



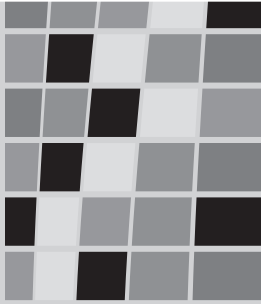
This document is an excerpt from the book

Children with Disabilities, Seventh Edition

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Childhood Disabilities Resources, Services, and Organizations

This appendix lists a number of organizations, Internet sources, and other resources that provide services and assist in research in the area of childhood developmental disabilities. The resources cited are a representative sample and are not intended to be all inclusive. A brief description follows each listing.

GENERAL

Federal Agencies

Administration on Developmental Disabilities (ADD)

<http://www.acf.hhs.gov/programs/add/>
Program within the U.S. Department of Health and Human Services promoting the independence and economic and social well-being of individuals with developmental disabilities and their families by ensuring that needed services and assistance for community life are available and that families participate in the design of such services.

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

<http://www.nichd.nih.gov/>
Established in 1962 as part of the National Institutes of Health. Funds research and offers information related to human development, health, and developmental disabilities.

Maternal and Child Health Bureau (MCHB)

<http://mchb.hrsa.gov>

Established in 1912 as part of the Health Resources and Services Administration (HRSA). Provides funding and governs programs designed to ensure equal access for all to quality health care in a supportive, culturally competent, family, and community setting.

Office of Disability Employment Policy

<http://www.dol.gov/odep>

One of the oldest presidential committees in the United States. Promotes acceptance of people with physical and intellectual disabilities in the world of work, in both the public and the private sectors. Promotes the elimination of barriers, both physical and attitudinal, to the employment of people with disabilities.

Office of Special Education and Rehabilitative Services (OSERS)

<http://www.ed.gov/about/offices/list/osers>

Part of the U.S. Department of Education. Responds to inquiries, and researches and documents information on operations serving the field of disabilities. Specializes in providing information on federal funding for programs serving people with disabilities, federal legislation affecting individuals with disabilities, and federal programs benefiting people with disabilities.

Social Security Administration

<http://www.ssa.gov>

Mission is to advance the economic security of the nation's people through compassionate and vigilant leadership in shaping and managing America's Social Security programs. Provides

information to the U.S. population on policy; programs and services; and, more specifically, resources for people with disabilities.

Finances

Children's Defense Fund (CFD)

<http://www.childrensdefense.org>
Private nonprofit organization dedicated to educating about, advocating for, and studying the needs of children, especially low-income children, minority children, and children with disabilities. Mission focuses on giving children a head start (child care), a healthy start (child health), a fair start (family income), a safe start (violence prevention, child welfare, and mental health), and a moral start (ethics, morality, and self-discipline).

Libraries and Clearinghouses

Cochrane Library

<http://www.thecochranelibrary.com>
Searchable, online database of systematic reviews of the effects of health care interventions related to pregnancy and neonatal outcomes. Also available on DVD-ROM.

Early Childhood

Research & Practice (ECRP)

<http://www.ecrp.uiuc.edu>
Web site of a peer-reviewed, bilingual electronic journal sponsored by the ERIC Clearinghouse on Elementary and Early Childhood Education (ERIC/EECE) at the University of Illinois at Urbana-Champaign. Covers topics related to the development, care, and education of children from birth to approximately age 8. Also includes articles and essays that present opinions and reflections, as well as letters to the editor.

Medline Plus Health Information

<http://www.medlineplus.gov>
Web site presents health information from NLM and contains extensive information for professionals and the public on diseases/conditions and medicines, lists of hospitals, a medical encyclopedia/dictionary, information in Spanish, and links to current clinical trials.

National Dissemination Center for Children with Disabilities (NICHCY)

<http://www.nichcy.org>
Web site contains information about specific disabilities, early intervention services for infants and toddlers, special education and related services for children in school, resources and connections in every state, individualized education programs, parent materials, disability organizations, professional associations, education rights and law requirements, and the

transition to adult life. Publishes *Research Connections in Special Education* and *OSEP Digests*.

National Library of Medicine (NLM)

<http://www.nlm.nih.gov>
Part of the National Institutes of Health. Is the world's largest medical library and is a national resource for all U.S. health sciences libraries. Collects materials in areas of biomedicine; health care; biomedical aspects of technology; humanities; and the physical, life, and social sciences.

PubMed

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi>
Search engine allows users to research and obtain peer-reviewed articles and abstracts published by major journals of medical research.

Professional Societies

American Academy of Pediatrics (AAP)

<http://aap.org>
The professional association of pediatricians. Committed to the optimal, physical, mental, and social health and well-being of infants, children, adolescents, and young adults. Publishes a major pediatric medical journal, *Pediatrics*.

American Academy of Pediatrics (AAP) Policies

<http://aappolicy.aappublications.org>
Web site includes policy statements and guidelines developed by the AAP. Also offers links to printable handouts for parents that provide important health messages based on these statements.

American College of Obstetricians and Gynecologists (ACOG)

<http://www.acog.org>
Professional organization of obstetrician-gynecologists, dedicated to the advancement of women's health through education, advocacy, practice, and research. Provides online physician directory. Bookstore offers patient information pamphlets, professional resources, and multimedia resources.

American Medical Association (AMA)

<http://www.ama-assn.org>
Develops and promotes standards in medical practice, research, and education; advocates for patients and physicians. Publishes a leading medical journal, *JAMA: The Journal of the American Medical Association*.

Association of University Centers on Disabilities (AUCD)

<http://www.aucd.org>
Represents the professional interests of the national network of 61 university centers for excellence in developmental disabilities education,

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research, and service (UCEs; formerly called university affiliated programs, or UAPs) that serve people with developmental disabilities.

National Association of Developmental Disabilities Councils

<http://www.nacdd.org>

Organization of developmental disability councils that exist in each state to provide information on and advocate for resources and services for people with developmental disabilities and their families.

Society for Disability Studies

<http://www.uic.edu/orgs/sds>

Works to explore issues of disability and chronic illness from scholarly perspectives. Publishes *Disability Studies Quarterly*; holds an annual conference that brings together scholars from a broad spectrum of fields as well as artists and community-based activists.

CHILD DEVELOPMENT AND DIAGNOSIS OF DISABILITIES

Birth Defects

Genetics Home Reference

<http://ghr.nlm.nih.gov>

Genetics Home Reference provides consumer-friendly information about the effects of genetic variations on human health.

March of Dimes

<http://www.marchofdimes.com>

Awards grants to institutions and organizations for development of genetic services, perinatal care in high-risk pregnancies, prevention of premature delivery, parent support groups, and other community programs. Campaign for Healthier Babies distributes information about birth defects and related newborn health problems. Spanish-language materials available.

National Society of Genetic Counselors

<http://www.nsgc.org>

Includes a searchable database of counselors.

Child Development

Ages and Stages: Birth to 12 months

<http://www.extension.iastate.edu/Publications/PM1530A.pdf>

Web site features a publication from the Iowa State University Extension program that presents information about the physical, mental, emotional, and social development of children between birth and 12 months of age. Provides

ideas and tips for parents to facilitate these milestones.

Child Development Institute

<http://www.childdevelopmentinfo.com>

Web site for parents on child development, parenting, child psychology, teenagers, health, safety, and learning disabilities.

East Tennessee Children's Hospital: Developmental Milestones

<http://www.etch.com/healthdevms.cfm>

Web site presents a brief overview of typical and atypical developmental milestones from birth to 15 months. Site also provides links to information about feeding and swallowing, physical therapy and occupational therapy, and language development.

KidsHealth

<http://kidshealth.org>

Sponsored by the Nemours Foundations Center for Children's Health. Web site offers a wide variety of information pertaining to child health issues. Contains helpful explanations of basic medical terminology and articles and resources for parents and professionals. Available in Spanish.

National Center for Education in Maternal and Child Health

<http://www.ncemch.org>

Disseminates publications and fact sheets to the public and professionals in the field and develops and maintains database of topics, agencies, and organizations related to maternal and child health.

