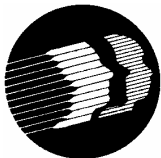


Children with Special Needs Internet Guide for Parents and Professionals



Delaware Health & Social Services

Birth to Three Early Intervention System



2003 - 2004



This guide was produced to help parents and professionals seeking information about children with special needs gain access to the various web sites that may address needs or questions they have. The Internet is a source of information that may or may not contain valid information. Information derived from these sites does not necessarily reflect the opinions or practices of anyone involved with the Birth to Three Early Intervention System. This guide serves as a resource only, not as an endorsement or validation for the information provided by the site. Information provided by the sites should not be construed as medical advice. Please consult your health care professional before making any decisions regarding your child's health care needs.

Basic Internet Directions:

- ◆ When you begin a search on the Internet, there are many search engines that can be used to search for a topic of choice. A search engine is a webpage database that gives an option to search for various topics. Each differs in the way the results of the search are displayed. Any search engine may be used depending upon the personal preference of the searcher, and you may find different sites located in each engine. You may also find that the search results of one day may be different than a previous day due to the many changes that occur on the Internet from day to day.
- ◆ Below are listings of search engines and websites that may be useful to you as you begin your search. The way that these engines and sites can be found is to do the following:
 1. When you begin use of the Internet, you will be on a main page that will be a search engine of its own. It could be any one, dependent on the server that that is used. For example, this could be America on-line, Netscape, AT&T, etc.
 2. If you want to search from this screen, simply go to the search box and enter the keywords of the topic of interest. Results will be displayed and you will be able to choose the topic or site of your choice. You will be able to return to that search site from the new site that you go to by clicking on the back square at the top of the screen.
 3. If this search engine is not what you want to use, find the long box at the top of the screen where the word 'address' is located. From here click once on the website address, for example <http://www.yahoo.com>. Doing this will turn it blue in color and then by hitting backspace it will be erased. A double click on this will allow you to have a cursor in the address box and from there you can blackout any part of it you wish.
 4. When it is blank, you may enter a new address that should always start with: `http://`
Sometimes you will need the `www` after this, and other times it is not needed (it should be entered if it is written that way on this sheet).
 5. When you are finished typing in the entire address, press 'enter' and the computer will search for the website of your request.
 6. If an error message is given, check the address and re-enter. Sometimes the server for the site is down and it may be advisable to try again another time.

Below are the addresses for some search engines and websites that may be helpful to you. Good Luck and enjoy surfing the Web.

Search Engines

Alta Vista	www.altavista.com
Amazon	www.amazon.com
Excite	www.excite.com
Go	www.go.com
Google	www.google.com
Ifind	www.ifind.com
Lycos	www.lycos.com
Meta Crawler	www.Metacrawler.com
Savvy Search	www.search.com
Snap	www.snap.com
Web Crawler	www.webcrawler.com
Yahoo	www.yahoo.com

Medline Search (Medical search engines)

Health Gate Medline Access	http://www.healthgate.com/
Health World Medline Access	http://www.healthy.net/library/search/medline.htm
MedScape	www.medscape.com/
Web.MD	www.webmd.com

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Government

Federal Register - U.S. Department of Education Announcement	www.Ed.Gov/Legislation/Fed Register/	Provides a choice of the U.S. Department of Education documents to be viewed.
Federal World Home Page	www.fedworld.gov/#hletr	Provides a way to search within the government for reports and information
GPO Access	www.gpoaccess.gov/databases.html	Provides a link to search different departments of government
HHS Agencies	www.hhs.gov/agencies	Home page for the office of Health and Human Services
IDEA Practices	www.ideapractices.org	Resource rich and highly interactive website that provides service providers and local administrators with information and support for IDEA-related concerns, issues, and strategies; also provides links
Social Security Online	www.ssa.gov/SSA_Home.html	Provides information about social security
U.S. Dept of Education	www.ed.gov	Home page for the U.S. Department of Education
U.S. Federal Government Agencies	www.lib.lsu.edu/gov/fedgov.html	U.S. Federal Government agencies directory

Laws concerning Disability

Americans with Disabilities Act (ADA)	handicap.bfn.org/public/ada.html	Library directory of topics on the Americans with Disabilities Act
Fape Solutions	http://fapesolutions.com/Letters/SelectLetter.asp	Provides information on the IEP, including state regulations and a resource center with IEP links
Laws Affecting Children with Special Needs	www.lrp.com/Fed.htm	Site comprised of a listing of materials and directories around issues of law available for order
National Center for Dissemination of Disability Research(NCDDR)	www.ncddr.org/index.html	Provides information on research in the area of children with disabilities and collaboration between federal agencies
Office of Civil Rights - Department of Education	www.ed.gov/about/offices/list/ocr/index.html	Homepage for the Office of Civil Rights that provides information on the law, recent publications, and links to related sites
The Consortium for Citizens with Disabilities (CCD)	www.c-c-d.org	Homepage that discusses the organization and provides information on recent news about disabilities
IDEA '97	www.ed.gov/offices/OSERS/IDEA/index.html	Provides information on the Individuals with Disabilities Education Act

Finance Issues

Center for Medicare and Medicaid Services	www.cms.hhs.gov	Information on Medicare, Medicaid, and Child Health insurance
Social Security Benefits for Children with Disabilities	www.ssa.gov/SSA_Home.html	Article discussing social security benefits for children with disabilities (government publication)
The Finance Project	www.financeproject.org	National initiative to create knowledge and share information that will lead to the improved well-being of children, families, and communities

