17 Months
Walks Alone	1 – 4 Years	9 – 18 Months
LANGUAGE		
First Word	1 – 4 Years	1 – 3 Years
Two-Word Phrases	2 – 7.5 Years	15 – 32 Months
SOCIAL/SELF-HELP		
Responsive Smile	1.5 – 5 Months	1 – 3 Months
Finger Feeds	10 – 24 Months	7 – 14 Months
Drinks From Cup Unassisted	12 – 32 Months	9 – 17 Months
Uses Spoon	13 – 39 Months	12 – 20 Months
Bowel Control	2 – 7 Years	16 – 42 Months
Dresses Self Unassisted	3.5 – 8.5 Years	3.25 – 5 Years

What Are the Types of Early Intervention Therapies and How Does Each Type Address Specific Aspects of a Baby's Development?

Physical therapy focuses on motor development. For example, during the first three to four months of life, an infant is expected to gain head control and the ability to pull to a sitting positions (with help) with no head lags and enough strength in the upper torso to maintain an erect posture. Appropriate physical therapy may assist a baby with Down syndrome, who may have low muscle tone, in achieving this milestone.

Before birth and in the first months of life, physical development remains the underlying foundation for all future progress. Babies learn through interaction with their environment. In order learn, therefore, an infant must have the ability to move freely and purposefully. An infant's ability to explore his or her surroundings, reach and grasp toys, turn his or her head head while watching a moving object, roll over and crawl are all dependent upon gross as well as fine motor development. These physical, interactive activities foster understanding and mastery of the environment, stimulating cognitive, language and social development.

Another long term benefit of physical therapy is that it helps prevent compensatory movement patterns that individuals with Down syndrome are prone to developing. Such patterns can lead to orthopedic and functional problems if not corrected.

Speech and language therapy is a critical component of early intervention. Even though babies with Down syndrome may not say their first words until 2 or 3 years of age, there are many pre-speech and pre-language skills that they must acquire before they can learn to form words. These include the ability to imitate and echo sounds; turn taking skills (learned through games like "peek-a-boo"); visual skills (looking at the speaker and objects); auditory skills (listening to music, speech, or speech sounds for lengthening periods of time); tactile skills (learning about touch, exploring objects in the mouth); oral motor skills (using the tongue, moving the lips); and cognitive skills (understanding object permanence and cause and effect relationships).

A speech and language therapist can help with these and other skills, including breastfeeding. Because breastfeeding employs the same anatomical structures used for speech, it can help strengthen a baby's jaw and facial muscles and lay the foundation for future communication skills.

Occupational therapy helps children develop and master skills for independence. Occupational therapy can help with abilities such as opening and closing things, picking up and releasing toys of various sizes and shapes, stacking and building, manipulating knobs and buttons, experimenting with crayons etc. Therapists also help children learn to feed and dress themselves and teach them skills for playing and interacting with other children.

Early intervention can also prevent a child with Down syndrome from reaching a plateau at some point in development. The

overarching goal of early intervention programs is to enhance and accelerate development by building on a child's strengths and by strengthening those skills that are weaker in all areas of development.

How Can Parents Benefit From Early Intervention Programs?

Programs of early intervention have a great deal to offer to parents in terms of support, encouragement and information. The programs teach parents how to interact with their infant or toddler, how to meet their child's specific needs and how to enhance development.

How Do I Sign Up for Early Intervention Services?

Each state has its own set of laws governing early intervention services. Parents can get a referral from their baby's doctor or find a local agency by visiting www.nectac.org. Once a referral has been made, the program staff must schedule and complete an initial evaluation within a specified time. Once the assessment is done, a caseworker is assigned to coordinate the various services for which the baby and family qualify. Early intervention services are individualized to meet the specific needs of each individual baby. The caseworker, therapists and family will determine areas of focus and set goals based on developmental milestones. These will be recorded in a document called the Individualized Family Service Plan (IFSP).

Who Pays for Early Intervention?

The evaluation to determine whether your child is eligible for early intervention is free of charge if performed by a state authorized entity. No child deemed eligible can be denied services based on ability to pay, but insurance companies may be billed and/or a sliding scale payment may be required, depending on the state. Parents should check with their state's early intervention center for information about authorized service providers and financial obligations. Frequently, there is little or no cost to parents for these services.

What Happens After Age 3?

The Individuals with Disabilities Education Act (IDEA), which regulates early intervention, also mandates that local school districts provide a free, appropriate, public education for preschool-age children with disabilities starting at the age of three, unless doing so would be inconsistent with state law or practice or the order of any court respecting the provision of public education to children between the ages of three and five.

NDSS RESOURCES

- [Therapies & Development](#)
- [A Healthy Start](#)
- [Health Care Guidelines](#)

EXTERNAL RESOURCES

- Division for Early Childhood of the Council for Exceptional Children
www.dec-sped.org
One of 17 divisions of the Council for Exceptional Children, this organization supports policies and practices that support families and enhance development in especially young children with disabilities and learning delays.
- Early Childhood Outcomes Center
www.the-eco-center.org
The ECO Center promotes the development of progress reports for young children with disabilities and the implementation of these reports on a local, state, and national level.

- Ed Pubs
www.edpubs.gov
A searchable database of the US Department of Education's online catalogue of free publications
- Education Resources Information Center (ERIC) Database
www.eric.ed.gov
Sponsored by the Institute of Education Sciences of the US Department of Education, this is a free online digital library of journal and non-journal education literature.
- National Dissemination Center for Children and Youth with Disabilities (NICHCY)
www.nichcy.org
800-695-0285
NICHCY is a central source of information on pre-adolescents and teens with disabilities. It features a clear and detailed guide to IDEA, the law authorizing early intervention services and special education, and State Resource Sheets to help you connect with disability agencies and organizations in your state.
- National Early Childhood Technical Assistance Center (NECTAC)
www.nectac.org
NECTAC supports the national implementation of the Individuals with Disabilities Education Act (IDEA) by working with each state to provide technical assistance for children with disabilities and their families. The website provides a list of early intervention programs by state.
- Open Books Open Doors
openbooksopendoors.com
Website contains resources for parents and teachers on best practices in literacy instruction for students with Down syndrome
- Technical Assistance Alliance for Parent Centers
www.taalliance.org
Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) in each state provide training and information to parents of infants, toddlers, children, youths with disabilities and professionals who work with them. The website provides a list of centers by state.

DVDS

- Down Syndrome: The First 18 Months. Blueberry Shoes Productions.
- Emma's Gifts. Endless Horizon Productions.

BOOKS

- Early Communication Skills for Children with Down Syndrome. Kumin, L. Bethesda, MD: Woodbine House. (2003)
- The Early Intervention Dictionary. Coleman, J. G. M. Bethesda, MD: Woodbine House. (2006)
- Fine Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals (Second Edition). Bruni, M. Bethesda, MD: Woodbine House. (2006)
- Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals. Winders, P. Bethesda, MD: Woodbine House. (1997)
- Negotiating the Special Education Maze: A Guide for Parents and Teachers (Fourth Edition). Anderson, W., Chitwood, S., Hayden, D., Takemoto, C. Bethesda, MD: Woodbine House. (2008)
- Steps to Independence: Teaching Everyday Skills to Children with Special Needs. Baker, B. & Brightman, A. Baltimore, MD: Paul H. Brooks Publishing Co. (2004)
- The New Language of Toys: Teaching Communication Skills to Special Needs Children (Third Edition). Schwartz, S. Bethesda, MD: Woodbine House. (2004)
- Teaching Reading to Children with Down Syndrome: A Guide For Parents and Teachers. Oelwein, P. Bethesda, MD: Woodbine House. (1995)

Assistive Technology 101



What Is Assistive Technology?

Assistive technology is any kind of technology that can be used to enhance the functional independence of a person with a disability. Often, for people with disabilities, accomplishing daily tasks such as talking with friends, going to school and work, or participating in recreational activities is a challenge. Assistive Technology (AT) devices are tools to help to overcome those challenges and enable people living with disabilities to enhance their quality of life and lead more independent lives.

Assistive technology can be anything from a simple (low-tech) device such as a magnifying glass, to a complex (high-tech) device, such as a computerized communication system. It can be big — an automated van lift for a wheelchair — or small — a Velcro attached grip attached to a pen or fork for example, for eating and writing. Assistive technology can also be a substitute — such as an augmentative communication device that provides vocal output for a child who cannot communicate with her voice.

Meeting Challenges with Assistive Technology

Assistive technology helps to level the playing field for individuals with disabilities by providing them a way to fully engage in life's activities. An individual may use assistive technology to travel about, participate in recreational and social activities, learn, work, communicate with others, and much more.

Here are several examples of AT that enables people with disabilities to enter into the community and interact with others.

- For greater independence with mobility and travel, people with physical disabilities may utilize mobility aids, such as wheelchairs, scooters, and walkers. Adapted car seats and vehicle wheelchair restraints promote safe travel.
- Hand-held GPS devices help persons with visual impairments navigate busy city streets and utilize public transportation.
- Building modifications at work sites, such as ramps, automatic door openers, grab bars, and wider doorways mean fewer barriers to employment, businesses, and community spaces, such as libraries, churches, and shopping malls.
- Special computer software and hardware, such as voice recognition programs and screen enlargement programs, enable persons with mobility and sensory impairments to carry out educational or work-related tasks.
- Education and work aids such as automatic page turners, book holders, and adapted pencil grips enable children to participate in classroom activities.
- Bowling balls with hand-grips and one-handed fishing reels are a few examples of how technology can be adapted for sporting activities. Light-weight wheelchairs have been designed for organized sports, such as basketball, tennis, and racing.
- Adaptive switches make it possible for a child with limited motor skills to play with toys and games.
- Accessibly designed movie theaters provide closed captioning and audio description for moviegoers with hearing and visual difficulties.
- Devices to assist a person with daily living tasks, such as cooking, dressing, and grooming, are available for people with special needs. For example, a medication dispenser with an alarm can be set to remind a person with memory loss to take daily medication. A person with use of only one hand can use a one-handed cutting board and a cabinet mounted can opener to cook meals with improved independence and safety.



Choosing the Right Assistive Technology Device(s) for Your Child

To determine the assistive technology needs of a child, an AT assessment should be conducted. The assessment can be conducted by the school, an independent agency, or an individual consultant. This assessment should take place in a child's customary environments -- home, school, and community.

It is important that the assessment address the child's strengths as well as his/her weaknesses. It is key, when discussing how the child participates in his/her world, to hear the perspectives of teachers, parents and siblings, as well as that of the child. The discussion should not be limited merely to what skills the child possesses but should include the ways in which a child communicates, what he likes and dislikes, and what kind of strategies and interventions are helpful in interacting with the child. Consideration must be taken on how a child's need for AT might change depending on the environment, for example on the playground, the classroom, a friend's house or in a public place like a mall or library. This type of input will provide clues as to what technology might work and how well your child will respond to it.

The end result of an assessment is a recommendation for specific devices and services. Once it is agreed that assistive technology would benefit a child, issues related to design and selection of the device, as well as maintenance, repair, and replacement of devices should be considered. Training (to use the device) and ongoing technical assistance is necessary not only for the child, but also for family members, teachers, service providers, and other people who are significantly involved in a student's life. It is also important to integrate and coordinate any assistive technology with therapies, interventions, or services provided by education and rehabilitation plans and programs.

Acquiring assistive technology does not just happen once in a lifetime. The type of devices your child needs may change depending on the child's age, abilities, physical status, and features of the immediate environment. Change in your child's life may necessitate a re-assessment of his or her assistive technology needs.

Learning More about Assistive Technology

Parents can help to identify potential AT for their child if they learn about the choices that are available. A good place to start is often with speech-Language therapists, occupational therapists and school professionals. There are many organizations that provide AT information and training to consumers and families such as parent training and Information centers (PTI's), community technology centers, state assistive technology programs and rehabilitation centers. If possible you should visit an AT center with your child to see and try out various devices and equipment. Some AT centers offer lending programs that allow families to borrow devices for a trial period.