Pediatric Development and Behavior

<http://www.dbpeds.org>

Independent web site created to promote better care and outcomes for children and families affected by developmental, learning, and behavioral problems by providing access to clinically relevant information and educational material for medical providers, other service delivery professionals, and parents.

WebMD Health

<http://my.webmd.com>

Provides a variety of useful information on mainstream health topics. Offers reliable information about identifying symptoms of illness and reports on highlighted topics.

ZERO TO THREE

<http://www.zerotothree.org>

National, nonprofit organization whose mission is to promote the healthy development of infants

and toddlers by supporting and strengthening families, communities, and those who work on their behalf. Web site includes various policies, research reports, and technical assistance resources for parents and professionals.

Environmental Toxicants

American Association on Intellectual and Developmental Disabilities (AAIDD) Environmental Health Initiative

<http://www.aaid.org/ehi/index.cfm>

AAIDD's goals are to raise awareness about the complex links between exposure to neurotoxic chemicals and developmental disabilities, and to raise awareness that those living with intellectual disabilities and related developmental disabilities may be at greater risk of secondary health effects from toxic exposures than individuals without disabilities.

National Library of Medicine, Environmental Health and Toxicology Webpages

<http://sis.nlm.nih.gov/enviro.html>

The NLM has aggregated a large number of resources at a single web portal.

Pediatric Environmental Health Specialty Units (PEHSU)

www.pehsu.net

There are 10 PEHSUs in the United States. Any health professional, parent, school teacher or other person can contact their regional PEHSU for information about children's health and the environment.

Genetics

GeneTests

<http://www.ncbi.nlm.nih.gov/sites/GeneTests/> Free medical genetics information resource developed for physicians, other health care providers, researchers, and the public. Provides *GeneReviews*, peer-reviewed articles describing the application of genetic testing to the diagnosis, management, and genetic counseling of patients; international directories for genetic testing laboratories and genetic and prenatal diagnosis clinics; and various educational materials.

Genetic Alliance

<http://www.geneticalliance.org>

International organization of families, health professionals, and genetic organizations dedicated to enhancing the lives of individuals living with genetic conditions through the provision of education, policy, and information services. Staff is available to address questions about

genetics and to connect callers with support groups and informational resources. An annual conference is held in Washington, D.C.

Genetics Society of America

<http://www.genetics-gsa.org>

Professional organization that aims to bring together genetic investigators and provide a forum for sharing research findings. Cooperates in the organization of an international congress held every 5 years under the auspices of the International Genetics Federation. Publishes the journal *GENETICS* and other resources.

Online Mendelian

Inheritance in Man (OMIM)

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

Web site database of human genes and genetic disorders with textual information, pictures, and reference information.

Neurocognitive Assessment

American Psychological Association

<http://www.apa.org/topics/testing/index.aspx>

Web site addresses major considerations and issues in psychological testing.

National Council on Measurement in Education

<http://www.ncme.org>

Organization working to advance the science and practice of measurement in education.

The Standards for Educational and Psychological Testing

<http://www.apa.org/science/programs/testing/standards.aspx>

A key reference for test developers and professionals, developed jointly by the American Educational Research Association (AERA), the American Psychological Association (APA), and the National Council on Measurement in Education (NCME).

Prematurity

BLISS

<http://www.bliss.org.uk>

Site created by parents for parents that provides information about causes of prematurity and levels of neonatal care.

Emory Pediatrics

Developmental Progress Clinic

<http://med.emory.edu/PEDIATRICS/NEONATOLOGY/DPC/index.htm>

Information regarding medical complications with implications for development focusing on prematurity and other neonatal medical

complications associated with developmental problems, developmental care in the neonatal intensive care unit, neurodevelopmental implications of neonatal trauma, developmental milestones specifically for children born prematurely, information regarding issues beyond infancy, Georgia state resources, frequently asked questions and answers, and web links.

Family Practice Notebook

<http://www.fpnotebook.com/NICCH16.htm>
Information on the outcomes of infants born prematurely. Also gives neurological outcomes for 24–26 weeks' gestation and links to the references that support these outcomes.

March of Dimes PeriStats Database

<http://www.marchofdimes.com/peristats/>
PeriStats provides free access to maternal and infant health-related data at the United States, state, county, and city level.

Mayo Clinic: Premature Birth

<http://www.mayoclinic.com/health/premature-birth/DS00137>
Provides information related to prematurity, such as causes of premature delivery, signs and symptoms during pregnancy, and when to seek medical help. Also includes information on the difficulties a child born prematurely may have, the course of care he or she will receive in the neonatal intensive care unit, and what to expect upon discharge.

Medline Plus: Premature Babies

<http://www.nlm.nih.gov/medlineplus/prematurebabies.html>
Resource for health care professionals. Sections include drug information, an encyclopedia, a dictionary, news pages, and other resources. Provides links to information (e.g., car-seat safety for premature infants) that can be printed out and shared with parents.

Parents of Premature Babies

<http://www.preemie-1.org>
Supports families and caregivers of premature infants. Offers a discussion forum and an e-mail list, as well as a unique mentoring program for new parents of premature infants who are matched with parents of an older premature infant.

Premature Babies: Caring for Your Baby

<http://familydoctor.org/handouts/283.html>
Web site maintained by the American Academy of Family Physicians as an all-encompassing resource to address typical parent concerns. Includes discussions about the special care

needed by premature babies, growth and development, feeding issues, sleep patterns, vision and hearing, immunizations, and travel concerns such as car seat placement.

Premature Babies Guide at Keep Kids Healthy

http://www.keepkidshealthy.com/newborn/premature_babies.html
General resource for parents. It defines the risk factors for having a premature baby; describes neonates at various gestational ages; defines common medical problems that premature babies often face; and answers common parent questions related to feeding, going home, and possible long-term problems.

Premature Baby–Premature Child

<http://prematurity.org>
Web site developed by parents of children who were born prematurely and who went on to have developmental issues.

Premature-infant.com

<http://premature-infant.com>
Web site has touching stories and supportive information for parents, along with insights for medical personnel. Contains resource links to related problems/concerns. Also provides information regarding gastroesophageal reflux disease, infant massage, kangaroo care, positioning, pain, respiratory syncytial virus (RSV), and feeding issues.

The Vermont Oxford

<http://www.vtoxford.org>
Web site provides information for the institutions that participate in its database. Database tracks the progress of high-risk infants within certain criteria and provides good statistical analysis and research options to those who participate.

DEVELOPMENTAL DISABILITIES AND DISABLING ILLNESSES

Acquired Immunodeficiency Syndrome (AIDS)

Centers for Disease

Control and Prevention (CDC)

National Sexually Transmitted Diseases (STD) and AIDS Hotline (English: 800-342-2437; Spanish: 800-344-7432; TTY: 800-243-7889; <http://www.cdc.gov>). Weekday hotline that provides confidential information on transmission and prevention of human immunodeficiency

virus (HIV)/AIDS and other STDs, testing, local referrals, and educational materials to the public.

Office of National AIDS Policy

<http://www.whitehouse.gov/onap/aids.html>
Provides broad direction for federal AIDS policy and fosters interdepartmental communication on HIV and AIDS. Works closely with the AIDS community in the United States and around the world.

Attention-Deficit/ Hyperactivity Disorder (ADHD)

A.D.D. Warehouse

<http://www.addwarehouse.com>
Mail-order resource for ADHD-related books, games, videotapes, and other materials for clinicians, parents, teachers, adults, and students.

Attention Deficit Disorder Association

<http://www.add.org>
National organization that provides education, research, and public advocacy. Especially focused on the needs of adults and young adults with ADHD.

CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder)

<http://www.chadd.org>
Support group for parents of children with attention disorders. Provides continuing education for both parents and professionals, serves as a community resource for information, and advocates for appropriate educational programs.

Autism Spectrum Disorders (ASDs)

American Academy of Pediatrics

<http://www.aap.org/healthtopics/autism.cfm>
Web site provides professional and family/community resources and information about autism spectrum disorders. Includes links for audiotaped interviews of experts for families and professionals about pertinent topics, to the *AAP Toolkit: AUTISM: Caring for Children with Autism Spectrum Disorders Resource Toolkit for Clinicians*, as well as policy statements pertinent to ASDs.