Early Intervention/Early Childhood

Child Development Media, Inc.	www.childdevmedia.com	Provides a listing of videos and training materials produced by leading behavior specialists, available for purchase
Division of Early Childhood	www.dec-sped.org	Provides information on conference, government actions, links, and publications
Early Intervention Related Links	www.dec-sped.org/usefullinks.html	Links to sites related to Early Intervention, children with special needs and their families. Information dealing with policy, research, and services included
I.E.P	www.ldonline.org/Id_indepth/iep/iep.html	Provides information about the Individualized Education Plan and what they mean to the family and child- This also discusses a lot about learning disabilities
The Hanen Early Language Program	www.hanen.org	Provides information about the program concerning language delay and updates of research- Also provides links and materials available for purchase

Transition

Allen, Shea, and Associates	www.allenshea.com	Professional services in the area of planning, research, training, materials development, and evaluation within the field of human services emphasizing developmental disabilities
Preparing Children with Disabilities for School	kidsource.com Go to search type in "transition for children with disabilities"	Article with information on how government supports readiness, special problems faced during transition, family role, teacher's role, elements of successful transition, transition timeline

Advocacy

ARC of the US	www.thearc.org	National organization of and for people with mental retardation and related disabilities and their families; resources, publications, FAQ's, and links
Children Now	www.childrennow.org	Group working to advocate for children and families. Provides information about the organization, articles, resources, newsletter, and links to other resources
Children's Defense Fund (CDF)	www.childrensdefense.org	Provides valuable information about the children's population in the U.S. and articles on several issues, also a Parent Resource Network
Family USA Foundation: The Voice for Health Care Consumers	www.familiesusa.org	Provides information about the organization, publications, and child health
Family Voices	www.familyvoices.org	Provides information sheets, publications, resources, and listing of their current projects; also available in Spanish
National Association of Protection and Advocacy Systems (NAPAS)	www.protectionandadvocacy.com	Contains references to training, material, and resources of value to disability advocacy organizations

Parent & Family: Information and Support

Baby Place: The internet Parenting Resource	www.baby-place.com	Provides information on pregnancy and birth, parenting, products and services, and general parent concerns
Beginnings for Parents of Children who are Hard of Hearing	beginningssvcs.com	Help parents be informed, empowered, and competent so they can be knowledgeable decision makers
California Childcare Health Program	http://www.ucsfchildcarehealth.org	Support in achieving healthy and safe practices in child care settings
Children's Liver Alliance	www.livertx.org	Provides link to CenterSpan support site for parents dealing with transplants
Children's Disabilities Information	www.childrensdisabilities.info	Resource guide for children's disabilities. Information empowering parents of children with special needs
Chromosome Deletion Outreach	Chromodisorder.org/index.html	Support group for families dealing with children with chromosome concerns
Circle of Inclusion	http://www.circleofinclusion.org	Offers demonstrations of and information about the effective practices of inclusive educational programs for children from birth through age 8
Contact Information	www.seliger.com	Provides grant writing services
Family Internet Home Page	www.familyinternet.com	Provides information on many areas for families and individuals in general
Our Kids	www.our-kids.org	Site dedicated to raising children with special needs
Parent News	www.parent.net	Provides facts, articles, movies, resources, and books
Parent's Rights and Responsibilities	www.ldonline.org/Id_indepth/parenting/parentrights.html	Parent Brochure - Rights and Responsibilities of parents of children with disabilities
Parents Place	www.parentsplace.com	Discusses pregnancy, health, family, work, and chat is available
Reference Circular Parents' Guide to the Development of Preschool Children with Disabilities: Resources & Services	www.loc.gov/nls/reference/circulars/parents.html	Wide range of information to assist in promoting the development of a child with disabilities from infancy to age 5. Listing of organizations, producers, and distributors who offer materials or services, also a listing of books
Special Child Magazine	www.specialchild.com/index.html	Online publication dedicated to parents of children with special needs
Support for Families of Children with Disabilities	http://www.supportforfamilies.org	Offer information, education, and parent-to-parent support

Sibling Relationships

Children with Disabilities: Understanding Sibling Issues (NICHY)	Ldonline.org Go to search and type in "siblings"	Article on sibling issues
Kids N' Sibs	www.ggw.org/freenet/k/kns/index.html	Provides an online newsletter for siblings of children with disabilities, off-line newsletter also available
The Sibling Support Project	www.thearc.org/siblingsupport/index.htm	Provides general information for siblings of all ages of children with special needs, resources, education, information on sibshops

Technology

Alliance for Technology Access	www.ataccess.org	Provides information on assistive technology centers, books, facts, and vendors
Applied Science and Engineering Labs	www.asel.udel.edu	Gives information on terms, devices, and types of equipment, also links to other resources
Assistive Technology devices and Services	interact.uoregon.edu/wrrc/IDEAA Tech.html	Information on IDEA amendments affecting assistive technology
Center for Computer Assistance to the Disabled	www.c-cad.org	Provides information on the organization and topics on computer assistance, information, referral, and links available
Delaware Assistive Technology Initiative (DATI)	www.asel.udel.edu/dati	Discusses assistive technology help for people and children in Delaware, newsletter available

Adaptive Toys

AdaptiveMall.com	www.adaptivemall.com	Assistive technology and adaptive devices at discount for children and youth with disabilities; full line of toys and games as well as many other categories of assistive devices
Family Village - Adaptive Toys	www.familyvillage.wisc.edu/at/adaptive-toys.html#info	Provides a listing of resources and vendors surrounding adaptive toys
Kaplan	www.kaplanco.com	Building activities, game boards, balloon kits, balls, etc. Four categories to choose catalogs from: exceptional children, early childhood, outdoor classroom, and math, science, technology & more
TFH (USA) LTD	www.tfhusa.com	Line of unique, adapted toys and products for children and adults with special needs
The Dragonfly Toy Company	www.dragonflytoys.com	For children with special play needs; online catalog and tips

Adaptive Clothing

Ability Apparel	www.ableapparel.com	Adaptive clothing to meet the special needs of children
Special Clothes, Inc.	www.special-clothes.com	Adaptive clothing for children with disabilities, helping boys and girls with special needs meet the world with pride and confidence
Stitches from the Heart	www.stitchesfromtheheart.com/home.html	Specializes in adaptive clothing for children with disabilities.