The Family Center on Technology and Disability (FCTD) offers a wide range of assistive technology resources for disability organizations, AT providers, educators and families of children with disabilities. Families are always welcome to visit the FCTD web site (www.fctd.info) to find other AT and disability organizations and to learn more about assistive technology.

The following list includes several organizations that offer a various resources on AT.

Abledata - www.abledata.com

Assistivetech.net - www.assistivetech.net

AbilityHub - www.abilityhub.com

PACER Center - Simon Technology Center - <http://www.pacer.org/stc/>

Technical Assistance Alliance for Parent Centers - www.taalliance.org

Association of State Technology Act Programs - www.ataporg.org/stateatprojects.asp



Visual Supports for Children with Down Syndrome

Posted on October 19, 2011 by Heidi

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3

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By: Marinet vanVuren

Marinet vanVuren is a South African born Speech and Language Therapist. For the past seven years she has worked with a range of Irish disability organisations including Enable Ireland, St Michael's House and the Children's Sunshine Home. She recently set up her own private speech and language therapy practice where she sees children of all disabilities with various speech, language and feeding difficulties.



We all benefit from visual supports. We have diaries and calendars; we watch the clock, write shopping lists and keep invitations. All children with Down Syndrome can benefit from visual supports. Visual supports are information that we can see through pictures, objects, gestures and written language. Children with Down Syndrome are strong visual learners. This means that they understand what they SEE better than what they hear. Because visual supports are concrete symbols, they assist children in processing the language, organising their thinking and remembering information. Visual supports are also an effective way to:

- Improve understanding of words, routines and situations
- Aid memory
- Give reassurance, confirmation and reduce anxiety

Examples of visual supports include:

- Visual schedules / timetables

- Choice boards
- Visually supported play
- Step-by-step directions
- Calendars
- Classroom rules
- Social stories
- Sign Language

Visual Supports for Young Children

Sometimes children with Down Syndrome understand more language than they are able to use. Visual supports are a great way to aid expressive communication.

Photographs can be taken of any object or routine and put somewhere accessible, for example

- food symbols on the fridge
- toy symbols on the toy box

Your child is then able to use the symbols to tell you what he/she wants by looking at the pictures, pointing to them or handing them over. Photographs can also be put on objects around the house to label them and help your child's understanding, e.g. toilet, fridge, door, etc. Always remember to write the word in clear font underneath the photograph. Avoid using block capitals, underlining or italics.

Making singing fun: If you Google 'Scope 2007 Nursery Rhymes to Sing, See and Sign' you will find free printable resources of familiar nursery rhymes, e.g. Baa Baa black Sheep, Old MacDonald, etc. These nursery rhymes are a perfect example of the effectiveness of visual supports to encourage communication and attention. The rhymes include sign language, picture symbols and the written word. Have a look!

Please note: visual supports won't stop your child from speaking. They are a way of adding to your child's skills and reducing frustration.

Visual Schedules/ Timetables for Home or School

A visual timetable is a display of the sequence of events within a set period. Timetables provide a person with consistent cues about their daily routine. It helps children organise their day and know the general sequence of events. Visual timetables can be arranged in many ways. Here is a brief description from Scope* of how to make your own visual timetable.

1. Make a list of the activities in the order they occur.
2. Decide on the complexity of the display: will the Timetable represent daily or weekly activities?
3. Decide where or how the Timetable will be displayed, for example, a wall chart or an A4 folder.
4. Select photographs/pictures/symbols/words which are meaningful to your child and which match their experience of the event or activity.
5. Decide on the size of each item. Items need to be large enough to be clearly seen by your child.
6. Work out the number of items that your child can cope with.
7. Work out what materials your display will be made of and how each item will be attached to the display, for example, blue track, self-adhesive Velcro, magnets. Items may need to be laminated to make them last longer.

8. Include a way of letting your child know that an activity is finished. You can attach a 'finished' envelope or box at the bottom of your Timetable where your child can post the picture once the activity is completed.

*Scope (2004). InterAACtion: Strategies for Intentional and Unintentional Communicators

In conclusion: I once read a poem (unfortunately I don't know the author) that described the use of visual supports beautifully:

- When I see ... I understand
- When I hear, I forget
- In one ear, and out the next.
- But it makes more sense to me
- When there's something I can see
- Whether I'm young, or if I'm old
- It helps to see what I am told
- A written word, a picture card
- Can simplify what might be hard.
- A visual aid describes it best
- And gives the voice and ears a rest
- From making friend to handling fear
- Showing me how makes it more clear
- There's not much left to explain
- When a picture shows my brain
- Who or where or what you mean
- On a clear computer screen
- To recall what you heard
- A picture paints a thousand words.

Featured Organization: The Down Syndrome Centre

We thank the Down Syndrome Centre for allowing us to reprint their copyrighted article. For more information about this organization please visit [The Down Syndrome Centre](#)

This entry was posted in OT, Psych, SLP and tagged 7 October 2011, Article, Down Syndrome, Newsletter, OT, SLP, Visual Supports. Bookmark the permalink.

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Speech and Language Practical Activities Factsheet

1. How to help develop your child's attention and listening skills

Developing your child's attention is very important for their language development.

Strategies

- Remove any distractions and background noise
- Ensure that you and your child are sitting face to face
- Make sure you have eye contact with your child
- Gain their attention by using their name

Activities

- Sing songs and rhymes with actions, e.g. Wheels on the Bus, Heads and Shoulders
- Play Musical Bumps/Statues – play some music and stop at intervals. Encourage your child to sit on a chair or on the floor as quickly as possible when the music stops, and to run or dance when the music plays.
- Go for a walk/Sit in a room and encourage your child to listen to the sounds they can hear, e.g. aeroplanes, dogs, cars

2. How to help develop your child's play skills

Developing your child's play skills is very important for their communication development.

Strategies

- Allow your child to take the lead, follow them in their play
- Comment on your child's play using short phrases and emphasise key words such as "teddy JUMPING"
- Give plenty of time for your child to talk, taking turns to speak.

Activities

- Exploratory Play
 - Allow your child to explore objects such as wet/dry, hard/soft e.g. fill a tray with pasta and allow your child to feel the textures
 - Use cause and effect toys such as pop up toys, wind up toys.

- Messy play
 - Finger painting, potato printing, use, play dough, putty, shaving foam.
- Pretend play
 - Keep everyday objects, e.g. boxes, egg cartons and encourage your child to play with them. For example a box can be a car, a boat or a hat
 - Have a tea part with a teddy or doll and feed them using pretend food
 - Do everyday actions with dollies and teddies: put them to sleep, feed them, etc.

3. How to help develop your child's social interaction skills

Developing your child's social interaction is very important for their language development

Strategies

- Encourage your child to look at you.
- Call his or her name, jangle keys, or by touch his/her face to help him or her look.
- When your child does look at you, show how pleased you are by giving specific praise for 'good looking'.

Activities

- Turn taking
 - Play games such as: building towers, taking turns to unload the shopping, rolling a ball
- Eye Contact
 - Play games such as: peek-a-boo, rolling a ball, ready steady go games, blowing bubbles

4. How to help develop your child's speech sound skills

Developing your child's speech sound skills is very important for their communication development

Strategies

- If your child is very difficult to understand encourage him/her to show you what you mean, or gesture to you.
- Avoid directly correcting the speech of your with specific speech difficulties.
- Speak clearly
- Speak slowly
- Make sure your child is looking at you when you talk.
- Visual clues are also important in learning speech sounds.
- Get your child's hearing checked

Activities

- Your Speech & Language Therapist may give you specific activities to carry out dependant on your child's speech difficulty.

5. How to help develop your child's language skills

Developing your child's language is very important for their communication development

Strategies

- Speak to your child using simple language while you play.
- Ensure you match their language e.g. if your child is using one word phrases, you only use one-two word phrases
- Use gestures (Makaton)/visuals when speaking
- Give plenty of time for your child to talk, taking turns to speak.
- Use choices as this will encourage your child to use the words e.g. "do you want milk or juice?"
- Create a need to talk, e.g. give you child a cup but with no drink in it, or a piece of paper to draw a picture but no pencils.

Activities

- Daily activities.
 - Talk through everyday activities as they are happening, e.g. breakfast time, it's time to eat, cereal or toast, butter the bread.
- Nursery rhymes.
 - Children like the repetition of simple nursery rhymes and it encourages copying/imitating e.g. 'Baa baa black sheep
- Model noises that toys make e.g.:
 - Cars – beep beep
 - Cow – moo, moo
 - Train – choo choo
 - Dog - woof woof
- Bubbles
 - Playing with bubbles allows you repeat simple functional words such as "up", "pop", "gone", "more?"
 - When the bubbles have gone ask your child "more?"



Behavior and Communication

By Libby Kumin and Jessica Pearsall

Editor's note: Dr. Libby Kumin is a professor of speech language pathology at Loyola College in Maryland, and an author, speaker and researcher on communication skills in people with Down syndrome. Jessica Pearsall, mother of a 12-year-old son with DS, is a parent advocate, presenter and support partner with Shared Support in MD.

Every behavior is a form of communication. When a child displays behaviors that are difficult or undesirable, understanding what the child is communicating through the behavior is the most important step in changing the behavior.

A behavior can have many underlying causes.

- Emotional: fear, anxiety, isolation, frustration
- Physical: metabolic, ADHD, sensory, hunger, thirst, tactile sensitivities
- Environmental: noise, movement, allergies, temperature
- Response to abuse and bullying
- Inability to ask for help
- Situation avoidance

When children and adults can't tell us what is bothering them, it is often difficult to determine the behavior's cause. A behavior may have multiple causes and peeling back the onion to find the origin is not always easy. One day, a fifth grade student with Down syndrome slapped several typical peers. The school team attempted to interpret what the behavior was communicating by investigating what happened right before the slaps. In a water fountain incident, the peer let the student with DS go in front of him and the student received a slap. The confused team could find no apparent reason for the slapping. Luckily, an insightful team member remembered that the slapping happened on the day the student visited the middle school he would attend the next year. This was a major change after six years at the elementary school. After exploring and addressing his fears, the slapping ceased.

Sometimes, a Functional Behavior Assessment (FBA) can determine the behavior's cause and an intervention plan developed to provide an alternative way of communicating. The FBA should lead to a positive behavior intervention plan (PBIP) to help reinforce good behavior and extinguish noncompliant or troublesome behavior. A proper FBA includes everyone who has information about the child's problematic behavior and includes:

- the antecedents (what happens before the behavior),
- the behavior, and
- the consequences (what happens after the behavior)

For example, when the teacher asks children to get in line, one child runs up without pushing his chair in, causing other children to trip. So, the teacher's announcement is the antecedent and the child running to the area and failing to push in his chair is the behavior. What is the consequence? It might be, that he is always first in line because he was the first one to get there. Does he want to be first in line? Or, is he sensitive to the clamor of moving children and chairs on the tile floor and trying to protect himself? By determining the underlying reason, the FBA team can remedy the situation through a PBIP that helps develop alternative acceptable communication skills.

Here are 23 strategies that support appropriate behaviors. Try them and see what works for you.

1) Prepare for expected situations. Sometimes, you are aware of upcoming situations and can help prepare

RESOURCES

[OVERVIEW](#)
[GENERAL INFORMATION](#)
[NEW AND EXPECTANT PARENTS](#)
[DELIVERING A DIAGNOSIS](#)
[MORE ALIKE CAMPAIGN](#)
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your child in advance. If you anticipate a stressful situation, talk about feelings and emotions using pictures and discuss what each emotion feels like, when it might happen, calming strategies and appropriate expression. For specific situations, practice how to behave by using scripts, social stories or video modeling. If a setting has been traumatic or confusing in the past, it may help to write a combination script and social story to prepare for the future.

2) Develop skills for telling what happened. Just as with other children, it is likely that your child will want to tell you about situations and events that occur at school, camp, community activities or jobs. Help your child learn how to retell a story. Provide visual cues, pictures or written cues and practice telling what happened.