Autism Society of America

<http://www.autism-society.org>
Provides information about autism, including options, approaches, methods, and systems available to parents and family members of children with autism and the professionals who work with them. Advocates for the rights and needs of individuals with autism and their families.

Autism Speaks

<http://www.autismspeaks.org>
Dedicated to helping families find answers, through funding research and education efforts and, most significantly, by spearheading the development of a national registry of individuals with autism.

International Rett Syndrome Association

<http://www.rettysyndrome.org>
Provides information, referral, and support to families and acts as a liaison with professionals.

National Center on Birth Defects and Developmental Disabilities (NCBDDD): Autism Information Center

<http://www.cdc.gov/ncbddd/autism/index.htm>
Web site has unique feature: link to the Autism Spectrum Disorders Kids' Quest, a series of informative sites provided by the NCBDDD for the purpose of educating children about developmental disabilities. Site also provides information about current research on autism spectrum disorders (ASDs) by the Centers for Disease Control and Prevention (CDC) and other federal agencies. Serves as a link for information regarding various state funding programs for ASDs.

Blindness

American Association for Pediatric Ophthalmology and Strabismus (AAPOS)

<http://aapos.org>
Provides resources for patients and families regarding frequently asked questions of ocular conditions. Resource for locating a pediatric ophthalmologist in your area.

American Foundation for the Blind (AFB)

<http://www.afb.org>
Works in cooperation with other agencies, organizations, and schools to offer services to individuals who are blind or who have visual impairments; provides consultation, public education, referrals, and information; produces and distributes talking books; publishes and sells materials for professionals in the blindness field.

American Printing House for the Blind (APH)

<http://www.aph.org>
Nonprofit publishing house for people with visual impairments. Has books in braille and large type and on audiotape and computer disk, as well as a range of aids, tools, and supplies for education and daily living.

Learning Ally (Previously Recording for the Blind & Dyslexic)

<http://www.learningally.org>

Produces and distributes textbooks on audio-tape, computer disk, and CD-ROM; individuals or institutions who have memberships may borrow these materials. Also provides reference librarian services for individual members.

Lighthouse

International (previously National Association for Visually Handicapped)

www.lighthouse.org

Provides informational literature, guidance, and counseling in the use of visual aids, emotional support, and referral services for parents of partially sighted children and for people who work with these children. Publishes free large-print newsletter.

National Braille Association

<http://www.nationalbraille.org>

Produces and distributes braille reading materials for people with visual impairment. Collection consists of college-level textbooks, materials of general interest, standard technical tables, and music.

National Federation of the Blind

<http://www.nfb.org>

Strives for complete inclusion of people who are blind into society on the basis of equality. Offers advocacy services for these individuals in such areas as discrimination in housing and insurance. Operates a job referral and listing system for individuals to find competitive employment. Runs an aids and appliances department, a scholarship program for college students, and a loan program for people who are going into business for themselves. Publishes monthly and quarterly publications.

National Library Service for the Blind and Physically Handicapped

<http://www.loc.gov/nls>

Administers a national library service through a network of participating public libraries to provide braille and recorded books and magazines on free loan to anyone who cannot read standard print because of visual or physical disabilities.

Prevent Blindness America

<http://www.preventblindness.org>

Committed to the reduction of preventable blindness. Provides information to people who are blind, professionals working with these individuals, and the public.

United States Association of Blind Athletes (USABA)

<http://www.usaba.org>

Aims to ensure that legally blind individuals have the same opportunities as their sighted peers in recreation and sports programs at all levels, from developmental to elite. Works to change negative stereotypes related to the abilities of individuals who are blind and other people with disabilities. Publishes a newsletter. Web site has links to related sites and event calendars with sport descriptions.

Cerebral Palsy

American Academy for Cerebral Palsy and Developmental Medicine (AACPDM)

<http://www.aacpdm.org/>

Multidisciplinary scientific society that fosters professional education, research, and interest in the problems associated with cerebral palsy.

Cerebral Palsy, Erbs Palsy, All Types of Cerebral Palsy

<http://www.cerebralpalsy.org>

Web site provides information about causes, risk factors, and types of cerebral palsy. Includes links and resources about types of help available and how to find help. Also discusses treatment interventions and special education issues.

Cerebral Palsy: Hope Through Research

http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm

Web site discusses diagnostic questions related to cerebral palsy. Includes questions related to causes and treatments available. Also provides information about current research projects being conducted concerning cerebral palsy. Available in Spanish.

Cerebral Palsy—Neurology Channel

http://www.neurologychannel.com/cerebral_palsy

Web site includes information about cerebral palsy, including types, causes, treatments, risk factors, complications, and prognosis. Also provides information about orthopedic and neurological surgeries for cerebral palsy.

Children's Disabilities and Special Needs

http://www.comeunity.com/disability/cerebral_palsy

Web site contains general articles related to cerebral palsy and articles about research concerning cerebral palsy in children born prematurely. Provides links to books and resources.

CP Resource Center

<http://www.cpparent.org>

Web site provides general information about cerebral palsy, its causes, and some treatments. Contains a dictionary to help parents understand medical terms they may hear. Also lists books for further reading.

United Cerebral Palsy

<http://www.ucp.org>

Provides direct services to children and adults with cerebral palsy that include medical diagnosis, evaluation and treatment, special education, career development, counseling, social and recreational programs, and adapted housing.

Deafness and Speech Disorders**ADARA (formerly Professional Workers with the Adult Deaf [PRWAD] and the American Deafness and Rehabilitation Association)**

<http://www.adara.org>

Serves professionals who work with deaf individuals and people interested in learning about deafness. Publishes a journal and newsletter by subscription; offers memberships.

Alexander Graham Bell Association for the Deaf

<http://nc.agbell.org>

A free membership organization that provides general information and information on resources related to hearing loss. They publish materials and books on these subjects and provide information about scholarships and financial aid for individuals who are deaf and hard of hearing.

American Society for Deaf Children

<http://www.deafchildren.org>

Provides information and support to parents and families with children who are deaf or hard of hearing.

American Speech-Language-Hearing Association (ASHA)

<http://www.asha.org>

Professional and scientific organization and certifying body for professionals providing speech-language and hearing services. Conducts research in communication disorders, publishes several journals, and provides consumer information and professional referral.

Apraxia—KIDS

<http://www.apraxia-kids.org>

Web site maintained by Childhood Apraxia of Speech Association of North America

(CASANA). Provides comprehensive information and resources, including a free online newsletter, related to diagnosis and treatment, educational programs, and the medical and insurance aspects of childhood apraxia. Spanish-language materials are available.

Augmentative and Alternative Communication—Rehabilitative Engineering Research Center (AAC-RERC)

<http://aac-rerc.psu.edu/>

Collaborative research programs that develop and disseminate information and activities that seek to advance and promote augmentative and alternative communication (AAC) technologies for individuals with disabilities who use them, as well as for professionals who manufacture, recommend, and distribute them.

Boys Town National Research Hospital

<http://www.boystownhospital.org/home.asp>;

<http://www.babyhearing.org/>

Two web sites that provide a variety of resources relating to children with hearing, language, and learning disabilities and the research currently underway at Boys Town National Research Hospital. The site titled “Baby Hearing” is offered in a Spanish-language version.

Centers for Disease Control and Prevention

<http://www.cdc.gov/hearingloss>

Web site provides comprehensive information about hearing loss. It is sponsored by the National Center on Birth Defects and Developmental Disabilities of the U.S. federal government’s Centers for Disease Control and Prevention. This web site and its Hearing Loss Team provides free brochures, fact sheets, and other educational materials.

Collaborative Early Intervention National Training e-Resource

<http://center.uncg.edu>

Target audience for web site is professionals who serve families with infants and toddlers who are deaf or hard of hearing. Provides graduate-level, web-based training for service providers. Site also offers an extensive list of resources for professionals and families.

Deafness Research Foundation

<http://www.drfr.org>

Solicits funds for the support of research into the causes, treatment, and prevention of deafness and other hearing disorders.

Described and Captioned Media Program

<http://www.dcmp.org/>

Government-sponsored distribution of open-captioned materials to eligible institutions, individuals, and families. Program promotes and provides equal access to communication and learning for students who are blind, visually impaired, deaf, hard of hearing, or deaf-blind.