Adaptive Equipment

Enabling Devices	www.enablingdevices.com	Exceptional Products for Exceptional People
Flaghouse	FlagHouse.com	Provides a one-stop shopping experience
Haverich	www.haverich.com	Wide variety of Orthopaedic Cycles
Mealtimes	www.new-vis.com	A resource for oral-motor, feeding, and mealtime programs

Activities

Alternative Leisure Company	www.alctrips.com	Provides information about trips and camps for children with disabilities
Special Olympics	www.specialolympics.org	Program of sports training and competition for individuals with mental retardation
The American Camping Association	www.acacamps.org	Provides a way to search the country for camps according to need

Entertainment

Disability Center	www.disabilitycentral.com Click on Active Teen	DC Active teen is managed by and for teens with disabilities. We are an online cyber community where we can socialize, educate one another and just have fun together.
Lycoszone	Lycoszone.Lycos.com	Light-hearted website that focuses on youngsters and teens.

National Disability Organizations

Association of University Centers on Disabilities	www.aucd.org	Provides information about organizations for people with disabilities, legislation, special projects, resources, membership, and links
American Association on Mental Retardation	www.aamr.org	Provides information on careers, publications, conferences, etc.
American Society for Deaf Children	www.deafchildren.org	Providing a link between those with experiences to share and people seeking answers; services, resources, and links
American Speech-Language-Hearing Association	www.asha.org	Provides information for professionals, students, and consumers
ARC of the US	www.thearc.org	National organization of and for people with mental retardation and related disabilities and their families; resources, publications, FAQ's, and links
Association of Birth Defect Children, Inc.	www.birthdefects.org	National clearinghouse to provide parents and professionals with information about birth defects and services for children with disabilities
Council for Exceptional Children	www.cec.sped.org	Provides information about membership, legislation, publications, etc.
Federation of Families for Children's Mental Health	www.ffcmmh.org	National parent-run organization focused on the needs of children and youth with emotional, behavioral, or mental disorders and their families
National Academy for Child Development	www.nacd.org	International organization of parents and professionals dedicated to helping children and adults reach their full potential. Articles, research, resources, products, and programs
National Alliance for the Mentally Ill	www.nami.org	Leading advocacy organization dedicated to improving the lives of persons with severe mental illnesses and severe anxiety disorders

National Association for the Education of Young Children (NAEYC)	www.naeyc.org	Nation's largest organization of early childhood professionals and others dedicated to improving the quality of early childhood education programs for children birth through age eight
National Council on Disability	www.ncd.gov	Independent federal agency making recommendations to the President and Congress on issues affecting 54 million Americans with disabilities
National Cystic Fibrosis Foundation	www.cff.org	Resource of information on Cystic Fibrosis; research, facts, publications, and news
National Early Childhood Technical Assistance System	www.nectas.unc.edu	National Technical Consortium working to support states, jurisdictions, and others to improve services and results for young children with disabilities and their families
National Easter Seal Society	www.seals.org	Non-profit, community-based health agency dedicated to helping children and adults with disabilities attain greater independence
National Health Information Center	www.health.gov/nhic	Health information referral service
National Information Center for Child and Youth with Disabilities(NICHCY)	www.nichcy.org	National information and referral center that provides information on disabilities and disability-related issues for families, educators, and other professionals, available in Spanish
National Institute of Mental Health	www.nimh.nih.gov	Mental health research organization; valuable information on specific mental disorders, diagnosis, and treatment (also in Spanish)
National Institute on Disability & Rehabilitation Research	www.ed.gov/about/offices/list/osers/nidrr/index.html	Provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities
National Mental Health Association	www.nmha.org	Dedicated to improving the mental health of all individuals and achieving victory over mental illnesses
National Federation of the Blind	www.nfb.org	Organization of parents and friends of blind children reaching out to each other to give vital support, encouragement, and information

National Organization on Disability	www.nod.org	Only National disability organization concerned with all disabilities, all age groups, and all disability issues
National Parent Network on Disabilities	www.npnd.org	Provide a presence and national voice for ALL families of children, youth and adults with disabilities
National Transition Alliance for Youth with Disabilities (NTA)	www.dssc.org/nta/html/index_2.htm	Promotes the transition of youth with disabilities toward desired post-school experiences, including gainful employment, post-secondary education and training, and independent living
Office of Special Education & Rehabilitation Services (OSERS)	www.ed.gov/about/offices/list/osers/osep/index.html	Supports programs that assist in educating children with special needs, provides for the rehabilitation of youth and adults with disabilities, and supports research to improve the lives of individuals with disabilities
Office of Special Education Programs (OSEP)	www.ed.gov/offices/OSERS/OSEP/index.html	Their mission and organization focus is on the free appropriate public education of children and youth with disabilities from birth through age 21
Research & Training Center on Family Support & Child Mental Health	www.rtc.pdx.edu	Activities focus on improving services to families whose children have mental, emotional or behavioral disorders through a set of related research and training programs