Start with this simple form and ask:

- Who was there?
- When did it happen?
- What happened?
- Where did it happen?

After the child masters who, what, when and where, another form (next column) supports the child in adding more details as he is retelling a story:


3) Create an agenda. Whenever possible, communicate the planned activities for the day, week, or month depending on the child's age and understanding of time concepts.

4) Prepare for change. Being able to transition and deviate from routines when necessary are important school and home skills. Communicate changes and transitions ahead of time. For younger children, use pictures.

5) Give choices. Always help people feel they have control. Try to use real choices. Don't use threats disguised as choices, such as "You can either wash your hands or go to bed" or "You can either finish this work or go to time out."

6) Try the Speak and Spin technique. If the child is in "debate" mode or talking on and on to avoid an activity, state simply what needs to be done, turn your back and walk away. Once clear instructions have been given, end the conversation.

7) Investigate a reaction to internal states. Hunger, thirst or sensory issues such as a scratchy sweater can manifest into a behavior. Consider this possibility and address it to stop a behavior.

 Heap praise. Positive words go a long way. Every chance you get, catch children doing something right. Try giving two positive comments for every negative one. Use specific and real praise, e.g. "Amy, it was very polite of you to introduce your new friend to our class. Thank you."

9) Ask for help. Your child can learn that everybody needs help sometimes and it's okay to ask. Specifically point out when, how, and who to ask for help. Let her see you and other family members seeking and accepting help in many situations. Thank others enthusiastically for their help. Work on scripts that your child can use to ask for help, such as "Excuse me" and "Could you help me?" Children must know they will not be penalized or ridiculed or they will avoid asking for help.

Use Social Stories (see resources) to specifically teach your child how to handle difficult situations. For example, if he will need help applying bug spray on a Boy Scouts camping trip, write a Social Story about what will happen at the campsite, including what to say to get the help he needs.

10) Ask for clarification and make repairs. Children need to ask for clarification when they don't understand what to do. They are more likely to ask at home than at school or in the community. They also need to be able to explain more fully (making repairs) when someone does not understand them. For more information on clarifications and repairs, see *Helping Children with Down Syndrome Communicate Better* (see resources).

11) Follow rules and routines. When a child does not follow the rules, behavior and cooperation are usually blamed. Consider other possible underlying causes, such as hearing loss, sensory processing disorder or auditory memory and receptive language problems.

12) Promote generosity. Children and adults with disabilities often receive help; however, nothing is more rewarding than being able to give to others. Ensure opportunities for responsibility and giving back to the community.

13) Empower leadership. Provide leadership opportunities, e.g. running a family meeting, making the family meeting agenda, planning a meal, making morning announcements at school, serving on student council, etc.

14) Discourage imitating inappropriate behavior. Children with DS often model typical peers — both appropriately and inappropriately. They get into trouble by repeating "bad" words or staying put when everyone

else runs away. To help children learn appropriate behavior for a situation, use video modeling or self-modeling (see resources).

15) Set boundaries and consequences. Be a person of your word. Set boundaries and consequences ahead of time and stick to them.

16) Offer breaks. Give natural breaks when working on difficult or stressful tasks. At school, walking to the rest room or water fountain, returning media books or taking notes to the front office are natural breaks.

17) Give simple, clear instructions. Keep instructions short. If possible, wait until the child responds to the instruction before you go on to the next instruction. Don't give a long list of instructions verbally. If possible, provide a check list or written instructions for children or adults who can read.

18) Try diversion. Redirect the child or adult to a different activity when possible.

19) Use humor. Almost everyone responds well to using humor.

20) Provide information on consequences (positive and negative). Use "if/when" strategies, e.g. "When you finish this activity you can use the computer."

21) Work with strengths whenever possible. Acknowledge efforts to use appropriate behavior, even with limited success.

22) Match the consequence to the behavior. Consequences or punishment should relate to and reduce the behavior. For a student who writes graffiti on the school walls, washing the walls would be appropriate. Writing a paper on proper school behavior would not be.

23) It is essential to communicate between home and school. Parents, teachers and community activity leaders can all reinforce and practice the same behaviors when they communicate and are on the same page.

As we stated at the beginning, every behavior is a form of communication. The cornerstone to effectively changing behavior is understanding why a child behaves that way.

Resources

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Social stories videos- Find at www.modelmekids.com

Success Stories. Social learning stories that can be personalized. Find at www.sandbox-learning.com.

National Down Syndrome Congress

30 Mansell Court, Suite 108
Roswell, GA 30076
(map) Toll Free: 800.232.NDSC (6372)
Local: 770.604.9500 Fax: 770.604.9898 E-
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NDSC Film Expert on "The Amazing Spider-Man 2"
May 23, 2014

Recent Tweets

Our hearts are broken over the passing of our friend Todd Martz. His influence will be felt for generations to come.
<http://t.co/gbNpRfgBGL> Aug 26, 2014

While we hesitate to give him more attention, @NDSC and @GDSFoundation strongly advocate sharing accurate resources:

**BREAK THE TASK
DOWN INTO
SMALL STEPS**

I have tried to break down the goals and tasks in this book into small steps that can be mastered easily. However, every student will learn in his own way. I'm sure that you will find times when this particular student just can't make the next step in the math goals. You will have to find a way to make the task shorter or less complex or try a completely new activity. Most parents and teachers who know how this student learns best can find a simpler or more effective way to teach the concept. Try it. Breaking down or modifying a task is a lot easier than most people think.

Adaptations and Modifications to General Classroom Work

In the early elementary years, it is possible that some children with Down syndrome may be able to do exactly the same work in math class as the other students. By second or third grade, however, almost all students with Down syndrome or other students who are concrete thinkers will need *adaptations* in the way math is taught or in how the student shows his learning. There will probably need to be some *modifications* in the content of what the student will be learning as he gets to the higher grade levels.

It is beyond the scope of this book to go into great detail about ways to make math work more appropriate for students with disabilities. I do want to stress the importance of determining the most appropriate adaptations for your child and spelling them out in his IEP. With increasing numbers of children with Down syndrome being included in general education, you cannot count on your child's teacher having the special education training to know how to modify classroom demands for your child. There are books dedicated to helping teachers modify the curriculum in the general classroom (Blenk, 1995; Hammekan, 1995, Beninghof, 1998; and Stainback & Stainback, 1992). (See References.) One of the most frequently mentioned programs is explained in the book, *Adapting Curriculum and Instruction in Inclusive Classrooms: A Teacher's Desk Reference* (Ebeling, D.G., Deschenes, C. & Sprague, J., 1994) from the Institute for the Study of Developmental Disabilities, Indiana University. This book and staff development kit categorizes nine types of adaptations:

1. **Size**—reduce the number of items
2. **Time**—extend amount of time for test or assignments
3. **Level of support**—provide more assistance
4. **Input**—modify the way the instruction is given to the student (for example, read the problems aloud to him, or provide manipulatives)
5. **Difficulty**—make the problems easier (for example, by using a calculator or simplifying the rules of a math game)
6. **Output**—adapt how the student reports his learning (for example, using stamps or labels with numbers printed on them, rather than writing them, or having an aide write down the student's answers)

7. **Participation**—the student participates in only part of the task (for example, the student could gather data about favorite ice cream flavors with the other students, but then not figure out what percentage like vanilla best)
8. **Alternate goals (modifications of classroom goals)**—have less complex goals than the rest of the class (for instance, learning single-digit subtraction instead of three-digit subtraction)
9. **Substitute curriculum and goals**—student has different instruction and activities for his specific goals

Because I have found that I often need reminders of each student's special needs, adaptations, and modifications, I have compiled a checklist that can be filled out at the beginning of the year for each student and given to all other teachers involved. I have modified the checklist to be more specific to mathematics education.

Parents can send the checklist to their child's teacher or bring it to the IEP meeting and discuss the most appropriate adaptations to help their child. You have the most accurate, complete knowledge of your child and can be of real assistance to the school.

Student Name: _____ Date: _____

Checklist for Adaptations and Modifications to the General Curriculum

The following adaptations are appropriate and necessary for this student. Check all that apply.

Pacing

- Extend time requirements
- Vary activity often
- Allow more breaks for student
- Omit timed assignments
- Work on vocabulary before lesson
- Pick out only major concepts for learning

Environment

- Reduce/minimize distractions
- Provide extra paper and pencils close to student

Presentation of subject matter

- Teach to student's learning style
 - Visual
 - Auditory
 - Tactile-kinesthetic
 - Experiential

Such as:

- Use visual whenever possible
- Use visually colorful computer programs
- Use pictures and mnemonics for memory
- Use chants or songs
- Use sand or Kool Aid in a pan for writing
- Use manipulatives and hands-on activities
- Write with finger on desk when learning
- Wet writing on chalkboard
- Practice with board games

Type of instruction

- Individual and small group instruction
- Functional application of academic skills
- More review
- Move around the room to gather information
- Errorless learning

Materials

- Large print
- Arrangement of nondistracting material on page
- Calculator for all math
- Graph paper
- Computer (not just as reward)

Assignments

- Visual daily schedule
- Calendars and assignment books
- Use written back-up for oral directions
- Request parent reinforcement
- Reduce paper and pencil tasks
- Shorten assignment
- Lower difficulty level

Testing and proof of learning

- Provide thorough reviews before tests
- Oral testing
- Correct missed problems for extra credit
- Test administered by aide or special ed person

Continued on next page . . .

Social interaction support

- Peer advocacy
- Shared experiences in school
- Extracurricular activities
- Structure activities to foster social interaction
- Train peer tutors
- Debrief peer tutors

Motivation and positive climate

- Offer choice
- Planned motivating sequence of activities
- Mostly positive reinforcement
- Verbal praise
- Concrete reinforcement, if needed
- Set up token system
- Use strengths/interests often
- Cultivate a general positive attitude

Individual hints for working with this student:

Section 3: How to Work with Professionals

Articles about the service providers associated with the specific disability



Health Care Information for Families of Children with Down Syndrome

American Academy of Pediatrics

Introduction

Down syndrome is a common condition caused by having “extra” copies of genes on the 21st chromosome. Those extra genes change development during pregnancy, and they continue to have effects after birth and throughout a person’s life. Each person with Down syndrome is unique, having some of the many possible health, learning, and related differences that can occur with this condition.

Some of the differences in people with Down syndrome are common and visible, like the facial appearance. Other changes are less common or less visible but can still cause problems or may need special treatments. The “special treatments” may include medicines, surgeries, or changes in what you should expect. There are no medicines or therapies that are needed by all people with Down syndrome. There are also no medicines or therapies that can “cure” Down syndrome.

Your child’s doctor should be your starting point. Your child needs regular doctor visits and a few special tests. Medical specialists may also need to be involved.

The medical issues for a child with Down syndrome change with age. For this reason, this document is divided into several age groups. Each age group includes a list of issues that may be important to your child at that age. Your doctor can check the full AAP guideline for more details (the web address is given below).

The information within each age group is sorted by the parts of the body that are affected (heart, ears, etc). Many tests only need to be done once. Some areas might need to be looked at again, or even many times, as the child grows to an adult.

This document focuses on medical topics that affect physical health. Other issues can affect social and school success, which may not need doctors or other medical resources but are still important issues for children with Down syndrome. Many people with Down syndrome understand more than they can say. They may need help to communicate in other ways. Most have good social skills, especially if they have friends with typical behavior as models. Respect for and attention to their abilities are often important missing pieces and may be enough to make a big difference in performance and behavior.

The information in these guidelines has grown with the help of families, Down syndrome clinics, and doctors around the world. Most of the information is easy to follow. However, some tests or specialists might be needed that are not available in your area. Your doctor can help to sort out the best next-steps when something can’t be done quickly or nearby.

When you visit the doctor, you might want to bring a notebook to write down information from each visit. A notebook will help you keep all of your child’s medical information in one place. This will be valuable when you meet with new doctors or with others involved in your child’s care.

