

Now I've Got It!

Internet Guide

Resources for Families of Children with Special Needs

Fall 2004

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Resources have been researched over a period of several years. The Information Superhighway moves at a very rapid clip. Some sites may no longer be available. Please feel free to annotate and amend this guide as needed.

ADVOCACY

Cure Autism Now

www.canfoundation.org

Updates on research studies and grant proposals with a hyperlink to autism news groups.

Wright's Law

www.wrightslaw.com

All the latest case law dealing with disability education..

ASSISTIVE TECHNOLOGY

Access Utah

www.accessut.org

This multi-page site has many valuable resources, a "Links" page that will take you to national disability related web sites, and perhaps the most important page on this website is the "Sales Bank".

DO-IT

doit@u.washington.edu

Disabilities, Opportunities, Internetworking and Technology. Lots and lots of information on assistive technology.

Ontario Rehabilitation Technology Consortium

www.oise.utoronto.ca/ORTC

Information about innovative devices for mobility, vision, hearing, communication and prosthetics.

Pacer Center

<http://www.pacer.org/stc/totsnTech.htm>

This site will take you directly to the latest research for infants and toddlers who have assistive technology needs.

DIAGNOSIS SPECIFIC

ADD/ADHD

www.oneaddplace.com

A virtual neighborhood consolidating in ONE PLACE information and resources relating to Attention Deficit Disorder (A.D.D.), AD/HD and Learning Disorders (LD)

American Foundation for the Blind

<http://www.afb.org>

Educational updates and support.

ASPEN Inc.

www.aspennj.org

Asperger Syndrome support network for information on Aspergers, PDD-NOS and high functioning autism.

Association of Birth Defect Children (ABCD)

www.birthdefects.org

Matches parents with children with any disorder, especially birth defects.

Blind Children's Center

<http://www.blindcntr.org/bcc>

Focusing specifically on the issues for the young blind and visually impaired.

Epilepsy Foundation

www.efa.org

Lots of great up to date information about seizure disorders.

Chromosome Deletion Outreach

<http://members.aol.com/cdousa/cdo.htm>

Matches for families of children with chromosome deletions, additions, inversions, translocations and rings.

House Ear Institute

<http://www.hei.org>

Support for families of deaf children or for deaf individuals

Center for the Study of Autism

www.autism.org

A wonderful site for autism and related disorders including: Angelman Syndrome, Asperger Syndrome, Fragile X Syndrome, Landau-Kleffner Syndrome, PDD, Prader-Willi Syndrome, Rett Syndrome and Williams Syndrome.

Learning Disabilities On Line

www.ldonline.org

Everything for the learning disabled including gifted resources.

Mental Health Net

<http://mentalhelp.net>

A guide to mental health on line with over 4,000 resources.

Congenital Heart Anomalies Support

www.csun.edu/~hcmth011/chaser/hlhsflier.html

Known as CHASER, this group connects families with other families with children with any type of heart defect.

Rare Genetic Diseases in Children

<http://mcrc22.med.nyu.edu/murphp01/homenew.htm>

An Internet resource gateway. This site seems to come and go so keep checking if you are not getting anywhere.

Down Syndrome

<http://www.epix.net/~mccross/down-syn.html>

A parent generated site.

National Stuttering Foundation

www.stuttersfa.org

The Stuttering Foundation provides free online resources, services and supports to those who stutter and their families as well as supports research into the causes of stuttering.

**Support Organization for Trisomy 18,
13 & Related Disorders**

www.trisomy.org

S.O.F.T. is a nonprofit volunteer organization offering support for parents who have had a child with a chromosome disorder, and education to families and professionals interested in the care of these children.

EDUCATION

Council for Exceptional Children

<http://www.cec.sped.org>

The Council for Exceptional Children (CEC) is the largest international professional organization dedicated to improving educational outcomes for individuals with exceptionalities, students with disabilities, and/or the gifted.

The Freudian Slip

www.enterthefreudianslip.com

Information on music therapy and resources for learning through music.

National Parent Information Network

<http://ericps.ed.uiuc.edu>

A clearinghouse on early childhood and elementary education topics. Administered by ERIC

Family Education

www.familyeducation.com

Support for education issues, including special education, from early intervention through college.

Gallaudet University

<http://www.gallaudet.edu>

A Washington, DC, based private university for the deaf.