General Disability Sites

Cornucopia of Disability Information (CODI)	http://codi.buffalo.edu	Information on disabilities including statistics, directories, databases, etc.
Internet Resources for Special Children	www.irsc.org	Provides links to the internet about disability areas
Institute for Child Health Policy	www.ichp.edu	Monthly electronic newsletter on Maternal Child Health Community
The ARC's Q&A on Respite Care	www.thearc.org/faqs/respit.html	Information on respite care
The Family Village	www.familyvillage.wisc.edu/index.html	Global community that integrates information, resources, and communication opportunities on the Internet for persons with disabilities, their families, and those who provide them service and support

The JP Das Developmental Disabilities Centre	www.quasar.ualberta.ca/ddc/INDEX.html	Containing valuable information and resources in five major areas: inclusive education, violence & disability, developmental disabilities, human ethics, and links by categories; for parents of children with developmental disabilities
Zero to Three: National Center for Infants, Toddlers, & Families	www.zerotothree.org	Goal is to strengthen and support families, practitioners, and communities to promote the healthy development of babies and toddlers; links and resources

Specific Disability Sites:

ADD/ADHD

A.D.D	www.cpgs.com/add	Treatment and Research Center
A.D.D. Clinic ADD (C.H.A.D.D.)	www.addclinic.com www.chadd.org	Diagnosis and treatment of Attention Deficit Disorder Works to improve the lives of those with ADD/ADHD through education, support, and advocacy
ADD/ADHD	www.sinbad.net/business/adds	Important information regarding the side effects of common medications
ADD/ADHD support group	www.adders.org	Online support group, also provides news, information, research, resources, and links
Feingold Association of the United States (FAUS)	www.feingold.org	Dedicated to increasing awareness of the connection between diet and the symptoms of ADD, ADHD, and learning disabilities
National Attention Deficit Association (ADDA)	www.add.org	Organization that seeks to help people with ADD lead happier, more successful lives through education, research, and public advocacy
Ritalin, ADHD, and Diagnosing Children	www.breggin.com/ritalin.html	Articles through the Center of Psychiatry and Psychology

Autism

AACAP	www.aacap.org/publications/factsfam/autistic.htm	Article on children with autism
Autism Network for Dietary Intervention	www.autismndi.com	Providing help and support for families using a Gluten & Casein Free Diet in the treatment of autism and related developmental disabilities
Autism Resources	www.vaporio.com/autism	Information and index of links regarding the developmental disabilities autism and Asperger's Syndrome
Autism Resources in the U.S.A.	www.autism-info.com	Site providing information on national organizations, resources, and research throughout the United States. Selection of state can be made
Autism Society of America	www.autism-society.org	Mission is to promote lifelong access and opportunities for persons within the autism spectrum and their families, to be fully included, participating members of their communities through advocacy, public awareness, education, and research related to autism
Autism Videos	www.autism.com/cont_ed_prog	Provides information on videos for sale
Autism-PDD (Pervasive Developmental Disorder) Network	autism-pdd.net	Information guide dedicated to autism spectrum disorders
Center for Study of Autism (CFA)	www.autism.org	The Center provides information about autism to parents and professionals, and conducts research on the efficacy of various therapeutic interventions. Much research is in collaboration with the Autism Research Institute in San Diego, California.
Community Services for Autistic Adults & Children (CSAAC)	www.csaac.org	Private, non-profit organization that offers services to individuals with autism
Cure Autism Now (CAN)	canfoundation.org	Dedicated to promoting and funding research with direct clinical application for treatment of autism

FEAT	www.feator.org	Families for Early Autism Treatment of Oregon providing resources, links, newsletter, and parent guide
Future Horizons	www.futurehorizons-autism.com	Provides information on videos, books, publications, and conferences; links and newsletter
Other sites	www.autism.org/links.html	List of internet resources and links concerning autism
TEACCH	www.teacch.com	Treatment and education of autistic and related communication handicapped children
The Autism Channel	www.autismchannel.net	Provides chat, information, and support to parents with children with autism or related disorders
The Autism Society of Delaware	www.wserv.com/delautism	Families and friends of individuals with autism providing education, advocacy, and public awareness throughout Delaware

Asperger's Syndrome

ASPEN - Asperger Syndrome Education Network, Inc.	www.aspennj.org	Education about issues, support, and advocacy
Asperger's Syndrome Collation of the US	www.asperger.org	Provides support and information to parents of children with Asperger's and related disorders
Asperger's Syndrome	www.wpi.edu/~trek/aspergers.html	Information about the disorder, internet resources and support networks, and reading lists
Asperger's Syndrome	www.autism-society.org go to search and type in "asperger's syndrome"	Answers to frequently asked questions, resource list
OASIS	www.udel.edu/bkirby/asperger	On-line Asperger's syndrome Information and Support
Welcome to A.S.P.I.E. Asperger's Syndrome Parent Information Environment	www.aspie.com	Provide support and information, share personal experiences

Bone Disorders

Fibrous Dysplasia	www.methodisthealth.com/ use search engine "A to Z"	Information about the disease
Osteogenesis Imperfecta	www.healthlinkusa.com/231.html	Links to websites which may include treatment, cures, diagnosis, prevention, support groups, risk factors, research, and more
Osteogenesis Imperfecta Foundation	www.oif.org	General information, links, and support; Free subscription to newsletter