Local parent support groups can be a very good place to learn about doctors, therapists, and other providers in your community. They may also be able to help with questions about daycare, preschools and schools, other local developmental programs, problems with behavior, help with child care, etc. Your doctor’s office should have names and contact information for groups in your area.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



“Health Care Information for Families of Children with Down Syndrome” was created in July 2013 by the American Academy of Pediatrics (AAP) to give parents and families information about the special health care needs for children with Down syndrome. This document should be used together with the care given by a child’s doctor.

This information is based on the “Health Supervision for Children with Down Syndrome” clinical report from the American Academy of Pediatrics, available here: <http://pediatrics.aappublications.org/content/128/2/393.full>

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Health Care Information for Families of Children with Down Syndrome

Child's Age: **The Prenatal Period (the time before birth)**

Consider testing as desired

Prenatal testing for genetic conditions is recommended for families who wish information to help them make decisions about a pregnancy. This testing should be done only after information about the tests has been discussed between the doctor and the family, and the family understands the risks and benefits of the testing.

Counseling

If Down syndrome (trisomy 21) or any other chromosome change that causes Down syndrome is found by prenatal testing, the family should receive counseling to explain the issues and provide support for the family.

Prenatal heart testing

Because there is a high risk of heart problems at birth in Down syndrome, echocardiography (an ultrasound picture of the heart) done during the pregnancy can provide information that may be useful for the remainder of the pregnancy and for the delivery. This information may help with decisions such as where to deliver the baby and the medical services needed late in pregnancy or at delivery.

Health Care Information for Families of Children with Down Syndrome

Child's Age: Birth to 1 Month

Complete physical examination

If the diagnosis of Down syndrome was made before birth or suspected after birth, a complete physical examination should be done to confirm the known physical features and to check for any possible associated conditions.

Genetic testing

If prenatal testing gave a diagnosis of Down syndrome and if the exam after birth agrees, then no further testing is probably needed in the newborn period. If the physical examination after birth raises the possibility of Down syndrome, testing by rapid (FISH) confirmation and a complete chromosome analysis are needed. The rapid analysis results are typically available within 48 hours, whereas the complete analysis might take 3-5 days for the results. A complete chromosome analysis is needed to provide full information, but to ensure prompt results, both should be obtained unless the complete analysis can be done as quickly as the rapid analysis.

Counseling

The prenatal or newborn diagnosis of Down syndrome can cause many concerns for parents. Talking with a medical genetics team (medical geneticist and genetic counselor) or others recommended by your child's doctor may be helpful.

Feeding

Infants with Down syndrome sometimes have low muscle control, which can cause feeding problems. For this reason, infants should be closely watched for slow feeding or choking and for good weight gain. Breastfeeding is strongly encouraged, but extra attention may need to be given to positioning and to keeping the baby awake or alert.

Heart

An echocardiogram (an ultrasound picture of the heart) is needed to check for any evidence of heart disease. This should be done even if a prenatal echocardiogram was done. If issues exist, it is very important to act early. Breathing that is too fast or cyanosis (a bluish color of the skin) are signs for possible concern.

Hearing and vision

Infants with Down syndrome are at risk for sensory issues, such as eye problems leading to vision loss or ear problems leading to hearing loss. It is important to have both vision and hearing checked by specialists (ophthalmology and ENT).

Thyroid

Thyroid hormone levels can be too low in newborns and need to be checked (a TSH test). Thyroid hormone imbalance can cause a variety of problems that might not be easy to detect without a blood test.

Blood test

After birth, white and red blood counts can be unusually high in infants with Down syndrome. These blood counts need to be checked.

Stomach or bowel problems (reflux, constipation, blockages)

Intestinal issues can occur. Spitting up, stomach swelling, or an abnormal stool pattern can be signs that there is an issue.

Infection

Because of an increased risk of infections (especially respiratory infections), infants should be protected from any unnecessary exposures to sick siblings, relatives, or others. It is also recommended to get checked quickly when any infection is suspected.

Developmental services

It is not too early in the first month of life to start to look for the developmental services (sometimes called "Early Intervention") that will be very important in early childhood.

Resources

Families of children with Down syndrome will need multiple resources, and now is a good time to start lining them up. Such resources might include specialized medical care, early intervention, physical therapy, and family counseling services.

Health Care Information for Families of Children with Down Syndrome

Child's Age: 1 Month to 1 Year

Regular well-care visits (check-ups)

While infants with Down syndrome might need multiple special visits to their doctor and specialty physicians, it is very important that they get regular well-care visits (check-ups). These visits will include checking your child's health, giving immunizations (shots), and building the relationships between the doctor and the family. Developing these relationships will help support the medical and other needs of the child and the family.

Monitor growth

It is important to check growth at every visit. Measurements include height, weight, weight for height, and head circumference. Discuss your child's diet, activity level, bowel and urine patterns, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.

Immunizations (shots)

Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.

Heart

If there were any signs of heart disease in the first month of life, heart monitoring is probably already in place. Heart problems could still worsen or new ones could arise. If concerns exist, it is very important to act early. Breathing that is too fast or cyanosis (a bluish color of the skin) are signs for possible concern.

Hearing and vision

Infants with Down syndrome are at risk for eye problems leading to vision loss or ear problems leading to hearing loss. It is important to have both vision and hearing checked by specialists (ophthalmologist and otolaryngologist/ear, nose, and throat doctor or ENT). The eyes should be tested at birth and again at 1 year or sooner if there are concerns. Hearing should be tested at birth and again every 6 months in early childhood to be sure that the baby's hearing is the best possible.

Thyroid

Thyroid hormone levels can be too low in infants and need to be checked (a TSH test). Low thyroid levels can cause a variety of problems that might not be easy to detect without a blood test. A TSH should be obtained at birth and again at age 6 months and 1 year.

Stomach or bowel problems (reflux, constipation, blockages)

Intestinal issues can occur. Spitting up, stomach swelling, or an abnormal stool pattern can be signs that there is an issue.

Neck instability

Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in the use of hands, walking, or bowel or bladder function. If x-rays are done and the results are abnormal, your child may be referred to a spine or neck specialist. It is recommended that the neck be positioned properly for any medical procedures.

Developmental services

Developmental services (for example, early intervention programs) can be of great benefit to the family with a child with Down syndrome. Developmental services can also help arrange for other related services. These services should provide information to your child's doctor to maintain a close working relationship with the doctor and the family.

Social support services

Many families need additional help with the issues that can arise with the care of children with Down syndrome. All families should discuss with their doctor the social services that may be available and their benefits.

Recurrence risk counseling

Families should get counseling about the possible risk of having another child with Down syndrome, if they choose to have more children. While the risk is usually low, other factors in the family history might be present, so counseling should be done after a complete review of the family history.

Health Care Information for Families of Children with Down Syndrome

Child's Age: 1 Year to 5 Years

Regular well-care visits (check-ups)

At the one-year check-up, you should look at the checklists for newborns and infants to be sure everything has been done as recommended. Follow-up on known problems with specialists and be sure that reports are sent to your child's primary doctor.

Monitor growth

It is important to check growth at every visit. Measurements include height, weight, body mass index (BMI), and head circumference. Discuss your child's diet, activity level, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.

Immunizations (shots)

Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.

Heart

The need to see a cardiologist during this age is based on the child's health history and examination. Children with cardiac lesions may need to be monitored even after repair for remaining lesions and development of pulmonary hypertension (high pressure in blood vessels of the lungs).

Hearing

Hearing should be checked every 6 months, with audiogram and tympanometry tests until normal hearing is documented by testing of both ears separately (usually by 4-6 years of age). Children with hearing loss should be referred to an otolaryngologist (ear, nose, and throat doctor or ENT). Higher risks of hearing problems can go with middle ear fluid and ear infections. Treatment of middle ear fluid often includes the use of ear tubes.

Vision

Vision should be checked at each visit to the doctor and with yearly checkups by a pediatric ophthalmologist (special eye doctor) or a general ophthalmologist who is good with children with disabilities. Crossing eyes or blocked tear ducts might be reasons for quicker action. Early use of eye patches, glasses, or both may help to fix eye crossing while lowering the need for surgery and the risk of vision loss.

Thyroid

The thyroid gland is usually normal in babies with Down syndrome. It can stop working normally for half of people with Down syndrome by adulthood. The symptoms of low thyroid can be hard to notice in people with Down syndrome, so a blood test (TSH) is needed every year, or sooner if symptoms change. When there is a problem, treatment is safe and can often be started by your primary doctor.

Blood tests

Tests for low iron or anemia (hemoglobin and other tests if needed) should be done every year.

Stomach or bowel problems (diarrhea, constipation)

Discuss toilet patterns at each visit, especially any ongoing problems with loose stools or constipation. These are common in children with Down syndrome. Some children with Down syndrome have celiac disease, which is a problem with tolerating some grains, including wheat. Testing can help to identify that condition, and may lead to changes in diet. Celiac disease can affect growth, stooling patterns, and behavior. Let your child's doctor know if your child is having:

- Very loose stools
- Hard to treat constipation (hard or painful stools)
- Slow growth/weight loss
- Belly pain or stomach swelling
- New or challenging behavior problems

Neck instability

Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in the use of hands, walking, or bowel or bladder function. If x-rays are done, and the results are abnormal, your child may be referred to a spine or neck specialist. Special neck positioning may be needed for some medical procedures. Let your child's doctor know if your child is having:

- Stiff or sore neck
- Change in stool or urination pattern
- Change in walking
- Change in use of arms or legs
- Numbness (loss of normal feeling) or tingling in arms or legs
- Head tilt

Sleep issues

Obstructive sleep apnea is a common problem for people with Down syndrome, especially those with low muscle tone. Some symptoms are obvious (snoring, restless waking at night, daytime sleepiness), but it can be hard to tell just by watching. AAP guidelines recommend that every child with Down syndrome have a sleep study by the age of 4 years. (That testing may be hard to find in some parts of the country.) Treatment can include special breathing equipment or surgery.

Skin

Discuss with your child's doctor if your child has very dry skin or other skin problems.

Brain and nervous system

Discuss with your child's doctor concerns about neurologic problems, such as seizures.

Dental

Delayed and missing teeth are common. Teeth often come in unusual order.

New treatments

Talk to your doctor about any new treatments or medications you may consider.

Recurrence risk counseling

Talk to your doctor about future pregnancy planning and chances of recurrence of Down syndrome and where prenatal diagnosis is available.

Developmental services (early intervention)

Review your child's development with your doctor. Referral to local early intervention services and other options for therapy may be needed. Speech progress can be very delayed in children with Down syndrome, but after some delays, most will learn to talk well. Until speech is easier for your child, he or she might need help finding other ways to communicate, such as using sign language, pictures, reading, or using electronic communication tools. Behavior problems are often linked to problems with communication, but may reflect other issues, including ADHD or autism. Language delays or hidden abuse are more common than autism but may be misdiagnosed. Talk with your doctor about how to explain social safety and "good and bad touch" as your child grows older.

Health Care Information for Families of Children with Down Syndrome

Child's Age: 5 to 13 Years

Regular well-care visits (check-ups)

It is important to have yearly well-care check-ups. These visits will assist in checking your child's health, giving shots, and answering your questions about your child's health.

Monitor growth

It is important to check growth at every visit. Measurements include height, weight, and body mass index (BMI). Discuss your child's diet, activity level, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.

Immunizations (shots)

Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.

Heart

The need to see a cardiologist (heart doctor) during this age is based upon a child's health history and examination. About half of children with Down syndrome are born with differences in how their heart is formed. Children with normal newborn testing for heart problems may not need more evaluation at this age.

Hearing

Hearing testing is needed every 6 months, until each ear can be tested alone. When a child can respond to testing in each ear alone, testing may be done every year. Children with hearing loss should be referred to an otolaryngologist (ear, nose, and throat doctor or ENT).

Vision

Vision should be checked at each well-care visit. It is also important to have an exam at least every 2 years by a pediatric ophthalmologist (special eye doctor) or a general ophthalmologist who is good with children with disabilities. Visits may be needed more often if your child has known eye or vision issues.