Hands and Voices

<http://www.handsandvoices.org>

A nationwide nonprofit organization that is a parent-driven, parent/professional collaborative group dedicated to supporting families and their children who are deaf or hard of hearing, as well as the professionals who serve them. Web site offers a wealth of information and resources related to hearing loss, technology, communication and educational methodologies, and advocacy.

Hearing Loss**Association of America (HLAA)**

<http://www.shhh.org>

Educational organization that provides assistance to individuals who are deaf or hard of hearing to participate fully in society. Publishes a journal, newsletter, and other materials; provides advocacy and outreach programs and an extensive network of local chapters and self-help groups; and hosts an annual convention.

Helen Keller National Center for Deaf-Blind Youths and Adults

<http://www.hknc.org/>

The center offers a residential training facility for deaf-blind individuals and has representatives in 10 regional offices across the nation who can assist with information, training, and support. Also maintains a national registry of people who are deaf-blind.

International Hearing Society

<http://ihsinfo.org/IhsV2/Home/Index.cfm>

Provides information on how to proceed when hearing loss is suspected. Also offers free consumer kit, facts about hearing aids, and a variety of literature on hearing-related subjects.

Laurent Clerc National Deaf Education Center

<http://clerccenter.gallaudet.edu/infotogo>

Web site provides a comprehensive resource related to the educational, linguistic, social, and emotional development of deaf or hard of hearing children. Information is included about assistive devices and hearing aids, learning sign language or speech reading, and classroom

issues related to education of children with deafness.

National Center for Stuttering

<http://www.stuttering.com/homepag.htm>

Provides free information for parents of young children just starting to show symptoms of stuttering; runs training programs in current therapeutic approaches for speech-language professionals; provides treatment for people older than 7 years of age who stutter.

National Consortium on Deaf-Blindness

<http://www.nationaldb.org/>

A national technical assistance and dissemination center for children and youth who are deaf-blind. Web site provides information about deaf-blindness, disability, education and technical assistance, technology, and medical and health resources.

National Institute on Deafness and Other Communication Disorders/National Institutes of Health

<http://www.nidcd.nih.gov/>

A web site, sponsored by the U.S. federal government, that provides health information about all hearing-related topics including ear infections, deafness and hearing aids, as well as balance, smell, taste, voice, and speech and language disorders. The institute offers free publications, information about clinical trial participation, and links to organizations related to deafness and communication disorders.

Speech and Language Development in Young Children

http://members.tripod.com/Caroline_Bowen/devell1.htm

Web site presents information about the acquisition of language in early childhood. Provides information about how language is learned and the role of the parent in facilitating these skills. Language and communication milestones are presented along with a section on when to seek professional help.

Speech Therapy Activities

<http://www.speechctx.com>

Web site provides free, printable speech-language activities for speech-language pathologists and parents.

Down Syndrome**The Association for Children with Down Syndrome**

<http://www.acds.org>

Offers information and referral services, including a free list of publications.

Down Syndrome: Health Issues

<http://www.ds-health.com>

For parents and professionals. Web site includes articles concerning specific health issues related to Down syndrome, such as gastroesophageal reflux, blood disorders, and thyroid function. Information also provided about health guidelines and controversies in the care of children and adults with Down syndrome.

National Down Syndrome Congress (NDSC)

<http://ndscenter.org>

Provides information, advocacy, and support. Has annual convention for families in the summer and publishes a newsletter, *Down Syndrome News*.

National Down Syndrome Society (NDSS)

<http://www.ndss.org>

National advocate for the values, acceptance, and inclusion of people with Down syndrome. Works with affiliate groups to advance research, increase public awareness, and improve education opportunities.

Epilepsy**American Epilepsy Society**

<http://www.aesnet.org>

Promotes research and education for professionals dedicated to the prevention, treatment, and cure of epilepsy.

Epilepsy Foundation

<http://www.efa.org>

Provides programs of information and education, advocacy, support of research, and the delivery of needed services to people with epilepsy and their families.

International League Against Epilepsy

<http://www.ilae-epilepsy.org>

Global nonprofit organization that disseminates knowledge about epilepsy and fosters research, education, training, and improved services and care. Has official working relationship with the World Health Organization.

Fetal Alcohol Spectrum Disorder**Family Empowerment Network (FEN)**

<http://www.fammed.wisc.edu/fen>

National nonprofit organization that exists to empower families affected by fetal alcohol syndrome and other drug-related birth defects, through education and support; also publishes a newsletter, *The FEN Pen*.

National Organization on Fetal Alcohol Syndrome (NOFAS)

<http://www.nofas.org>

Nonprofit organization founded in 1990; dedicated to eliminating birth defects caused by alcohol consumption during pregnancy and to improving the quality of life for those individuals and families affected.

PREVLIN: Prevention Online (National Clearinghouse for Alcohol and Drug Information)

<http://ncadi.samhsa.gov>

The world's largest resource for current information and materials concerning substance abuse. Distributes brochures, offers resources for parents and teachers on prevention, and has English- and Spanish-speaking information service staff available to answer questions.

Genetic Syndromes and Inborn Errors of Metabolism

There are many support organizations and networks for children with various syndromes and inborn errors of metabolism and their families. Resources for more common syndromes (e.g., Down syndrome) appear in their own sections in this appendix, but a representative sample of others is listed here. For a more complete listing, contact the National Organization for Rare Disorders (NORD [see later listing]).

5p Minus Society

<http://www.fivepminus.org>

Family support and information group for parents, grandparents, and guardians of individuals with 5p- (cri-du-chat) syndrome. Publishes a newsletter and sponsors an annual meeting.

Angelman Syndrome Foundation, Inc.

<http://www.angelman.org>

Organization that sponsors research, and provides information to families and providers. Sponsors a biennial conference and has a mentorship program for newly diagnosed families.

The American Society of Human Genetics

<http://www.ashg.org>

Professional organization for human genetics specialists. Publishes *The American Journal of Human Genetics* and other resources.

Arthrogyrosis Multiplex Congenita Support, Inc.

<http://www.amcsupport.org>

Group that aims to provide more information and support for families of children with arthrogyrosis multiplex congenital. Provides

resources for physical therapists and other providers to families.

Association for Glycogen Storage Disease

<http://www.agsdus.org>

Association that aims to create public awareness, provide family support, and stimulate research. A quarterly newsletter, *The Ray*, is published, and a conference is held annually.

Avenues

<http://www.avenuesforamc.com>

Publishes a semiannual newsletter that provides lists of parents, physicians, and experienced medical centers concerned with people with arthrogryposis multiplex congenita.

Children's Craniofacial Association

<http://www.ccakids.com>

Supports families and children with craniofacial patients, encourages public awareness and education, and publishes a quarterly newsletter, and educational booklets.

Children's Tumor Foundation: Ending Neurofibromatosis through Research

<http://www.ctf.org>

Foundation dedicated to improving the health and well-being of individuals and families affected by neurofibromatosis by supporting research, providing information for families, assisting in developmental clinical centers and expanding public awareness.

Cornelia de Lange Syndrome Foundation

<http://www.cdlsusa.org>

Supports parents and children affected by de Lange syndrome, encourages research, and disseminates information to increase public awareness through a newsletter and informational pamphlet.

Ehlers Danlos National Foundation

<http://www.ednf.org>

Funds research and provides information and support to families and medical providers. Sponsors annual conference.

FRAXA Research Foundation

<http://www.fraxa.org>

Supports scientific research aimed at finding a treatment and a cure for fragile X syndrome. Funds grants and fellowships at universities worldwide. Runs an e-mail list on which individuals may post strategies and questions. Publishes *FRAXA Newsletter*, *Medication Guide for Fragile X Syndrome* (by Michael Tranfaglia) and *Fragile X A to Z: A Guide for Families* (edited by Wendy Dillworth; downloadable from the web site free of charge).

Little People of America, Inc.

<http://www.lpaonline.org>

Nationwide organization dedicated to helping people of short stature. Provides fellowship, moral support, and information to people who are shorter than typical, or individuals with dwarfism. The toll-free helpline provides information on organizations, products and services, and doctors in the caller's area.