Brain Injury

Brain Injury Association, Inc.	www.biausa.org	Comprehensive web site for persons with brain injury and their families; state offices, resources in various media, treatment and rehabilitation, National Directory
Brain Injury Association of Kentucky	www.braincenter.org	An information gateway regarding acquired brain injury
Brain Injury Guide	members.aol.com/bigkate4/big.htm	Personal page providing information, story, and links
Brain Injury Information Network	tbinet.org	Statistics, coma information, email support groups, resources and links
Brain-Net	www.btinternet.com/~brain.net/	International Consultancy in child development; U.K. site about brain injury available in English, Dutch, and Italian
Coma Waiting Place	www.waiting.com	Directed to those who are waiting while someone is in a coma, information about brain injury, resources, and support
The Perspectives Network (TPN)	www.tbi.org	Focuses to communicate public awareness and knowledge of acquired brain injury
Traumatic Brain Injury Model Systems	www.tbinc.org	Links to publications, a database, news, the center for outcomes measurement, and other areas

Cerebral Palsy

CP: Resource Center	www.twinenterprises.com	Provides answers to FAQ's, a book list, and resources
Cerebral Palsy	www.comeunity.com	In children: articles and resources for parents
How Can I Help?	www.iinet.com.au/~scarffam/cpa.html	Information for friends and relatives of a child with cerebral palsy
NICHCY- General Information about Cerebral Palsy	www.kidsource.com/NICHCY/cerebral_palsy.html	General information about Cerebral Palsy including definition, incidence, characteristics, educational implications; and a list of resources and organizations
United Cerebral Palsy Association (UCPA)	www.ucpa.org	Seeks to advance the independence, productivity and full citizenship of people with cerebral palsy and other disabilities

Cleft Lip & Palate

Cleft Lip and Palate Surgery	www.plasticsurgery.org/publiceducation/procedures/index	Plastic surgery information
Cleft Lip and Palate Association	www.clapa.com	Provides articles, education, support and feeding tips
Cleft Lip Palate Foundation	www.cleftline.org	Education, news, support, health care for cleft palate. Website also in Spanish
Cleft Lip/Cleft Palate: Internet Resources	www.samizdat.com/#cleft	List of articles with links
International Institute for Birth Defects	www.cleft.net/info	Information, support, research, and prevention on Cleft Lip/Palate
Kid's Health/Cleft Lip and Palate	http://kidshealth.org/parent/medical/ears/cleft_lip_palate.html	Articles addressing treatment, dental care and available therapy.
Wide Smiles	www.widesmiles.org	Support, inspiration, information, and networking for families dealing with the challenges associated with clefting

Cystic Fibrosis

CF.com	www.cysticfibrosis.com	Provides support, resources, and information
Cystic Fibrosis - Doctor's Guide to the Internet	www.pslgroup.com/CF.htm	The latest medical news and information for patients or friends/parents of patients diagnosed with Cystic Fibrosis and related disorders
Cystic Fibrosis Care	www.cfcare.com	Provides people with cystic fibrosis, family members, and the CF community with quick and easy access to education, information, and breaking stories on the latest treatments and issues
Cystic Fibrosis Foundation	www.cff.org	Resource of information
Cystic Fibrosis Research, Inc.	www.cfri.org	Information on research in the field
Cystic Fibrosis Web Links	www.people.virginia.edu/~rh9u/cflinks.html	Cystic Fibrosis Weblinks to information
Family Guide to Cystic Fibrosis Genetic Testing	www.phd.msu.edu/DNA/cf_family.pdf	Basic information for families

Deaf/Blind

American Association of the Deaf-Blind	www.tr.wou.edu/dblink/aadb.htm	National consumer advocacy organization for people who have combined hearing and vision impairments
Boys Town National Research Hospital-Center for Hearing Loss in Children	www.babyhearing.org	
Deaf/Blind Online	www.sscsco.esu.k12.oh.us/dblinks.html	Provides technical assistance to families, educational personnel, and other service providers through training efforts and the dissemination of information on innovative approaches to educating children and youth with dual-sensory impairments

Helen Keller National Center for Deaf/Blind Youth	www.helenkeller.org/national	Provides state resources, links, and publications
National Information Clearinghouse on Children who are Deaf/Blind	www.tr.wou.edu/dblink	Provides links, state resources, databases, and publications
National Technical Assistance Consortium for Deaf/Blind	www.tr.wou.edu/ntac	Provides statistics and workshop information

Down Syndrome

Assoc. for Children with Down Syndrome(ACDS)	www.acds.org	Provides facts, support, and resources
Breastfeeding a Child with Down Syndrome	www.breastfeeding.asn.au/bfinfo/down.html	Information on this subject
Facts on Breastfeeding And Down Syndrome	http://www.lalecheleague.org/FAQ/down.html	Topics of interest to parents of breastfed children with down syndrome
Diagnosis Down Syndrome	Leeworks.net/DDS	Personal site with stories dedicated to parents
Down Syndrome Health Issues	www.ds-health.com	Provides essays about children with down syndrome for other parents written by a pediatrician and father
Down Syndrome Online Advocacy Group	www.dsoag.com	Scientific and educational effort aimed at utilizing the communication power of the Internet to increase public understanding and support for clinical and biomedical research into Down syndrome
Down Syndrome WWW page	nas.com/downsyn	English, Spanish, and French speaking site that provides articles, essays, snapshots, links, information, and resources
Down Syndrome-A Parents Resource	www3.sympatico.ca/terry.edwards/Shelby.html	Parent site with personal stories, photos, and resources
DownsCity	www.downscity.com	Provides a directory, mailing lists, resources, and links
DownsNet	www.downsnet.org	Contains information on research, a library, and services on Down Syndrome