Thyroid

The thyroid gland is usually normal in babies with Down syndrome. It can stop working normally for half of people with Down syndrome by adulthood. The symptoms of low thyroid can be hard to notice in people with Down syndrome, so a blood test (TSH) is needed every year, or sooner if symptoms change. When there is a problem, treatment is safe and can often be started by your primary doctor.

Blood tests

Tests for low iron or anemia (hemoglobin and other tests if needed) should be done every year.

Stomach or bowel problems (diarrhea, constipation)

Discuss toilet patterns at each visit, especially any ongoing problems with loose stools or constipation. These are common in children with Down syndrome. Some children with Down syndrome have celiac disease, which is a problem with tolerating some grains, including wheat. Testing can help to identify that condition, and may lead to changes in diet. Celiac disease can affect growth, stooling patterns, and behavior. Let your child's doctor know if your child is having:

- Very loose stools
- Hard to treat constipation (hard or painful stools)
- Slow growth/weight loss
- Belly pain or stomach swelling
- New or challenging behavior problems

Neck instability

Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in function. If x-rays are done, and the results are abnormal, your child may be referred to a spine or neck specialist. Special neck positioning may be needed for some medical procedures. Let your child's doctor know if your child is having:

- Stiff or sore neck
- Change in stool or urination pattern
- Change in use of arms or legs
- Head tilt
- Change in walking
- Numbness (loss of feeling) or tingling in arms or legs

Sleep issues

Obstructive sleep apnea is a common problem for people with Down syndrome. This is a sleep problem that can affect a child's behavior and ability to pay attention. It can also affect the heart. Some symptoms are obvious (snoring, restless sleep, waking at night, daytime sleepiness), but it can be hard to tell just by watching. AAP guidelines recommend that every child with Down syndrome have a sleep study by the age of 4 years. (That testing may be hard to find in some parts of the country.) Let your child's doctor know if your child is having:

- Loud breathing
- Snoring
- Waking up often at night
- Daytime sleepiness
- Restless sleep (moving around a lot)
- Uncommon sleep positions (like sitting up to sleep or sleeping with neck arched back)
- Pauses in breathing during sleep
- Behavior problems

Skin

Discuss with your child's doctor if your child has very dry skin or other skin problems.

Brain and nervous system

Discuss with your child's doctor concerns about neurologic problems, such as seizures.

Behavior and mental health

Some children with Down syndrome can have behavior or mental health issues that affect how they play and work at home, at school, or in the community. Let your child's doctor know if your child is having problems that make it hard for them to function in the home, community, or school, including:

- Anxiety
- High activity level
- Wandering off
- Not listening
- Other behavior concerns
- Attention problems
- Sad mood or lack of interest in activities
- Loss of skills (not being able to do the things they used to do)
- Obsessive compulsive behaviors (behaviors that are repeated frequently)

Development

As for all children, your child's well child visit is a chance to discuss his/her development, including:

- **School progress and development:** discuss your child's development, school placement, and service needs
- **Transition:** Children can need extra support at times of transition: discuss transition from elementary to middle school
- **Social/independence skills:** discuss developing social skills, self-help skills, and a sense of responsibility. Discuss working toward independence (doing things by him- or herself) with bathing, grooming, and self-care

Sexuality and puberty

Children need help to learn appropriate touch in social situations and correct names for body parts. Puberty can bring many changes. As your child approaches and enters puberty, discussions can include:

- Changes in puberty
- Managing sexual behaviors (such as masturbation)
- Gynecologic (women's health) care for girls with Down syndrome, including periods and mood changes related to (menstrual) periods.
- Fertility, birth control, prevention of sexually transmitted infections
- Risk for a person with Down syndrome having a child with Down syndrome

Health Care Information for Families of Children with Down Syndrome

Child's Age: 13 to 21 Years or Older

Regular well-care visits (check-ups)

It is important to have yearly well-care check-ups. These visits will assist in checking your child's health, giving shots, and answering questions about your child's health.

Monitor growth

It is important to check growth at every visit. Measurements include height, weight, and body mass index (BMI). These measurements are very important to assessing the overall health of the child. Discuss diet, activity level, and growth. Your child's doctor can help with question about any need for vitamins or supplements.

Immunizations (shots)

Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.

Heart

The need to see a cardiologist (heart doctor) during this age is based on a child's health history and exam. Let your child's doctor know if your child is having increasing fatigue (low energy) or shortness of breath at rest or during activity. If new symptoms appear, an echocardiogram (an ultrasound picture of the heart) may be needed.

Hearing

Hearing testing is recommended at least every year. This may be needed more often if your child has hearing or ear problems.

Vision

Ophthalmology examination by an eye doctor is recommended at least every 3 years or more often if there are known eye or vision issues.

Thyroid

The thyroid gland is usually normal in babies with Down syndrome. It can stop working normally for half of people with Down syndrome by adulthood. The symptoms of low thyroid can be hard to notice in Down syndrome, so a blood test (TSH) is needed every year, or sooner if symptoms change. When there is a problem, treatment is safe and can often be started by your primary doctor.

Blood tests

Tests for low iron or anemia (hemoglobin and other tests if needed) should be done every year.

Stomach or bowel problems (diarrhea, constipation)

Discuss toilet patterns at each visit, especially any ongoing problems with loose stools or constipation. These are common in children with Down syndrome. Some children with Down syndrome have celiac disease, which is a problem with tolerating some grains, including wheat. Testing can help to identify that condition, and may lead to changes in diet. Celiac disease can affect growth, stooling patterns, and behavior. Let your child's doctor know if your child is having:

- Very loose stools
- Hard to treat constipation (hard or painful stools)
- Slow growth/weight loss
- Belly pain or stomach swelling
- New or challenging behavior problems

Neck instability

Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in function. If x-rays are done, and the results are abnormal, your child may be referred to a spine or neck specialist. Special neck positioning may be needed for some medical procedures. Let your child's doctor know if your child is having:

- Stiff or sore neck
- Change in stooling or urination
- Change in use of arms or legs
- Head tilt
- Change in walking
- Numbness (loss of normal feeling) or tingling in arms or legs

Sleep issues

Obstructive sleep apnea is a common problem for people with Down syndrome. This is a sleep problem that can affect a child's behavior and ability to pay attention. It can also affect the heart. Some symptoms are obvious (snoring, restless sleep, waking at night, daytime sleepiness), but it can be hard to tell just by watching. AAP guidelines recommend that every child with Down syndrome have a sleep study by the age of 4 years. (That testing may be hard to find in some parts of the country.) Let your child's doctor know if your child is having:

- Loud breathing
- Snoring
- Waking up often at night
- Daytime sleepiness
- Restless sleep (moving around a lot)
- Uncommon sleep positions (like sitting up to sleep or sleeping with neck arched back)
- Pauses in breathing during sleep
- Behavior problems

Skin

Discuss with your child's doctor if your child has very dry skin or other skin problems.

Brain and nervous system

Discuss with your child's doctor concerns about neurologic problems, such as seizures.

Behavior and mental health

Some youth with Down syndrome can have behavior or mental health issues that affect how they play and work at home, at school, or in the community. Let your child's doctor know if your child is having problems that make it hard for him or her to function in the home, community, or school, including:

- Anxiety
- High activity level
- Wandering off
- Not listening
- Other behavior concerns
- Attention problems
- Sad mood or lack of interest in activities
- Loss of skills (not being able to do the things they used to do)
- Obsessive compulsive behaviors (behaviors that are repeated frequently)

Sexuality

Young people need help to learn the right kind of touch in social situations and the correct names for body parts. Puberty brings many changes and it may help to talk with your child's doctor about several things.

Discussions may include:

- Changes in puberty
- Managing sexual behaviors (such as masturbation)
- Gynecologic (women's health) care for girls with Down syndrome, including periods and mood changes related to (menstrual) periods.
- Fertility, birth control, prevention of sexually transmitted infections
- Risk for a person with Down syndrome having a child with Down syndrome

Transitions

Discussion topics may include:

- School placement and goals for education. These should plan for transition and vocational (job skills) training.
- Guardianship and long-term financial planning.
- Adult work and places to live: family relationships, group homes and independent living opportunities, workshop settings, and other community-supported employment
- Working toward independence with bathing, grooming, self-care, and skills of community living
- Places for health care as an adult

Aging

Discussion of special health problems for adults with Down syndrome. This includes a tendency to early-aging and higher risk for Alzheimer disease in some people.

Occupational Therapy & Down Syndrome

If you are a parent reading this website, you likely have a child with Down syndrome, as I do. My intent with this article is to provide you with some information about how an occupational therapist (OT) may be able to help you and your child.

Occupational therapists who work with children have education and training in child development, neurology, medical conditions, psychosocial development, and therapeutic techniques. Occupational therapists focus on the child's ability to master skills for independence.

These can include:

- Self care skills (feeding, dressing, grooming, etc.)
- Fine and gross motor skills
- Skills related to school performance (eg: printing, cutting, etc.)
- Play and leisure skills

When your child is an infant, your immediate concerns relate to his health and growth, development of the basic motor milestones, social interaction with you and others, interest in things going on around him, and early speech sounds and responses.

At this stage an OT may become involved to:

- Assist with oral-motor feeding problems (this can also be addressed by Speech Pathologists). Due to hypotonia and weakness of the muscles of the cheeks, tongue and lips, feeding is difficult for some infants with Down syndrome. OTs suggest positioning and feeding techniques, and can be involved in doing feeding studies, if necessary.
- Help facilitate motor milestones, particularly for fine motor skills. Occupational therapists and Physical therapists work closely together to help the young child develop gross motor milestones (eg: sitting, crawling, standing, walking). OTs work with the child at this stage to promote arm and hand movements that lay the foundation for later developing fine motor skills. The low muscle tone and loose ligaments at the joints associated with Down syndrome are real challenges to early motor development and occupational therapy can help your child meet those challenges.

When your child is a toddler and preschooler, she will likely have some independent mobility and will be busy exploring her environment. To assist her development you will want to provide her with many opportunities for learning, you will want to encourage the beginning steps in learning to feed and dress herself, you will want her to learn how to play appropriately with toys and interact with other children, you will be encouraging speech and language skills, and you will continue to provide opportunities for refinement of gross motor skills.

At this stage an OT may become involved to:

Facilitate the development of fine motor skills. This is an important stage in the development of fine motor skills for children with Down syndrome. Now they will be developing the movements in their hands that will allow them to do many things as they get older, but many children need some therapy input to ensure that these movements do develop. Children do this through play; they open and close things, pick up and release toys of varying sizes and shapes, stack and build, manipulate knobs and buttons, experiment with crayons etc. Your child may face more challenges learning fine motor skills because of low muscle tone, decreased strength and joint ligament laxity.

Help you promote the beginning steps of self help skills. An OT can help parents break down the skills so expectations are appropriate, and can suggest positioning or adaptations that might help the child be more independent. For example, a child may have more success feeding herself with a particular type of spoon and dish.

Then your child enters the school system and the focus of your energies changes somewhat again! You help your child adjust to new routines, you attend school meetings to plan your child's educational program, you focus on speech and communication, you help your child practise fine motor skills for school (such as learning to print), you expect your child to develop more independence in self help activities, and you search out extracurricular activities that will expose your child to a variety of social, physical and learning experiences.

At this stage an OT may become involved to:

Facilitate fine motor skill development in the classroom. Many OTs work in the school system and provide programs to help children with Down syndrome learn printing, handwriting, keyboarding, cutting etc. They will also look at physical positioning for optimal performance (eg: desk size etc.) and assist with program adaptations based on the child's physical abilities.

Facilitate self help skills at home and at school. As with all children, our kids with Down syndrome vary in personality, temperament, and motivation to be independent. Some children with Down syndrome have a desire to do things themselves, such as dress and feed themselves. These children may learn these skills by watching others and participating from a young age. Other children may be happy to let others do things for them, and may resist attempts to help them learn these skills. In these cases an OT may be able to help a parent work out these challenges, while helping the child develop better motor skills to be successful in self help skills.