Heath Resource Center

<http://search.acenet.edu>

Information for post secondary education with specific information on the education of individuals with disabilities.

SERI

<http://www.seriweb.com>

Special Education Resources on the Internet (SERI) is a collection of Internet accessible information resources of interest to those involved in the fields related to Special Education. This collection exists in order to make on-line Special Education resources more easily and readily available in one location.

GENERAL INFORMATION

Access Utah

<http://www.accessut.state.ut.us>

The central directory for disabilities information for the State of Utah.

CODI

<http://codi.buffalo.edu>

A cornucopia of disability information based out of Buffalo, New York.

Disability Resource Guide

<http://www.disabilityresources.org>

An incredible updated list of disability resources and supports to be found on the Internet.

Exceptional Parent

www.eparent.com

A premier site from a longtime leader in the area of parenting children with special needs.

Family Village

www.familyvillage.wisc.edu

Great one-stop shopping for families with children with special needs. This site can take you almost anywhere.

Internet Resources for Special Children

<http://www.irsc.org>

Works like a search engine for many disorders.

National Information Center for Children and Youth with Disabilities

www.nichcy.org

A federally supported clearinghouse for child/family disabilities issues. State-by-state information as to who is in charge.

Pacer Center

<http://www.pacer.org>

Pacer Center is a nonprofit organization that serves families of children and adults with disabilities.

MEDICAL INFORMATION

Health Touch

[www.healthtouch.com/
level1/hi_toc.htm](http://www.healthtouch.com/level1/hi_toc.htm)

Tons of information on a variety of health related topics.

March of Dimes

<http://www.modimes.org>

Great web page with a "fairy" who will research any childhood disease or syndrome for you

Med Web:Pediatrics

www.medweb.emory.edu/MedWeb

Emory University's premier medical library site. General information on medical topics.

National Institute of Health

www.nih.gov

Just type "childhood" into this search engine and hold on.

National Library of Medicine

<http://www.ncbi.nlm.nih.gov/PubMed>

A huge government clearing house for all things medical. Very heady stuff.

NORD

www.rarediseases.org

National Organization of Rare Disorders- has lots of latest research on treatment, diagnosis. Beware! Fees are charged for in-depth research papers.

Online Mendelian Inheritance in Man

[http://www.ncbi.nlm.nih.gov/entrez/
query.fcgi?db=OMIM&cmd=Limits](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM&cmd=Limits)

From the National Center for Biotechnology Information, this database is a catalog of human genes and genetic disorders. Very heady stuff but a good place to do your own research for your own "Lorenzo's Oil"

PEDBASE

www.icodata.com/health/pedbase/pedlynx.htm

A pediatric database with over 5000 childhood illnesses.

PediaNet

www.pedianet.com

Pediatrics information Internet site.

RX List

www.rxlist.com

Drug information and pharmacology.

PARENTING

Parenthood Web

<http://parenthoodweb.com>

Pediatricians and psychiatrists respond to questions left on their e-mail.

Parenting Q&A

www.parenting-qa.com

Quick answers to difficult parenting questions.

Family.com

www.family.com

Disney's site full of bulletin boards and chat rooms.

Parent's Place

www.parentsplace.com

A fun general parenting guide for everything from pregnancy to preschoolers.

RECREATION

Access-Abel Travel

www.access-able.com

Everything you need to know when traveling with someone with a disability.

The American Camping Association

<http://search.acacamps.org/search.html>

Search for camps based on location and special need.

SUPPORT GROUPS

Alliance of Genetic Support Groups

www.geneticalliance.org

Support groups from everywhere.

Beach Center on Families and Disability

www.beachcenter.org

Parent training, professional and emotional support, education and training across the life span for families with members with disabilities.

Father's Network

www.fathersnetwork.org

Links to over forty web sites regarding disabilities, fatherhood, single parenting, divorce and family issues.

Parents Helping Parents

www.php.com

*Lots of great links and family support.
Bilingual Spanish/English*

Resource Foundation for Children with Challenges

www.specialchild.com/RFCC

Provides families up-to-date information on available therapies, disability legislation, special education issues, specific disorders, and many other topics. The Parent-Matching program, entails uniting parents with one another who have the same or similar disorder.

Sibling Support

<http://www.thearc.org/siblingsupport/sibshops-about>

Support for brothers and sisters with family members with developmental delay or serious health conditions.