Growth Charts for Children with Down Syndrome	www.growthcharts.com/charts/DS/charts.htm	Growth charts for children with Down Syndrome
National Association of Down Syndrome	www.nads.org	Not-for-profit organization providing information and understanding
National Down Syndrome Congress	www.ndscenter.org/	National advocacy group that provides leadership in all areas related to persons with down syndrome
National Down Syndrome Education and Research Institute	www.downsyndrome.com	Instructional videos available and links
National Down Syndrome Society	www.ndss.org	Assists families in addressing needs of children born with down syndrome and sponsors and encourages scientific research
Recommended Down Syndrome Sites	www.ds-health.com/ds_sites.htm#natl	Links to internet sites
Down Syndrome on the Internet	www.Downsyndrome.com	Includes government resources, educational resources, medical information and resources, support groups, newsletters, and valuable links
The Lighter Side of Down Syndrome	www.geocities.com/Heartland/Hills/3153/dsmain.html	Personal site with stories and resources
UPSIDE	www.telebyte.net/upside/upside.html	Informal society of individuals, parents, and friends

Dwarfism

Dwarfism.org	www.dwarfism.org	Centralized dwarfism resources
Human Growth Foundation	www.hgfound.org	Helps individuals with growth related disabilities, their families, and health care professionals by providing education, research, and advocacy
Little People of America	www.lpaonline.org	Provides support and information to people of short stature and their families. Resources, data, and links

Fetal Alcohol Syndrome

Alcohol Related Birth Injury - Fetal Alcohol Syndrome	www.arbi.org	Offers educational research and legal resources for the prevention and treatment of alcohol-related birth injuries
Fetal Alcohol Syndrome	www.come-over.to/FAS	Provides a wide range of information including resources and links
Fetal Alcohol Syndrome Family Resource Institute - FAS	www.fetalalcohol.syndrome.org	Non Profit Organization offers support groups, prevention programs, and information about this condition. Membership details included
National Organization on Fetal Alcohol Syndrome	www.nofas.org	General information of FAS

Fragile X

FRAXA Research Foundation	www.fraxa.org	Provides current information and links
National Fragile X Foundation	www.nfxf.org	Gives general information, resources for families, and links

Genetic Disorders and Birth Defects

Association of Birth Defect Children, Inc (ABDC)	www.birthdefects.org	Provides free phone information, written materials, special reports and newsletters to parents and professionals
March of Dimes Birth Defect Foundation	www.marchofdimes.org	Organization that focuses on the birth of healthy babies
The Genetic Alliance	www.geneticalliance.org	Find a support group, useful resources, newsletters, and publications
The Teratology Society	www.teratology.org	Site that provides information on birth defects, research, and prevention

Hearing Impairments

Alexander Graham Bell Assoc. for the Deaf	www.agbell.org	Nonprofit membership organization that was established in 1890 to empower persons who are hearing impaired; information, provider & support network
American Speech-Language-Hearing Association (ASHA)	www.asha.org	Promote interests of and provide the highest quality services for professionals in audiology, speech-language pathology, and speech and hearing science, and to advocate for people with communication disabilities
Captioned Films/Videos Program	www.cfv.org	Provides open-captioned films and videos, free for loan, for deaf and hard-of-hearing persons, teachers, organizations, and parents
Closed Captioning Web	www.captions.org	Information on closed captioning services, law and links
Hand Speak: A sign language dictionary online	www.handspeak.com	Visual language dictionary online.
I See What You Say	www.lipreading.com	Concerned with speech-reading skills, video with manual available
National Association of the Deaf	www.nad.org	Safeguards the accessibility and civil rights of 28 million deaf and hard of hearing Americans in a variety of areas
National Institute on Deaf & other Communication Disorders (NIDCD)	www.nih.gov go to search and type in "NIDCD"	Mission is to uncover new knowledge that will lead to better health for everyone- Provides information on current research
Phonic Ear	www.phonicear.com	Leading developer and manufacturer of assistive listening devices, products, tools, and links
The Deaf Resource Library	www.deaflibrary.org	Collection of reference material and links to educate and inform people about deaf cultures in Japan and the U.S.
Where do we go from Hear?	www.gohear.org/index.html	Provides information for families of infants and children diagnosed with hearing loss and professionals who work with these individuals

Hydrocephalus & Spina Bifida

Children with Spina Bifida	http://www.waisman.wisc.edu/~rowley/sb-kids/index.html	Resource page for parents and professionals
Hydrocephalus Association	www.HydroAssoc.org	Provides support, education, resources, and advocacy
Hydrocephalus Center	www.patientcenters.com	Provides articles and resources
Spina Bifida Association of America	www.sbaa.org	Provides toll free information & referral services, newsletter, publications, and links
The Hydrocephalus Foundation, Inc. (HyFI)	www.hydrocephalus.org	Dedicated to providing support, resources, and networking opportunities

Hyperlexia

American Hyperlexia Association Home Page	www.hyperlexia.org	Provides basic information and links
Hyperlexia and Language Disorders	www.geocities.com/HotSprings/9402/	Provides articles and links
Hyperlexia Parents Page	Westwingpublishing.com/hyperlexia	Information for parents with personal stories, articles, and chat available

Juvenile Diabetes

Juvenile Diabetes Foundation International - The Diabetes Research Foundation	www.jdf.org	Research, publications, chapters, and advocacy
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)	www.niddk.nih.gov	Information on health, programs, research, and FAQ's
Diabetic Gourmet	http://diabeticgourmet.com/Healthy_Living/Juvenile_Diabetes/	Provides parents of children with juvenile diabetes articles, resources, news and recipes