Address any sensory needs your child may have. Sometimes a parent has a concern about things their child does that may relate to the child's sensory development. For example, a child may excessively put toys in her mouth, she may have poor awareness of her body in space, she may squeeze everything too hard or drop things a lot, or she may not tolerate very well some routines like washing and brushing hair. An OT can offer suggestions to help the child and parents deal with these issues.

As parents we must be concerned with the well-being of our child in all respects. We have so many things to think about and keep track of: medical and dental needs, motor and communication needs, educational needs, advocacy, social and behavioral needs : the list seems to go on and on! We need the help of trained professionals to guide us and to work with our children to help them achieve their potential in life. An occupational therapist is one member of the team that we can rely on to provide professional assistance throughout the growth and development of our children.

In the US, OT services can be obtained through Early Childhood Intervention programs, public and private schools, and from private therapists.

NDSS thanks Maryanne Bruni, BSC OT(C) for preparing this piece.

NDSS RESOURCES

- [Early Intervention](#)

EXTERNAL RESOURCES

- [Fine Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals \(Second Edition\)](#). Bruni, M. Bethesda, MD: Woodbine House. (2006)



Speech & Language Therapy for Children & Adolescents with Down Syndrome

Children with Down syndrome have strengths and challenges in development of communication skills, including receptive (understanding) language and expressive (speaking and composing sentences) language skills and reading. It takes a team to help children and adolescents progress well in speech and language; that team typically includes speech-language pathologists, physicians, classroom teachers, special educators and families. Speech-language pathologists have information and expertise to help address the speech and language problems faced by many children with Down syndrome. Physicians treat ear, nose and throat conditions and metabolic and hormonal concerns that may affect respiration, hearing, voice and articulation. School learning is language based, so classroom teachers, special educators and speech-language pathologists help in modifying language and curriculum to help children learn. Parents play an important role in their child's speech and language development because home and daily activities are the core of communication.

What Are the Language Characteristics of Children and Adolescents with Down Syndrome?

Research and clinical experience demonstrate that some areas of language are generally more difficult for children with Down syndrome while other areas are relatively easier. Children with Down syndrome have strengths in the area of vocabulary and pragmatics (social interactive language). They often develop a rich and varied vocabulary as they mature. They have good social interactive skills and use gestures and facial expressions effectively to help themselves communicate. They generally have the desire to communicate and interact with people. Syntax and morphology (including grammar, verb tenses, word roots, suffixes and prefixes) are more difficult areas, possibly because of their complex and abstract nature. Children with Down syndrome frequently have difficulty with grammar, tenses and word endings and use shorter sentences to communicate.

Most children with Down syndrome are able to understand much more than they can express. As a result, their test scores for receptive language are higher than for expressive language. This is known as the receptive-expressive gap.

Children with Down syndrome learn well through visual means, so often reading and the use of computer programs focusing on language skills can help them learn. Seeing words and images associated with sounds and being able to read words can help speech and language develop. For some children, the written word can provide helpful cues when using expressive language.

What Are the Speech Characteristics of Children and Adolescents with Down Syndrome?

There are a wide range of abilities that children with Down syndrome demonstrate when using speech. Speech intelligibility (speech that can be easily understood) is one of the most difficult areas for people with Down syndrome at all ages. Many children have difficulty with the strength, timing and coordination of muscle movements for speech. Speech involves coordinating breathing (respiration), voice (phonation), and the production of speech sounds (articulation). Factors that can contribute to speech intelligibility problems include: articulation problems with specific sounds, low oral-facial muscle tone, difficulty with sensory processing and oral tactile feedback, use of phonological processes (e.g. leaving off final sounds in words) and difficulties

in motor planning for speech.

What Does a Speech-Language Pathologist Do?

A speech-language pathologist (SLP) can provide evaluation and treatment for the speech and language difficulties experienced by children and adolescents with Down syndrome. They can help develop a comprehensive treatment plan to address all of the areas in which the child may be experiencing difficulty, including receptive and expressive language, semantics (vocabulary), syntax (grammar), pragmatics (uses of language and social and conversational skills) classroom language skills, speech, oral motor planning and oral motor strengthening. SLPs can work with families and teachers to design and implement an effective school, home and community program to help children develop stronger communication skills.

What Language Skills Are Needed for School?

Parents can help by working as a team with their school personnel to develop an individualized treatment program. In school settings in the United States, the plan will be part of the IEP (Individualized Education Program). Speech and language IEPs may include diagnosis and evaluation, individual therapy sessions, group therapy sessions, classroom-based therapy sessions and/or outcome goals. The IEP may also include provisions for information, consultation and guidance to parents and classroom teachers.

When children are in inclusive settings, the speech-language pathologist may consult with the teacher to provide information about a child's speech and language needs, and may suggest modifications, such as providing the student with written rather than verbal instructions or including fewer items on a class worksheet. Accommodations such as preferential seating to help problems in hearing and listening may be used. Certain skills may also help prepare a child to get the most out of classroom learning; children who have learned to follow directions, have a good grasp of classroom routine and have basic subject knowledge are well prepared for a successful educational experience. Other communication skills needed include the ability to talk and interact with other children, teachers, custodians, cafeteria staff and other school personnel such as school bus drivers.

It is difficult for children in school when their speech and language can't be understood by the teacher or other children in the class. Behavior problems are sometimes related to frustration in not being understood and the relationship between communication and behavior should be explored. In the schools, a child can be referred for a Functional Behavioral Analysis. Based on the findings, a Positive Behavior Intervention Program can be developed.

What Can Parents Do to Help Their Child's Speech?

Parents can provide practice in speech and language skills at home and in the community. Varied and inclusive home and community experiences help children and adolescents with Down syndrome continue to acquire and use new communication skills. Activities that involve social interaction, such as scouting or participating in youth groups, can help young people with Down syndrome develop and practice speech and language skills. When a child has more opportunities to communicate, his or her skills will expand.

The speech-language pathologist can provide information and can design a home activities program to help the child practice the communication skills being addressed in therapy. It is important that parents stay in regular contact with the speech-language pathologist so that their child can practice speech and language skills. Regular phone or e-mail contact, a journal or audiotapes can provide that continuous contact. Parents can also seek additional services as needed. Books, workshops, conferences and newsletters can provide state-of-the-art information.

How Can I Get Help for My Child?

Parents are often frustrated because they feel that their child needs more speech and language therapy than is being provided by the school. School systems are the major provider of speech-language services, but they have guidelines that determine whether a child is eligible for their services. Sometimes eligibility depends on whether a child's test scores are below those for his or her age; other criteria include the relationship between cognitive and language levels. Parents should make sure they are aware of the eligibility criteria, as well as the federal, state or local legislation and policies that apply to service delivery in speech and language.

Although most children receive speech and language services through their local educational system, speech-language pathology services are also available in hospitals, rehabilitation centers, university clinics and private practices. Parents should seek additional help for their children when needed.

How Can I Find a Qualified Speech-Language Pathologist (SLP)?

Qualified SLPs are certified by the American Speech-Language-Hearing Association and licensed by the state. After professionals have been certified, they can use CCC-SLP (Certificate of Clinical Competence in Speech-Language Pathology) following their names. This means they have completed a master's degree in an accredited program, completed required hours of clinical practice internship and passed a national certification examination. The American Speech-Language-Hearing Association or a specific state's Speech-Language-Hearing Association can refer parents to local SLPs. Members of Down syndrome support groups can also often refer parents to local speech-language pathologists who have experience working with children with Down syndrome.

NDSS thanks Libby Kumin, PhD, Professor of Speech-Language Pathology/Audiology, Loyola College in Maryland for preparing this piece.

NDSS RESOURCES

- [Ear, Nose & Throat Issues & Down Syndrome](#)
- [Health Care Guidelines](#)

EXTERNAL RESOURCES

- American Speech-Language-Hearing Association
www.asha.org
Provides resources and an online search tool to help parents connect with certified Audiologists and Speech-Language Pathologists
- National Institute on Deafness and Other Communication Disorders Clearinghouse
www.nidcd.nih.gov
Conducts and supports research in the normal and disordered processes of hearing, balance, taste, smell, voice, speech and language

BOOKS

- Body Talk, Teaching Students with Disabilities about Body Language. Crissey, Pat. Bethesda, MD: Woodbine House. (2013)
- Classroom Language Skills for Children with Down Syndrome. Kumin, L. Bethesda, MD: Woodbine House. (2001)
- Helping Children with Down Syndrome Communicate Better: Speech and Language Skills for Ages 6-14. Kumin, L. Bethesda, MD: Woodbine House. (2008)
- The New Language of Toys: Teaching Communication Skills to Special Needs Children (Third Edition). Schwartz, S. Bethesda, MD: Woodbine House. (2004)
- Speech and Language Development and Intervention in Down Syndrome and Fragile X Syndrome. Roberts, J., Chapman,

R., and Warren, S. Baltimore, MD: Brookes Publishing. (2008)

- Teaching Reading to Children With Down Syndrome: A Guide For Parents and Teachers. Oelwein, P. Bethesda, MD: Woodbine House. (1995)

DVDS

- Discovery - Pathways to Better Speech for Children with Down Syndrome Blueberry Shoes Productions. (2005)
- Try Reading Again: How to Motivate and Teach Older Beginners, Age 10 and Up. Horstmeier, D. Bethesda, MD: Woodbine House. (2012)
- What Did You Say? A Guide to Speech Intelligibility. Blueberry Shoes Productions. (2006)

Section 4: Resources

Where to go for further information





SFCD

Joan Cassel Memorial Library, Support for Families

Library Hours: MWF 9:30am - 4:30pm; T,TH 9:30am - 8:30pm; and when workshops/groups are on site

Items by Resource Type, Title - with Author, Date, Down Syndrome, Location & Language

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Title	Author	Date Publish	Category	Section	Location	Language
Resource Type: Books						
Adolescents with Down Syndrome : toward a more fulfilling life	Pueschel, Siegfried M.	c1997	Down Syndrome			English
Adults With Down Syndrome	Pueschel, Siegfried M.	c2006	Down Syndrome			English
Allow me : a guide to promoting communication skills in adults with developmental delays	Ruiter, Irma D. / Con, Lily / Weitzman, Elaine	c2000	Down Syndrome			English
Another season : a coach's story of raising an exceptional son 1st Broadway trade pbk. ed.	Stallings, Gene. / Cook, Sally.	1998	Down Syndrome	BIOGRAPH		English
As up we grew with Barbara	Moise, Lotte E.	c1980	Down Syndrome	BIOGRAPH		English
Babies With Down Syndrome : A New Parents' Guide 3rd ed.	Skallerup, Susan J.	2008	Down Syndrome			English
Babies with Down syndrome : a new parents' guide (The special-needs collection) 2nd ed.	Stray-Gundersen, Karen.	1995	Down Syndrome			English
Barbara & Fred--grownups now : living fully with developmental disabilities 1st ed.	Moise, Lotte E.	c1998	Down Syndrome	BIOGRAPH		English
Be good to Eddie Lee	Fleming, Virginia M. / Cooper, Floyd.	c1993	Down Syndrome	CHILDREN		English
Bebés Con Síndrome De Down : Nueva Guía Para Padres vol. Spanish 3. ed.	Skallerup, Susan J.	2009	Down Syndrome	LANGUAGE		Spanish
Biomedical concerns in persons with Down syndrome	Pueschel, Siegfried M.	c1992	Down Syndrome			English
Bittersweet baby	Kanat, Jolie, 1952-	c1987	Down Syndrome	BIOGRAPH		English
Buddy's shadow (Turtle books)	Becker, Shirley, 1936- / Fargo, Todd, 1963-	c1991	Down Syndrome	CHILDREN		English
		c1997	Down Syndrome	POETRY		English