The National Fragile X Foundation

<http://www.FragileX.org>

Provides information, medical and genetic referrals, sponsors research grants, and provides educational resources.

National Gaucher Foundation

<http://www.gaucherdisease.org>

Publishes quarterly newsletter, operates support groups and chapters, provides referrals to organizations for appropriate services, and funds research on Gaucher disease.

National MPS Society

<http://www.mpsociety.org>

Raises money to provide student fellowships and fund research for mucopolysaccharide disorder, collaborates with other lysosomal storage diseases, patient support groups, supports families by providing resource guides, publish a newsletter, *Courage*, and hold a yearly conference.

The National Organization for Rare Disorders (NORD)

<http://www.rarediseases.org>

A nonprofit patient advocacy organization dedicated to orphan diseases (disorders occurring in fewer than 200,000 individuals in the United States). NORD provides information about diseases, referrals to patient organizations, research grants and fellowships, advocacy for the rare-disease community, and medication assistance programs.

National PKU Alliance

<http://www.npkua.org>

Raises money to fund research, supports local phenylketonuria (PKU) organizations, educates communities about issues faced by individuals and families affected with PKU.

National Tay-Sachs and Allied Diseases Association

<http://www.NTSAD.org>

Promotes genetic screening programs nationally, has updated listing of Tay-Sachs disease-prevention centers in a number of countries, provides educational literature to general public and professionals, and coordinates peer group support for parents.

National Urea Cycle Disorders Foundation
<http://www.nucdf.org>

Provides information and support for families. Supports and stimulates medical research and increased awareness by the public and the legislators of issues related to urea cycle disorders.

Organic Acidemia Association

<http://www.oaanews.org>

A volunteer nonprofit organization whose mission is to empower families and health care professionals with knowledge in organic acidemia metabolic disorders.

Osteogenesis Imperfecta Foundation

<http://www.oif.org>

Supports research on osteogenesis imperfecta and provides information to those with this disorder, to their families, and to other interested people.

Prader-Willi Syndrome Association

<http://www.pwsausa.org>

National organization that provides information education and support services on Prader-Willi syndrome to parents, professionals, and other interested people. Provides research funding, bimonthly newsletter, and an annual national conference for families and professionals.

Rare Diseases Clinical Research Network

<http://rarediseasesnetwork.epi.usf.edu>

National network made up of 19 distinctive consortia that are working together to improve availability of rare disease information, treatment, clinical studies, and general awareness for both patients and the medical community. The RDCRN also aims to provide up-to-date information for patients and to assist in connecting patients with advocacy groups, expert doctors, and clinical research opportunities.

Support Organization for Trisomy 18, 13, and Related Disorders (SOFT)

<http://www.trisomy.org>

Chapters in most states provide support and family packages with a newsletter and appropriate literature underscoring the common problems for children with trisomy 13 or trisomy 18 during pregnancy, life and after passing. Holds a yearly conference for families and professionals.

Tourette Syndrome Association

<http://www.tsa-usa.org>

Offers information, referral, advocacy, education, research, and self-help groups for those affected by Tourette syndrome.

Excerpted from *Children with Disabilities*, Seventh Edition

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Tuberous Sclerosis Alliance

<http://www.tsalliance.org>

Offers public information about manifestations of the disease to newly diagnosed individuals, their families, and interested professionals. Referrals are made to support groups located in most states. Funds research through membership fees and donations.

United Leukodystrophy Foundation

<http://www.ulf.org>

Maintains 24-hour hotline to provide family support, provides educational resources, supports research, puts out a quarterly newsletter, and runs an annual conference.

The United Mitochondrial Disease Foundation

<http://www.umdf.org>

Promotes research and education for the diagnosis, treatment, and cure of mitochondrial disorders and provides support to affected individuals and families.

Intellectual Disability

American Association on Intellectual and Developmental Disabilities (AAIDD)

<http://www.aaidd.org>

Professional organization that promotes cooperation among those involved in services, training, and research in intellectual disabilities. Encourages research, dissemination of information, development of appropriate community-based services, and the promotion of preventive measures designed to further reduce the incidence of intellectual disability.

The Arc of the United States

<http://thearc.org>

National advocacy organization working on behalf of individuals with intellectual disabilities and their families; has more than 1,000 state and local chapters.

President's Committee for People with Intellectual Disabilities (PCPID)

<http://www.acf.hhs.gov/programs/pcpid/index.html>

Advises the President and the Secretary of Health and Human Services on all matters pertaining to intellectual disabilities; publishes annual reports and information on the rights of people with intellectual disabilities.

Learning Disorders

Dyslexia Research Institute

<http://www.dyslexia-add.org>

Provides training, workshops, and seminars for professionals.

International Dyslexia Association (IDA)

<http://www.interdys.org>

Devoted to the study and treatment of dyslexia; provides information and referrals; sponsors conferences, seminars, and support groups; and has two regular publications and more than 40 branches in the United States and abroad.

LD Online

<http://www.ldonline.org>

Resources on learning disabilities for parents, students, teachers, and other professionals. Interactive web site provides basic information on learning disabilities and the latest research and news; also offers e-mail consultation by experts on learning disabilities, resource lists, personal stories, bulletin boards, and materials/resources for purchase.

Learning Disabilities**Association of America (LDA)**

<http://www.ldanatl.org>

Encourages research and the development of early detection programs, disseminates information, serves as an advocate, and works to improve education for individuals with learning disabilities.

National Center for Learning Disabilities (NCLD)

<http://www.ld.org>

Promotes public awareness of learning disabilities and provides computerized information and referral services to consumers and professionals on learning disabilities. Publishes *Their World*, an annual magazine for parents and professionals.

Schwablearning.org

<http://www.schwablearning.org>

An online parent's guide to helping children with learning disabilities and attention-deficit/hyperactivity disorder (ADHD), including information on identifying disabilities and on managing home, school, and learning. Site also has resources and publications for families.

Neural Tube Defects**Spina Bifida Association of America**

<http://www.sbaa.org>

Provides information and referral for new parents and literature on spina bifida; supports a public awareness program; advocates for individuals with spina bifida and their families; supports research; and conducts conferences for parents and professionals.

Neuromuscular and Musculoskeletal Disorders**Cure CMD**

<http://curecmd.org/>

Support group for families affected by congenital muscular dystrophy, also provides research funding.

Families of SMA

<http://www.fsma.org/>

Support group for families affected by spinal muscular atrophy.

Guillain-Barré Syndrome Foundation International

<http://www.gbsfi.com>

Provides emotional support to individuals with Guillain-Barré syndrome and their families; fosters research; educates the public about the disorder; develops nationwide support groups; and directs people with this syndrome to resources, meetings, newsletters, and symposia.

Harvard Neuromuscular Disease Project

http://www.childrenshospital.org/cfapps/research/data_admin/Site2549/mainpageS2549P0.html

Conducts research in the genetics of neuromuscular diseases, especially muscular dystrophy.

Manton Center for Orphan Disease Research

http://www.childrenshospital.org/cfapps/research/data_admin/Site2673/mainpageS2673P0.html

Research center devoted to the study of rare diseases, including inherited neuromuscular conditions.

Muscular Dystrophy Association

<http://www.mdaua.org>

Health care agency that fosters research and provides direct services to individuals with muscular dystrophy; is concerned with conquering muscular dystrophy and other neuromuscular diseases.

Myasthenia Gravis Foundation of America

<http://www.myasthenia.org/>

Support group for myasthenia gravis.

National Scoliosis Foundation

<http://www.scoliosis.org>

Nonprofit organization with state chapters; dedicated to informing the public about scoliosis and promoting early detection and treatment of scoliosis. Publishes *Spinal Connection Newsletter*.

Scoliosis Research Society

<http://www.srs.org>

Sponsors and promotes research on the etiology and treatment of scoliosis and spinal disorders.

Spinal Muscular Atrophy Foundation (SMA Foundation)

<http://www.smafoundation.org/>

Provides support for research into potential therapies for SMA.

Traumatic Brain Injury (TBI)**Brain Injury Association of America**

<http://www.biausa.org>

Provides information to educate the public, politicians, businesses, and educators about brain injury, including effects, causes, and prevention.