Language/Speech Disorders

American Speech-Language-Hearing-Association (ASHA)	www.asha.org	Promotes interest of services for professionals and people advocating for people with communication disorders
Apraxia Kids	www.apraxia-kids.org/index.html	Provides information and how apraxia affects families and children, links and support groups
Born Learning	http://www.bornlearning.org/	Supports families with children who are late talkers
Children Learning Language-How Adults Can Help	http://www.childdevmedia.com/highlight2.cfm?product_id=411	In this video Naomi Baron guides viewers along a child's journey from babbling to complex sentences
Enhancing Communication Skills Through Reactive Language Strategies	http://www.childdevmedia.com/highlight2.cfm?product_id=369	Video provides the viewer with strategies that can be used to help children improve their communication skills
Hanen Resources	http://www.childdevmedia.com/highlight2.cfm?product_id=370	Committed to helping children communicate to the best of their abilities and to providing parents, caregivers and teachers with knowledge and support to make this a reality
KidsEars	www.kidsears.com/kidspeak.html	Provides listing of milestones and suggestions
Kidsource Online: Spoken Language Problems	www.kidsource.com/LDA/spoken_language.html	Basic explanation of oral language disorders
Language is Key	http://www.wri-edu.org/bookplay/	Educational program that shows parents and teachers how to promote children's language development during the preschool years. Program includes the following components: Talking and Books (VHS 20+ minutes), Talking and Play (VHS 20+ minutes), Resource Guide with handouts
Learning to Communicate: The First Three Years	http://www.childdevmedia.com/highlight2.cfm?product_id=398	Videotape illustrates the milestones of normal communication development in the first three years of life
Making the Most of Early Communication	http://www.childdevmedia.com/highlight2.cfm?product_id=406	Video emphasizes the importance of making use of the child's available senses, using familiar routines and turn taking games, and using systematic and direct instruction for encouraging communication
Medline Plus	www.nlm.nih.gov/medlineplus/	Promotes public education, research,

	aphasia.html	rehabilitation and support services to assist families
National Institution of Deafness and Other Communications Disorders	http://www.nidcd.nih.gov/	Provides facts, research, resources, news and events related to communication disorders
Parents as Teaching Partners	http://www.edact.com/product.cfm?c_id=82&p_id=529&path=-1,1,82	easy-to-do, low-cost activities that teachers can suggest to parents
Speech and Language Delays: What Do They Mean for Your Child?	http://www.childdevmedia.com/highlight2.cfm?product_id=399	Videotape briefly outlines the development of communication skills in the first three years of life
Speech and Language Disorder	www.mankato.msus.edu/dept/comdis/kuster2/splang.html	Provides listing of sites related to speech and language disorders
Successful Language Development Strategies in the Early Childhood Classroom	http://www.edact.com/product.cfm?p_id=528&path=-1	For English Language Learners and Native Speakers-successful language development techniques
Talking Together: The Movie	http://www.childdevmedia.com/highlight2.cfm?product_id=368	Video demonstrates how to focus on and take advantage of the natural uses of language

Learning Disabilities

Essential Learning Institute	www.ldhope.com	Information on LD with audio introduction option
LD Online	www.ldonline.org/index.html	Interactive guide to learning disabilities for parents, teachers, and children
Learning Disabilities Association of America	www.ldanatl.org	Dedicated to enhancing quality of life, alleviating restricting effects, and supporting endeavors to determine causes of learning disabilities
Learning Disabilities Clinic	www.slam.nhs.uk/services/pages/detail.asp?id=417	Private educational treatment facility for children, adolescents, and adults, dedicated to helping individuals achieve their full learning potential.
National Center for Learning Disabilities	www.nclld.org	Provides information, resources, referral services, public awareness, advocacy and more
Special Kids	www.specialkids1.com	Reaching and teaching kids with disabilities through videos, CD-Roms, and picture books

The Learning Center	learningcenteronline.com	Information about testing and enrichment, Educational and counseling services to children and adults
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Leukodystrophy

United Leukodystrophy Foundation	www.ulf.org	Dedicated to providing patients and their families with information and support, increasing public awareness, and promoting and supporting research
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Low Syndrome

Low Syndrome Association	www.lowesyndrome.org	Basic information and links
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Mental Retardation

American Association on Mental Retardation	www.aamr.org	Promotes global development and dissemination of progressive policies, sound research, effective practices, and universal human rights for people with intellectual disabilities
Best Buddies	www.bestbuddies.org	A nonprofit organization dedicated to enhancing the lives of people with mental retardation by providing opportunities for socialization and employment
National Center for Birth Defects and Developmental Disabilities	www.cdc.gov/ncbddd/dd/ddm r.htm	Answers the question what is mental retardation?
The ARC	www.thearc.org	Organization committed to the welfare of all children and adults with mental retardation and their families

Muscular Dystrophy

Muscular Dystrophy Association	www.mdausa.org	Information on research, services, publications, and clinics
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Muscular Dystrophy Family Foundation	www.mdff.org	Provides services, resources, home medical equipment and adaptive devices to help people with muscular dystrophy and their family members live independent and productive lives
Muscular Dystrophy Parent Project	www.parentprojectmd.org/	Provides a network of communications, support for parents and children, and information on the disease, treatment, care, and conferences