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Resource Type: Books						
Bus girl : poems	Josephson, Gretchen, 1954- / Lubchenco, Lula O.					
Changed by a child : companion notes for parents of a child with a disability 1st ed.	Gill, Barbara, 1946-	1997	Down Syndrome			English
Choosing Naia : a family's journey	Zuckoff, Mitchell.	c2002	Down Syndrome	BIOGRAPH		English
Classroom Language Skills For Children With Down Syndrome : A Guide For Parents And Teachers (Topics In Down Syndrome) 1st ed.	Kumin, Libby.	2001	Down Syndrome			English
Communication skills in children with Down syndrome : a guide for parents (Topics in Down syndrome)	Kumin, Libby.	1994	Down Syndrome			English
Communication Skills In Children With Down Syndrome : A Guide For Parents (Topics In Down Syndrome)	Kumin, Libby.	1994	Down Syndrome			English
Count us in : growing up with Down syndrome 1st Harvest ed.	Kingsley, Jason, 1974- / Levitz, Mitchell, 1971-	1994	Down Syndrome	BIOGRAPH		English
Cómo favorecer las habilidades comunicativas de los niños con síndrome de Down : una guía para padres 1st ed.	Kumin, Libby.	1997	Down Syndrome	LANGUAGE		Spanish
Developmental Disabilities Literacy Promotion Guide : for Pediatric Healthcare Providers	Utmann, Monica	2010	Down Syndrome			English
Differences in common : straight talk on mental retardation, Down syndrome, and life	Trainer, Marilyn.	1991	Down Syndrome			English
Down is up for Aaron Eagle : a mother's spiritual journey with Down syndrome 1st ed.	Noble, Vicki.	c1993	Down Syndrome	BIOGRAPH		English
Down syndrome : a promising future, together	Hassold, Terry J.	c1999	Down Syndrome			English
The Down Syndrome Nutrition Handbook : A Guide To Promoting Healthy Lifestyles 1st ed.	Medlen, Joan E. Guthrie.	c2002	Down Syndrome			English
		2011	Down Syndrome			English

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Resource Type: Books						
Down Syndrome Parenting 101 : Must-have Advice For Making Your Life Easier 1st ed.	Hale, Natalie.					
The Down Syndrome Transition Handbook : Charting Your Child's Course To Adulthood (Topics in Down syndrome) 1st ed.	Simons, Jo Ann.	2010	Down Syndrome			English
Early Communication Skills For Children With Down Syndrome : A Guide For Parents And Professionals (Topics in Down syndrome) 3rd ed.	Kumin, Libby.	c2012	Down Syndrome			English
Emily Good as Gold 1st ed.	Rubin, Susan Goldman.	c1993	Down Syndrome	YOUTHFIC		English
Emily in love 1st ed.	Rubin, Susan Goldman.	c1997	Down Syndrome	YOUTHFIC		English
The eyes of Raymond Hu : brush paintings	Hu, Raymond	1996	Down Syndrome	ART		English/Chinese
Fasten Your Seatbelt : A Crash Course On Down Syndrome For Brothers And Sisters 1st ed.	Skotko, Brian. / Levine, Susan P.	2009	Down Syndrome			English
Fine Motor Skills In Children With Down Syndrome : A Guide For Parents And Professionals (Topics In Down Syndrome) 2nd ed.	Bruni, Maryanne.	2006	Down Syndrome			English
Gifts : mothers reflect on how children with Down Syndrome enrich their lives	Soper, Kathryn Lynard.	2007	Down Syndrome			English
Gifts 2 : How People With Down Syndrome Enrich The World 1st ed.	Soper, Kathryn Lynard.	2009	Down Syndrome			English
Gross Motor Skills For Children With Down Syndrome : A Guide For Parents And Professionals (Topics In Down Syndrome) Second edition.	Winders, Patricia C.	2014	Down Syndrome			English
The Guide To Good Health For Teens & Adults With Down Syndrome	Chicoine, Brian. / McGuire, Dennis Eugene.	c2010	Down Syndrome			English
The half child 1st U.S. ed.	Hersom, Kathleen.	1991	Down Syndrome	YOUTHFIC		English
Helping Children With Down Syndrome Communicate Better : Speech And Language Skills For Ages 6 - 14 (Topics in Down syndrome) 1st ed.	Kumin, Libby.	c2008	Down Syndrome			English
		2007	Down Syndrome	YOUTHFIC		English

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Resource Type: Books						
Kellie's Book : The Art Of The Possible	Greenwald, Kellie Blake. / Greenwald, Kellie Blake.					
Life as we know it : a father, a family, and an exceptional child 1st Vintage Books ed.	Bérubé, Michael, 1961-	c1996	Down Syndrome	BIOGRAPH		English
Making plans : a financial guide for people with down syndrome and their families		c2003	Down Syndrome			English
The man who loved clowns Book Club/Fair ed.	Wood, June Rae	c1992	Down Syndrome	YOUTHFIC		English
**Me, Hailey! (Turtle books)	Plucker, Sheri, 1970- / Fargo, Todd, 1963-	c2005	Down Syndrome	CHILDREN		English
Medical & surgical care for children with Down syndrome : a guide for parents (Topics in Down syndrome)	Van Dyke, Don C.	1995	Down Syndrome			English
Medical & Surgical Care For Children With Down Syndrome : A Guide For Parents (Topics In Down Syndrome)	Van Dyke, Don C.	1995	Down Syndrome			English
The Memory Keeper's Daughter	Edwards, Kim, 1958-	2006	Down Syndrome	FICTION		English
Mental Wellness In Adults With Down Syndrome : A Guide To Emotional And Behavioral Strengths And Challenges 1st ed.	McGuire, Dennis Eugene. / Chicoine, Brian.	2006	Down Syndrome			English
My Friend Isabelle [childrens] 1st ed.	Woloson, Eliza. / Gough, Bryan, ill.	2003	Down Syndrome	CHILDREN		English
My Sister, Alicia May [Childrens]	Tupper Ling, Nancy. / Bersani, Shennen	2008	Down Syndrome	CHILDBIO		English
My Sister, Alicia May [Childrens]	Tupper Ling, Nancy. / Bersani, Shennen	2008	Down Syndrome	CHILDBIO		English
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National Down syndrome congress 1997 compendium : 25th anniversary NDSC convention, Phoenix, AZ, creating the vision for the next 25 years!			Down Syndrome			English
Nuestra hija tiene síndrome de Down : la experiencia de una familia con una niña especial (Guías para padres ; 65.)	Rogers, Cheryl. / Dolva, Gun.	2002	Down Syndrome	LANGUAGE		Spanish

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Our Brother Has Down's Syndrome [children] : An Introduction For Children	Cairo, Shelley. / Cairo, Jasmine. / Cairo, Tara. / McNeil, Irene	c1985	Down Syndrome	CHILDBIO		English
A parent's guide to Down syndrome : toward a brighter future Rev. ed.	Pueschel, Siegfried M.	c2001	Down Syndrome			English
A Room Of Golden Shells : 100 Works First edition.	Woodbine House (Firm)	2013	Down Syndrome			English
Show me no mercy : a compelling story of remarkable courage	Perske, Robert.	c1984	Down Syndrome	YOUTHFIC		English
Sindrome De Down Hacia UN Future Mejor Guía Para Los Padres Spanish	Pueschel, Siegfried M.	1991	Down Syndrome	LANGUAGE		Spanish
Sindrome De Down Y Education (Spanish Edition) Spanish	Florez, Jesus	1991-06	Down Syndrome	LANGUAGE		Spanish
The source for down syndrome	Chamberlain, Catherine E. / Strode, Robin M.	c1999	Down Syndrome			English
A special kind of hero : Chris Burke's own story 1st ed.	Burke, Chris, 1965- / McDaniel, Jo Beth.	1991	Down Syndrome	BIOGRAPH		English
Stutsbear and the bionic busboy : my secret diary so stay out unless you are my friend, this means you	Mercadel, Walter F.	c1994	Down Syndrome	YOUTHFIC		English
Taking Down Syndrome To School [Children] ("Special Kids In School" Series) 1st ed.	Glatzer, Jenna. / Dineen, Tom, ill.	c2002	Down Syndrome	CHILDREN		English
Targeting Language Delays : IEP Goals & Activities For Students With Developmental Challenges First edition.	Lee, Caroline, 1947-	2014	Down Syndrome			English
Teaching children with Down syndrome about their bodies, boundaries, and sexuality : a guide for parents and professionals 1st ed.	Couwenhoven, Terri.	c2007	Down Syndrome			English
Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality : A Guide for Parents and Professionals (Topics in Down syndrome) First	Couwenhoven, Terri.	October 10, 2007	Down Syndrome			English
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This copyrighted broadcast 1st ed.	Greenwald, Hank.	1999	Down Syndrome	BIOGRAPH		English
Understanding Down syndrome : an introduction for parents 1st American ed.	Cunningham, Cliff.	1996	Down Syndrome			English
We'll Paint The Octopus Red [Childrens] 1st ed.	Bodeen, S. A. (Stephanie A.), 1965- / DeVito, Pam, ill.	c1998	Down Syndrome	CHILDREN		English
We'll Paint The Octopus Red [children] 1st ed.	Bodeen, S. A. (Stephanie A.), 1965- / DeVito, Pam, ill.	c1998	Down Syndrome	CHILDREN		English
When Down Syndrome And Autism Intersect : A Guide To DS-ASD For Parents And Professionals First edition.	Froehlke, Margaret, editor of compilation. / Zaborek, Robin, editor of compilation.	2013	Down Syndrome			English
Where's Chimpy?	Rabe, Berniece. / Schmidt, Diane.	1988	Down Syndrome	CHILDREN		English
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Resource Type: Bound Materials						
Compendium : 2010 Magic Moments at Walt Disney World Florida (38th Annual NDSC Convention)	Tolleson, David	2010	Down Syndrome	LANGUAGE		English/Spanish
Compendium : Golden Dreams (37th Annual NDSC Convention)	Tolleson, David	2009	Down Syndrome			English
Compendium : We're More Alike than Different (36th Annual NDSC Convention)	Tolleson, David	2008	Down Syndrome	LANGUAGE		English/Spanish
Down Syndrome Information packet		2006	Down Syndrome	LANGUAGE		Spanish
Down Syndrome Information packet		2006	Down Syndrome	LANGUAGE		Chinese
National Down Syndrome Society New Parent Packet : Resources	National Down Syndrome Society	New York, NY	Down Syndrome	PROF DEV		English
Resource Type: DVDs						
Dakota's Pride : One Father's Search for the Truth about Down Syndrome... First	Sagmiller, Dakota	November 21, 2007	Down Syndrome	VISUAL	Librarian's Shelf	English
Discovery [videorecording] : Pathways To Better Speech For Children With Down Syndrome	Schermerhorn, Will. / Schlesinger, Michael. / Blueberry Shoes Productions.	c2005	Down Syndrome	VISUAL		English
Down Syndrome [videorecording] [English, Spanish, Chinese, Vietnamese, Arabic] : The First 18 Months	Schermerhorn, Will. / Buckley, Sue. / Capone, George.	c2003	Down Syndrome	LANGUAGE		English/Spanish /Chinese
Praying with Lior [videorecording] : A documentary Film	Trachtman, Ilana	c2007	Down Syndrome			English
Strong Love [videorecording]	Bonnie Burt Productions	2007	Down Syndrome			English
What Did You Say? [videorecording] : A Guide To Speech Intelligibility In People With Down Syndrome	Kumin, Libby. / Schermerhorn, Will. / Woodbine House (Firm)	c2006	Down Syndrome	VISUAL		English
Resource Type: Pamphlets						
Aging and Down Syndrome [pamphlet] : A Health & Well-Being Guidebook	Moran, Julie / Hogan, Mary / Service, Kathy	2013	Down Syndrome			English

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Your baby and Down syndrome (Spanish) [pamphlet] : answers to questions you might have		n/d	Down Syndrome			Spanish
Your baby and Down syndrome [pamphlet] : answers to questions you might have		n/d	Down Syndrome			English
Resource Type: Toys						
Animal Fun For Everyone! [Toy # 754] First edition.	Pitzer, Marjorie W., author.	n/d	Down Syndrome	AUDITORY		English
Crown On Your Head [Toy # 755] First board book edition.	Tillman, Nancy, author.	2011	Down Syndrome	AUDITORY		English
I Can, Can You? [toy # 750] 1st ed.	Pitzer, Marjorie W.	2004	Down Syndrome	AUDITORY		English
I Like Berries, Do You?[Toy # 752] (Special-needs Collection) First edition.	Pitzer, Marjorie W., author, photographer.	2013	Down Syndrome	AUDITORY		English
Kids Like Me-- Learn ABC's [Toy # 751]	Ronay, Laura. / Kishimoto, Jon Wayne.	2009	Down Syndrome	AUDITORY		English
Kids Like Me...learn Colors [Toy # 756] 1st ed.	Ronay, Laura. / Kishimoto, Jon Wayne.	c2009	Down Syndrome	AUDITORY		English
My Up & Down & All Around Book[Toy # 753] 1st ed.	Pitzer, Marjorie W.	c2008	Down Syndrome	AUDITORY		English

102 lines printed

Websites, Organizations, and Other Resources – Down Syndrome

Down syndrome-Specific

Down Syndrome Connection of the Bay Area

www.dsconnection.org

Provides education, advocacy, and support groups for the entire family and developmental based classes for babies, children, teens and adults with Down syndrome.