Traumatic Brain Injury Resource Guide

<http://www.neuroskills.com>

Web site includes educational information, books, local support groups, and research.

**INTERVENTIONS,
SERVICES, AND OUTCOMES****Assistive Technology****ABLEDATA**

<http://www.abledata.com>

National database of information on assistive technology and rehabilitation equipment.

Alliance for Technology Access

<http://www.ataccess.org>

A resource and demonstration center open to people with disabilities, their families, and professionals and others interested in adaptive technology.

Assistive Technology Outcomes Measurement System (ATOMS)

<http://www.atoms.uwm.edu>

A center which has done research and developed publications on outcomes of the use of assistive technology.

Center for Applied Special Technology (CAST)

<http://www.cast.org>

CAST is a nonprofit research and development organization that works to expand learning opportunities for all individuals, especially those with disabilities, through Universal Design for Learning.

Independent Living Aids

<http://www.independentliving.com>

Sells aids that make daily tasks easier for those with physical disabilities; also carries clocks, calculators, magnifying lamps, and easy-to-see low-vision and talking watches for individuals with visual impairments.

Michigan's Assistive Technology Resource

<http://www.copower.org/At/atlinks.htm>

Provides free information on low-tech devices and equipment available for individuals with disabilities.

National Center for Technology Innovation (NCTI)

<http://www.nationaltechcenter.org>

NCTI assists researchers, developers, and entrepreneurs in creating innovative learning tools for all students, with special focus on students with disabilities.

Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)

<http://www.resna.org>

Multidisciplinary organization of professionals interested in the identification, development, and delivery of technology to people with disabilities. Offers numerous publications.

Behavior and Mental Health**American Academy of Child and Adolescent Psychiatry (AACAP)**

<http://www.aacap.org>

National nonprofit organization comprised of child and adolescent psychiatrists. Provides information for professionals and families to aid in the understanding and treatment of childhood and adolescent developmental, behavioral, and mental health disorders. Parent and caregiver fact sheets and information on research, practice, and membership are available on the web site.

American Psychiatric Association (APA)

<http://www.psych.org>

International organization for physicians, dedicated to the diagnosis and treatment of mental health and substance-use disorders.

American Psychological Association (APA)

<http://www.apa.org>

National scientific and professional organization that develops and promotes standards in psychological practice, research, and education. Dedicated to the dissemination of psychological knowledge to professionals, students, and the general public through meetings, reports, and publications.

Association for Behavior Analysis International (ABA International)

<http://www.abainternational.org>

International organization that promotes the experimental, theoretical, and applied analysis of behavior. Disseminates professional and public information. Also publishes two scholarly journals, *The Behavior Analyst* and *The Analysis of Verbal Behavior*.

Behaviour Change Consultancy

<http://www.behaviourchange.com>

Provides advice, support, project management, policy development, and training to schools, local educational authorities, and parents on the subjects of disaffection. Also gives advice on social, emotional, and behavioral difficulties, as well as behavior management.

Bright Futures at Georgetown University

<http://www.brightfutures.org/mentalhealth>

Web site explains the Bright Futures materials that help providers operationalize the guidelines for mental health promotion in children. Site also contains materials to download, including a mental health fact sheet, a listing of supporting organizations, and training tools.

Head Start/Administration on Children and Families

<http://www.headstartinfo.org>

Web site contains a wealth of information on the Head Start and Early Head Start programs. A special feature is The Mental Health Toolkit, an annotated bibliography of a variety of articles, books, and federal programs, services, and publications.

Journal of Applied Behavior Analysis

<http://seab.envmed.rochester.edu/jaba>

Psychology journal that publishes research about applications of the experimental analysis of behavior to social problems. Published by The Society for the Experimental Analysis of Behavior.

Research and Training Center (RTC) on Family Support and Children's Mental Health

<http://www.rtc.pdx.edu>

This federally funded RTC is dedicated to promoting effective community-based, culturally competent, family-centered services for families and their children who are or may be affected by mental health, emotional, or behavioral disorders.

Early Intervention

Child and Family Studies Research Programs

<http://jeffline.tju.edu/cfsrp/>

Conducts research and offers resources and training for professionals working with infants, toddlers, and young children with disabilities and their families.

Child Development Web

<http://www.childdevelopmentweb.com/Information/EIprograms.asp>

Web site offers information on early intervention for parents and families of children who might be eligible for services. Early Intervention Programs section is part of the Information Link on The Child Development web's home page. Site contains information on obtaining services in the United States, an explanation of early intervention programs and processes, and a breakdown of the services that are available through early intervention. Provides contact information for early intervention in each state.

Contemporary Practices in Early Intervention

<http://www.teachingei.org>

A distance-learning program to train early interventionists to provide evidence-based, culturally competent, family-centered early childhood practices to infants, toddlers, and young children with disabilities and their families.

Early Childhood Outcomes Center

<http://www.fpg.unc.edu/~eco>

Offers information and resources for state and local early childhood administrators, technical assistance providers, teachers, other direct service providers, and families.

Kid Source

<http://www.kidsource.com>

Web site defines early intervention and provides support for intervening as early as a disability or developmental difficulty has been identified. Site also contains a basic, although limited, reference list.

The National Early Childhood Technical Assistance Center (NECTAC)

<http://www.nectac.org/>

Offers tools and information on a vast range of topics for early childhood professionals.

National Scientific Council on the Developing Child at Harvard University

<http://www.developingchild.net>

Presents scientific research on early childhood and early brain development to guide public policy.

Education

American Educational Research Association (AERA)

<http://www.aera.net>

International professional organization with the goal of advancing educational research and its practical education. Members are educators, counselors, evaluators, graduate students, behavioral scientists, and directors or administrators of research, testing, or evaluation.

Association on Higher Education and Disability (AHEAD)

<http://www.ahead.org>

Professional organization committed to full participation in higher education for people with disabilities.

Association for Supervision and Curriculum Development (ASCD)

<http://www.ascd.org>

Professional membership organization for educators with interest in instruction, curriculum, and supervision. Publishes the journal *Educational Leadership*.

Building the Legacy: IDEA 2004—Part C

<http://idea.ed.gov> and <http://idea.ed.gov/explore/view/p/root,statute,IC>

Comprehensive information about IDEA 2004 Part C, which funds and regulates early intervention services for infants and toddlers with disabilities and their families.

Council for Exceptional Children (CEC)

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

Provides information to teachers, administrators, and others concerned with the education of gifted children and children with disabilities. Maintains a library and database (ERIC Clearinghouse on Disabilities and Gifted Education; <http://www.ericec.org>) on research in special and gifted education; provides information and assistance on legislation. Publishes the journals *Exceptional Children* and *Teaching Exceptional Children*.

Federal Resource Center for Special Education (FRC)

<http://www.rrfcnetwork.org>

Supports a nationwide technical assistance network to respond to the needs of students with

disabilities, especially those from underrepresented populations. Web site provides information and links from a variety of federally funded projects.

National Association of Private Special Education Centers (NAPSEC) (formerly National Association of Private Schools for Exceptional Children)

<http://www.napsec.org>

A nonprofit association that represents more than 200 schools nationally and more than 600 at the state level through its Council of Affiliated State Associations. Provides special education and therapeutic services for children in public or private educational placements. Also provides a free referral service to parents and professionals seeking appropriate placement for children with disabilities and publishes a directory of member schools.

National Dissemination Center for Children with Disabilities

<http://nichcy.org/laws/idea/legacy>

This web site presents a training curriculum on IDEA 2004, the federal law governing special education and early intervention for children with disabilities.

National Information Center for Educational Media (NICEM)

<http://www.nicem.com>

Provides database of educational audiovisual materials, including videotapes, motion pictures, filmstrips, audiotapes, and slides.

Tots 'n Tech Research Institute

<http://tnt.asu.edu/>

Provides information on assistive technology and other adaptation options for infants and toddlers.

What Works Clearinghouse (WWC)

<http://ies.ed.gov/ncee/wwc>

The WWC was established in 2002 by the Institute of Education Sciences at the U.S. Department of Education to provide educators, policymakers, researchers, and the public with a central and trusted source of scientific evidence about “what works” in education.