Paralysis and Spinal Cord Injury

American Paralysis Association	www.apacure.com	Information on news, research, publications, discussion, and events related to spinal cord injury and paralysis
National Spinal Cord Injury Association	www.spinalcord.org	Improving care, producing results in research, and addressing everyday living issues that confront all people in wheelchairs
Spinal Cord Injury Resources	www.makoa.org/sci.htm	Links containing general resources, newsletters, articles, and fact sheets
WheelWeb.Com: The Spinal Cord Injury Resource	www.wheelweb.com	Purpose is to educate people about SCI and advance the lives of those who have it

Prader-Willi Syndrome

GeneClinics	www.geneclinics.org/profiles/pws	Basic information on the disorder
PedBase- Doctor's Guide	www.pslgroup.com/dg/200c2.htm	Basic information on the disorder
Prader-Willi Syndrome Association	www.pwsausa.org	Information on organizations, FAQ's, research, brochures, and support

Rare Disorders

National Organization for Rare Disorders(NORD)	www.rarediseases.org	Committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service; newsletter, and search databases
Genetic/Rare Conditions Support Groups & Information Site	www.kumc.edu/gec/support/groups.html	Allows for a search of support groups according to disability; information on genetic conditions or birth defects for professionals, educators, and individuals
Rare Genetic Diseases	www.familyvillage.wise.edu/lib_gene.htm	Who to contact, make connections with other families, and related websites

Rett Syndrome

International Rett Syndrome Association (IRSA)	www.rettysyndrome.org	Purpose is to support and encourage medical research, determine the cause and find a cure for Rett syndrome, to increase public awareness, and to provide informational and emotional support to families; available in French, Dutch, Italian, Portuguese, and Spanish
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Seizure Disorders

American Epilepsy Society	www.aesnet.org	Promotes research and education for professionals dedicated to the prevention, cure, and treatment of epilepsy
Lycoszone	Lycoszone.Lycos.com Go to search and type in "epilepsy"	Light-hearted website that focuses on epilepsy and seizure disorders for youngsters and teens.
Epilepsia	www.epilpsia.com	Official journal of The International League Against Epilepsy (on-line journal)
Epilepsy Contact Database	www.datasync.com/~josw/epilepsy.htm	A database of families and bookstore developed to unite and educate those affected by and afflicted by epilepsy
Epilepsy Foundation of America	www.efa.org	Provides information on advocacy, services, publications, research, etc.

Epilepsy International	www.epilepsy_international.com/	Provides a large, comprehensive and well-designed educational and informational resource for those working with and/or dealing with epilepsy on a day-to-day basis in English and Spanish language
Parent Site	Kisepilepsy.com	Support platform for parents and other caregivers of children
The Epicenter	http://137.172.248.46/epilepsy.htm	Provides basic information and answers FAQ's

Spinal Muscular Atrophy

Families of Spinal Muscular Atrophy	www.fsma.org	Provides information, resources, research articles, membership information, photos, and links
Spinal Muscular Atrophy	www.mda.org.au/specific/mda_sma.html	Fact sheet on spinal muscular atrophy

Tourette Syndrome

The Facts about Tourette Syndrome	Members.tripod.com/~tourette13	A collection of general information, FAQ's, causes, related problems, and links
Guide to the Diagnosis & Treatment of Tourette Syndrome	www.mentalhealth.com/book/p40-gtor.html	Booklet intended to provide information to professionals who wish to become more knowledgeable about Tourette Syndrome
National Tourette Syndrome Association	www.tsa-usa.org	National organization dedicated to providing up-to-date, accurate information about Tourette Syndrome
TS "Plus"	www.tourettesyndrome.net	Current research and information on TS, its treatment, and educational issues. Files for parents, educators, and health care professionals to download

Tuberous Sclerosis

Global TS Information Link (GTSIL)	www.edae.gr/tuberous.html	Provides information about TS and the organization with a bookstore, newsletter, and links
National Tuberous Sclerosis Association	www.tsalliance.org	Provides information about TS, the organization and gives resources and parent support
National Tuberous Sclerosis Association- Brochure- My child has Tuberous Sclerosis	www.tsalliance.org/publications/52810_NTSA.pdf	Brochure providing families of children with TS information, education and support

Vision Impairments

American Council of the Blind	www.acb.org	Provides general information about the Council, including recent issues of the monthly publication, The Braille Forum
American Foundation for the Blind	www.afb.org	National resource for people who are blind or visually impaired, and the organizations that serve them; information, newsletters, events, on-line journal
Art Through Touch	Members.aol.com/ATTouch	Organization that provides tuition and a range of high quality art activities for blind and visually impaired people
Blind Children's Learning Center	www.blindkids.org	Center that seeks to develop the full potential of children and youth with a visual impairment, in the greater Orange County community, regardless of ability to pay
Blindness Resource Center (NYISE)	www.nyise.org/blind.htm	Provides information on resources for the blind
EyeNet - American Academy Of Ophthalmology	www.aao.org	Public information, resource guide, and on-line education center
Microphthalmia, Anophthalmia and other Eye Disorders	www.angelfire.com/mi/microphthalmia	Designed to bring families together to share personal stories and experiences, links available
National Association for Visually Handicapped	www.navh.org	Provides a merchandise store, links, resources, excerpts library, and mailing list

National Federation of the Blind	www.nfb.org	Comprehensive consumer and advocacy organization that provides public education, information and referrals
Visual Impairment Guide	www.viguide.com	Guide to internet resources about visual impairments for parents and teachers

Williams Syndrome

Williams Syndrome Association	www.williams-syndrome.org	Provides information on the disorder, medical guidelines, resource libraries, and internet links
Williams Syndrome Foundation	www.wsf.org	Provides basic information, personal stories and photos, information on organizations, and contact with families

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