Down Syndrome Education International

www.dsinternational.org/en-us

Conducts and supports scientific research and evidence-based resources to improve education for children with Down syndrome worldwide. Website includes research/articles database.

Down Syndrome: Health Issues

www.ds-health.com

A site written and maintained by a pediatrician with a child with Down syndrome.

Downsyn: Parent Forum

www.downsyn.com

Global Down Syndrome Foundation

www.globaldownsyndrome.org

Provides fundraising, education, awareness and government advocacy for the Linda Crnic Institute for Down Syndrome.

National Association for Down Syndrome

www.nads.org

Offers information, support, and advocacy for persons with Down syndrome and their families.

National Down Syndrome Congress

www.ndsccenter.org

Provides information, advocacy and support concerning all aspects of life for individuals with Down syndrome, with a major emphasis on dignity and independence.

National Down Syndrome Society

www.ndss.org

A national organization providing comprehensive online resources, publications, advocacy opportunities, and more. A wonderful place to start if you are a caregiver or professional.

National Institute of Child Health and Human Development, National Institutes of Health

www.nichd.nih.gov/health/topics/down/Pages/default.aspx

A part of the U.S. Department of Health and Human Services. Includes general information as well as clinical trials and research studies.

National Institute of Dental and Craniofacial Research

www.nidcr.nih.gov/oralhealth/Topics/DevelopmentalDisabilities/PracticalOralCarePeopleDownSyndrome.htm

Tips and strategies for providing oral care to people with Down syndrome.

T21 Online Community

www.t21online.com

Uno Mas! Bulletin Board and Parent Forum

www.unomas.proboards.com

Developmental and/or Intellectual Disabilities

Developmental Disabilities Resources for Healthcare Providers

www.DDHealthinfo.org

A collection of information and programs on developmental disabilities, from California Department of Developmental Services (DDS) and UC San Diego's School of Medicine.

Exceptional Parent Magazine

800-247-8080, www.eparent.com

Provides support and information to families of children and adults with disabilities and special healthcare needs as well as to health professionals and education professionals.

The Presidents Committee for People with Intellectual Disabilities (PCPID)

www.acf.hhs.gov/programs/pcpid/

Dedicated to improving the lives of individuals with intellectual disabilities. Website contains its history, its goals, facts and research about Intellectual Disabilities.

SF State & Support for Families Website on Speech and Language Development

www.speechlanguageinfo.myefolio.com/main/home (English)

Parent resource website on speech and language development in multiple languages.

Special Olympics

www.specialolympics.org

Through year-round sports training and competition, it endeavors to empower those with intellectual disabilities around the world.

Woodbine House

www.woodbinehouse.com

Publisher specializing in quality books, DVDs, children's books kits, etc. about children with special needs.

Special Education

Building the Legacy: IDEA 2004

idea.ed.gov

Major topics covered by IDEA 2004. It has excellent sections on Early Intervening Services/RTI, IEPs, Discipline, Highly Qualified Teachers, Procedural Safeguards, and other important topics.

Community Alliance for Special Education (CASE) and Disability Rights California *Special Education Rights and Responsibilities Handbook*

www.disabilityrightsca.org/pubs/PublicationsSERREnglish.htm

Covers basic rights, evaluations and assessments, eligibility, and more in a Q&A format. Based on special education laws and court decisions in effect at the time of publication.

Division of Early Childhood (DEC)

www.dec-sped.org

Promotes evidence-based practices that support families and professionals to enhance the development of young children who have or are at risk for developmental delays and disabilities.

The Education Resources Information Center (ERIC) Digests

www.eric.ed.gov

ERIC Digests are secondary research articles that synthesize research in specific topics of education.

Office for Civil Rights (OCR), U.S. Department of Education

Frequently Asked Questions about Section 504

www2.ed.gov/about/offices/list/ocr/504faq.html

OCR serves student populations facing discrimination as well as the advocates and institutions promoting systemic solutions to civil rights problems.

Resources for Early Childhood project, Ohio Resource Center

www.rec.ohiorc.org/InclusiveClassroom

Early childhood educators and parents can learn how to make inclusion happen, including the Learning Experiences, Planning Options and Universal Design for Learning pages.

U.S. Department of Education, Office of Special Education and Rehabilitative Services, Office of Special Education Programs

1-877-433-7827, edpubs.ed.gov

Website has U.S. Department of Education publications and other products. May also order paper copies. All publications are provided at no cost.

Wrightslaw Special Education Law and Education

Provides accurate, reliable information about special education law, education law, and advocacy for children with disabilities. Fantastic resource.

Parent to Parent

Center for Parent Information and Resources (CPIR)

www.parentcenterhub.org

Central resource of information to the community of Parent Training Information (PTI) Centers and Community Parent Resource Centers (CPRCs). *Find parent center(s) in your state here.*

San Francisco/California Region

The Arc San Francisco

www.thearcsf.org

Nonprofit service, education, and career center for adults with developmental disabilities and their families.

California Foundation for Independent Living Centers

www.cfilc.org/find-ilc/

www.ilrcsf.org (San Francisco ILRC)

Independent Living Centers provide direct services to youth and adults with disabilities in order to help them live independently. Go to the CFILC website to find the center in your county.

Down Syndrome Connection of the Bay Area

www.dsconnection.org

Provides education, advocacy, and support groups for the entire family and developmental based classes for babies, children, teens and adults with Down syndrome.

Family Resource Center Network of California (FRCNCA)

www.frcnca.org

A coalition of California's 47 Family Resource Centers. Early Start Family Resource Centers (ESFRC) provide parent to parent support, outreach, information and referral services to families of children with disabilities and the professionals who serve them.

Golden Gate Regional Center

1535 Market St, Suite 220, San Francisco CA 94103

415-546-9222; Intake Line 888-339-3305; intake@ggrc.org

www.ggrc.org

State-funded organization that helps individuals with developmental disabilities in Marin, San Francisco and San Mateo counties access services. *For the regional center in your county, go to the CA Department of Developmental Services (www.dds.ca.gov, 916-654-1690).*

San Francisco Unified School District (SFUSD)

Early Childhood Special Education Services

1520 Oakdale Ave, San Francisco, CA 94124; Tel: 415-401-2525; Fax: 415-920-5075

Special Education Central Office

3045 Santiago St, San Francisco, CA 94116; Tel: 415-759-2222; Fax: 415-242-2528

www.sfusd.edu/en/programs-and-services/special-education/overview.html

SFUSD Community Advisory Committee for Special Education (CAC)

www.cacspedsf.org

Champions effective special education programs and services and advises the Board of Education on priorities in the Special Education Local Plan Area (SELPA). The State Education Code mandates that each SELPA have a CAC and that a majority of CAC members are parents. *If you are not in SF, ask your local school for information about your local CAC.*

State Council on Developmental Disabilities

www.scdd.ca.gov

Established by state and federal law as an independent state agency to ensure that people with developmental disabilities and their families receive the services and supports they need.

Support for Families (SFCD)

1663 Mission St, 7th Floor, San Francisco, CA 94103

415-920-5040, info@supportforfamilies.org

www.supportforfamilies.org

The family resource center and parent training information center in San Francisco. Provides information, education, and support for families and professionals of children with disabilities, concerns, or special health care needs.

Since 1982, Support for Families has offered information, education, and parent-to-parent support free of charge to families and professionals of children with any kind of disability, concern, or special health care need in San Francisco.

All services are free of charge:

- Phonenumber & Drop-In Center
- Resource Library with Computer and Internet Access
- Support Groups
- Educational Workshops
- Family Special Events
- Parent Mentor Program
- Short-term Counseling
- Community Outreach & Satellites
- Information & Resources



**SUPPORT FOR FAMILIES
OF CHILDREN WITH DISABILITIES**

1663 Mission St, 7th Floor
San Francisco, CA 94103
415-282-7494 (Office)
415-920-5040 (Phonenumber)
info@supportforfamilies.org
www.supportforfamilies.org

HOURS

MWF 9:30am – 4:30pm
TTH 12:30pm – 8:30pm

PUBLIC TRANSIT

BART: 16th St Mission (3 blocks to 13th)
MUNI: 14 Mission, 49 Van Ness, Van Ness Metro Station



FOLD

**PLACE
STAMP
HERE**



SUPPORT FOR FAMILIES OF
CHILDREN WITH DISABILITIES
1663 Mission St., 7th Floor
San Francisco, CA 94103

INFORMATION PACKET
EVALUATION

FOLD

TAPE TO SEAL



DOWN SYNDROME INFORMATION PACKET EVALUATION

1. Are you a: PARENT/CAREGIVER PROFESSIONAL OTHER (CIRCLE ONE)

2. This packet	Strongly Agree 👍	Agree	Neutral	Disagree	Strongly Disagree 👎	N/A
Helped increase my knowledge about my child's needs or disability, and/or the needs of children with disabilities and their families	5	4	3	2	1	N/A
Helped increase my feelings of support	5	4	3	2	1	N/A
Helped increase my knowledge of resources or services	5	4	3	2	1	N/A
Helped provide strategies to advocate for my child and/or children I serve as well as participate in the decision-making process	5	4	3	2	1	N/A
(The following questions are for <u>Parents/Caregivers Only</u>)						
Helped increase my ability to communicate with professionals	5	4	3	2	1	N/A
Helped increase my knowledge of parent participation activities at the school as well as school reform	5	4	3	2	1	N/A
(The following questions are for <u>Professionals Only</u>)						
Helped increase my ability to communicate with families and service providers	5	4	3	2	1	N/A
Helped increase my knowledge of family-centered care	5	4	3	2	1	N/A

3. On a scale of 1 to 5, with 5 being the best, how would you rate the value of this packet?

Great Value 👍 5 4 3 2 1 👎 Little Value

Comments:

4. On a scale of 1 to 5, with 5 being the best, how would you rate the quality of this packet?

Great Quality 👍 5 4 3 2 1 👎 Little Quality

Comments:

5. Would you recommend this packet to others? Yes No

6. What did you find **most** useful?

7. What did you find **least** useful?

8. Any other articles or information you would like to see?

9. Has this information made it more likely that special education issues can be resolved without having to go to Fair Hearing? Yes No Not Applicable

If not, why not?

(Optional Information) Name:

Phone Number:

Evaluations help us improve our services and report back to our funders, which allows us to continue to provide our services - including these packets - free of charge. **Please complete and return this evaluation in one of four ways:**

1. Mail this evaluation to our office by folding this sheet of paper into thirds (see other side of page).
1. Scan or take a photo of this evaluation and email it to newsletter@supportforfamilies.org
2. Fax this evaluation to 415-282-1226
3. Or fill out the evaluation online: www.surveymonkey.com/s/sfcd-info-packet

THANK YOU!