Family and Sibling Supports

Beach Center on Disability

<http://www.beachcenter.org>

Research and training center that disseminates information about families with members who have developmental disabilities. Publishes a newsletter, and offers many other publications.

Bureau of Primary Health Care

<http://bphc.hrsa.gov/quality/Cultural.htm>

Web site uses a variety of stories to illustrate values and principles one needs to appreciate and understand when providing culturally competent care to individuals with disabilities or special health care needs.

The Center for Universal Design

<http://www.ncsu.edu/project/design-projects/udi/>

Provides publications and information to parents and professionals concerning accessible housing design and financing issues; makes referrals to local organizations.

Center on Human Policy

<http://thechp.syr.edu/>

Involved in a range of local, state, national, and international activities, including policy studies, research, information, and referral.

Children's Disabilities Information

<http://www.childrensdisabilities.info/prematurity/followup.html>

Support site for parents that contains articles, lists of books, and web links on premature infants and prematurity. Has several links for parents of children with disabilities, including parenting children with special needs, articles on several disorders, and support network links. Contains general information that is written in easily understandable terms.

The Compassionate Friends

<http://www.compassionatefriends.org>

National and worldwide organization that supports and aids parents in the positive resolution of the grief experienced upon the death of a child; fosters the physical and emotional health of bereaved parents and siblings.

Easter Seals

<http://www.easter-seals.org>

Nonprofit, community-based health agency dedicated to increasing the independence of people with disabilities, especially those with autism. Offers a range of quality services, research, and programs.

Exceptional Parent

<http://www.eparent.com>

Magazine published since 1971 that provides straightforward, practical information for families and professionals involved in the care of children and young adults with disabilities; many articles are written by parents.

Family Village: A Global Community of Disability-Related Resources

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

Global community that integrates information, resources, and communication opportunities on the Internet for people with cognitive and other disabilities, for their families, and for people who provide services and support to these individuals.

Family Voices

<http://www.familyvoices.org>

Web site for a national, grassroots clearinghouse for information and education concerning the health care of children with special health needs. Contains links to all state chapters and the various projects the organization conducts.

Federation for Children with Special Needs

<http://www.fcsn.org>

Offers parent-to-parent training and information; projects include Technical Assistance for Parent Programs (TAPP), Collaboration Among Parents and Health Professionals (CAPP), and Parents Engaged in Educational Reform (PEER). Part of the National Early Childhood Technical Assistance System (NEC*TAS) consortium.

National Organization on Disability

<http://www.nod.org>

Promotes the acceptance and understanding of the needs of citizens with disabilities, through a national network of communities and organizations; facilitates exchange of information regarding resources available to people with disabilities.

PACER Center (Parent Advocacy Coalition for Educational Rights)

<http://www.pacer.org>

Provides education and training to help parents understand special education laws and to obtain appropriate school programs for their children. Workshops and program topics include early intervention, emotional disabilities, and health/medical services. Also provides a disability-awareness puppet program for schools, child abuse—prevention program services, newsletters, booklets, extensive written materials, and videotapes.

Parent Educational Advocacy Training Center (PEATC)

<http://www.peatc.org>

Professionally staffed organization that helps parents to become effective advocates for their

children with school personnel and the educational system.

Parent to Parent

<http://www.p2pusa.org>

State and local chapters provide one-to-one, parent-to-parent support by matching trained parents with newly referred parents on the basis of their children's disabilities and/or family issues they are encountering or have encountered.

The Sibling Support Project

<http://www.siblingsupport.org>

National program dedicated to the interests of brothers and sisters of people with special health and developmental needs. Primary goal is to increase the availability of peer support and education programs for such siblings.

Special Child

<http://www.specialchild.com>

Sponsored by the Resource Foundation for Children with Challenges (RFCC). Web site provides parent testimonials, diagnosis-related information, parent support, and a wide variety of information regarding educational and early intervention services.

TASH

<http://www.tash.org>

Advocates inclusive education and community opportunities for people with disabilities, disseminates research findings and practical applications for education and community living, and encourages sharing of experience and expertise. Publishes a newsletter and a journal.

Team Advocates for Special Kids (TASK)

<http://www.taskca.org>

Offers training, education, support, information, resources, and community awareness programs to families of children with disabilities and the professionals who serve them. Conducts an advocacy training course and other workshops, and publishes a bimonthly newsletter. TASK's Tech Center (a member of the Alliance for Technology Access) conducts one-to-one guided exploration of technology to determine appropriate adapted hardware and software for people with disabilities.

Tools for Coping with Life's Stressors

<http://www.coping.org>

Web site contains many links to help parents in coping with issues related to raising a child with special health care needs, such as tools for communication and tools for a balanced lifestyle. Also provides information about early identification and intervention.

Feeding, Growth, and Nutrition

American Dietetic Association

<http://www.eatright.org>

World's largest association of food and nutrition professionals. Web site offers healthy lifestyle and nutrition tips and referrals to registered dietitians. Publishes the *Journal of the American Dietetic Association*.

ComeUnity's Resources for Feeding and Growth of Children

<http://www.comeunity.com/premature/child/growth/resources.html>

Web site contains links to recommended parent discussion lists, articles, and hospitals/institutions that offer feeding therapy.

Dysphagia Resource Center

<http://www.dysphagia.com>

Web site contains links to resources on swallowing and swallowing disorders.

Food and Drug Administration (FDA)

<http://www.fda.gov>

Part of the U.S. Department of Health and Human Services. Provides the latest federal warnings and updates about foods, drugs, medical devices, vaccines, animal feed, cosmetics, and radiation-emitting products. Has links for children, consumers, patients, and health care professionals.

Formula Manufacturers

The following web sites contain information about special formulas required by some infants and children with developmental disabilities:

- <http://www.meadjohnson.com>
(Enfamil Premium Infant, Pregestimil, metabolic formulas)
- <http://www.abbottnutrition.com>
(Similac Advance, Similac Soy Isomil, metabolic formulas)
- <http://www.shsna.com>
(metabolic, ketogenic, and hypoallergenic formulas)
- <http://www.gerber.com>
(Gerber Good Start)

New Visions

<http://www.new-vis.com>

Provides education and therapy services to professionals and parents working with children with feeding, swallowing, oral-motor, and pre-speech problems. Mealtimes catalog offers therapy materials, tapes, and books.

Health Care

AAP Medical Home Information

http://www.medicalhomeinfo.org/how/care_delivery/

This site features several tools and protocols that can assist with coordination of care for children with chronic conditions.

Guide to the Health Care Reform and Affordable Care Act

<http://www.whitehouse.gov/healthreform/healthcare-overview#healthcare-menu>

White House guide to Health Care Reform and the Affordable Care Act of 2010.

Institute for Child Health Policy

<http://www.ichp.edu>

Mission is to research, evaluate, formulate, and advance health policies, programs, and systems that promote the health and well-being of children and youth through applied knowledge to health-related systems and outcomes for children and youth.

Maternal and Child Health Bureau/CDC National Survey of CYSHCN (2005–2006)

<http://nschdata.org/viewdocument.aspx?item=256>

<http://mchb.hrsa.gov/cshcn05/NF/intro.htm>

These sites offer searchable statistics on child and adolescent health in the United States.

State-level Data from the National Survey of CYSHCN 2005–2006

<http://cshcndata.org/Content/Default.aspx>

Allows searching of state-level data about child and adolescent health.

Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home

<http://aappolicy.aappublications.org/cgi/content/abstract/pediatrics;128/1/182?rss=1>

Publication jointly authored by the AAP, the American Academy of Family Physicians, and the American College of Physicians, published in July 2011, that provides an overview of the role and components of transition with an algorithm for providers.

20th Anniversary of Americans with Disabilities Act

http://www.census.gov/newsroom/releases/archives/facts_for_features_special_editions/cb10-ff13.html

This is a link provided by the U.S. Census Bureau detailing the American with Disabilities Act.

Legal Issues

Administration for Children and Families (ACF)

<http://www.acf.dhhs.gov>

Web site is from the federal agency that provides assistance to the various entities that provide family assistance, child support, child care, Head Start, child welfare, and other programs related to helping families and children.

American Bar Association Center on Children and the Law

<http://www.abanet.org/child>

Offers information and advocacy to professionals and parents of children and adolescents with disabilities.

American Civil Liberties Union (ACLU)

<http://www.aclu.org>

Nonprofit organization that is the largest public-interest law firm in the United States. Offers links to disability rights topics.

Center for the Child Care Workforce

<http://www.ccw.org>

Web site is maintained by a division of the American Federation of Teachers Educational Foundation that was set up to support the education of children, advocacy of early child care and education, and compensation of professionals who work with children. Site provides many resources available for teachers about educating children and a newsletter to help professionals keep current on issues of interest.

Disabilities Rights Education and Defense Fund (DREDF)

<http://www.dredf.org>

Law and policy center to protect the rights of people with disabilities. Offers referral and information regarding the rights of people with disabilities. Educates legislators and policy makers about issues affecting the rights of people with disabilities; also educates the public about the Americans with Disabilities Act (ADA) of 1990 (PL 101-336).

Do2Learn

<http://www.do2learn.com>

Web site discusses the legal rights of children with special health care needs and their parents in regard to creating the individual family service plan (IFSP). Includes parent-friendly links to sites that provide information about amendments to the Individuals with Disabilities Education Act (IDEA) and other legal concerns.

Early Child Development

<http://www.worldbank.org/children>

Web site is a knowledge source designed to assist policy makers, program managers, and practitioners in their efforts to promote the healthy growth and integral development of young children. Site is in Spanish, Portuguese, French, and Arabic.

Illinois Department of Human Services

<http://www.dhs.state.il.us/ei>

Web site provides a library of information services to parents, providers, educators, policy makers, students, and others interested in early intervention issues. Resource library contains books, periodicals, audiovisual, and other reference materials that can be issued for use on loan. Information is for multiple audiences, but the site also offers *Early Intervention*, a quarterly newsletter directed specifically toward parents.

Indiana First Steps Early Intervention

<http://www.infirststeps.com/matrix/default.asp>

Target audience includes therapists, parents, service coordinators, and other service providers for children from birth to age 3. Provides information pertaining to therapists; mainly on administrative issues, enrollment, reimbursement, and training. Parent information available for choosing a provider; also provides other early childhood links.

National Association of Protection and Advocacy Systems (NAPAS)

<http://www.icdri.org/legal/natpai.htm>

Web site provides links to protection and advocacy agencies, located across the United States, mandated by federal law to serve and protect the rights of people with disabilities.

National Early Childhood Technical Assistance Center

<http://www.nectac.org>

Program that provides responsive technical assistance to the programs supported under the Individuals with Disabilities Education Act (IDEA) for infants and toddlers with disabilities (Part C of IDEA) and for preschoolers with disabilities (Section 619-Part B of IDEA) in all states and participating jurisdictions, as well as to the projects funded by the Office of Special Education Programs under the Early Education Program for Children with Disabilities. Offers informational links to IDEA, publications, and other resources.

Office of Special Education Programs (OSEP)

<http://www.ed.gov/about/offices/list/osers/osep/index.html>

Web site is from the division of the Department of Education that oversees IDEA. Provides information regarding IDEA and other special education initiatives.

Parents Helping Parents (PHP)

<http://www.php.com>

Web site is sponsored by a California-based not-for-profit organization for parents of children with disabilities. An international consulting organization for family resources. Site provides valuable information for parents regarding laws concerning the rights of children with disability, and health care issues. Provides regional and state-specific information about support groups for parents and siblings, as well as information on topics such as special education, IDEA, the No Child Left Behind Act of 2001 (PL 107-110), and other special education initiatives.

Medications**Drug InfoNet**

<http://www.druginfonet.com>

Web site that provides information about drugs, diseases, and pharmaceutical manufacturing, as well as links to related sites.

Occupational and Physical Therapy**American Occupational Therapy Association (AOTA)**

<http://www.aota.org>

Professional organization of occupational therapists; provides such services as accreditation of educational programs, professional publications, public education, and continuing education for practitioners.

American Physical Therapy Association (APTA)

<http://www.apta.org>

Professional membership association of physical therapists, physical therapist assistants, and physical therapy students. Operates clearinghouse for questions on physical therapy and disabilities. Publishes bibliographies on a range of topics.

Oral Health Care**American Academy of Pediatric Dentistry**

<http://www.aapd.org>

National organization representing the specialty of pediatric dentistry. Dedicated to improving

and maintaining the oral health of children, adolescents, and people with special health care needs. Publishes the journal *Pediatric Dentistry*.

American Society of Dentistry for Children

<http://www.ucsf.edu/ads/asdc.html>

Professional organization for specialists in pediatric dentistry. Dedicated to improving the dental health of children through the dissemination of knowledge to professionals and the general public through educational programs, public service efforts, and research. Publishes the *Journal of Dentistry for Children*.

National Institute of Dental and Craniofacial Research

<http://www.nidr.nih.gov>

Institute dedicated to the promotion of oral, dental, and craniofacial health through study of ways to promote health, prevent diseases and conditions, and develop new diagnostics and therapeutics.

Special Care Dentistry

<http://www.SCDonline.org>

National organization of dentists, dental hygienists, dental assistants, nondental health care providers, health program administrators, hospitals, agencies that serve people with special needs, and other advocacy and health care organizations. Publishes the journal *Special Care in Dentistry*.

Recreation and Sports

American Alliance for Health, Physical Education, Recreation and Dance (AAHPERD)

<http://www.aahperd.org>

National organization supporting and assisting individuals involved in physical education, recreation, dance, as well as health, leisure, fitness, and education. An alliance of six national associations. Offers numerous publications.

American Association of Adapted Sports Programs

<http://www.aaasp.org>

Mission is to enhance the health, independence, and future economic self-sufficiency of youth with physical disabilities by facilitating a national sports movement and assisting communities in creating the best member programs possible for youth with disabilities who wish to compete.

Disabled Sports USA (DS/USA)

<http://www.dsusa.org>

Offers summer programs and competitions, fitness programs, "fitness is for everyone" videos,

and winter ski programs. Local chapters offer activities (e.g., camping, hiking, biking, horseback riding, 10K runs, water skiing, whitewater rafting, rope courses, mountain climbing, sailing, yachting, canoeing, kayaking, aerobic fitness, skiing). Provides year-round sports and recreational opportunities to people with orthopedic, spinal cord, neuromuscular, and visual impairments, through a national network of local chapters.

Girl Scouts of the USA

<http://www.girlscouts.org>

Open to all girls ages 5–17 (or kindergarten through grade 12). Runs camping programs, sports and recreational activities, and service programs. Incorporates children with disabilities into general Girl Scout troop activities. Published the book *Focus on Ability: Serving Girls with Special Needs*.

International Committee of Sports for the Deaf

<http://www.deaflympics.com>

Gives a history of accomplishments of deaf athletes. Links to regional confederations and technical delegates throughout the world.

Little League Baseball, Challenger Division

<http://www.littleleague.org/divisions/challenger.asp>

Online resource provides information and opportunities for boys and girls with disabilities to experience the emotional development and the fun of playing Little League baseball.

National Center on Physical Activity and Disability

<http://www.ncpad.org>

Encourages and supports people with disabilities who wish to increase their overall level of activity and participate in some form of regular physical activity. Offers searchable directories of organizations, programs, and facilities that provide opportunities for accessible physical activity; adaptive equipment vendors; conferences and meetings; and references to journal articles, books, videos, and more. Provides fact sheets on a variety of physical activities for people with disabilities.

The National Sports Center for the Disabled

<http://www.nscd.org>

Provides therapeutic recreation programs designed for individuals with disabilities who require adaptive equipment and/or special

instruction. Offers summer and winter programs; has some scholarships.

Special Olympics International

<http://www.specialolympics.org>

Largest organization to provide year-round sports training and athletic competition for children and adults with intellectual disabilities and certain other significant cognitive impairments. Local, state, and national games are held throughout the United States and in more than 150 countries; world games held every 4 years.

Wheelchair Sports, USA

<http://www.wsusa.org>

Governing body of various sports of wheelchair athletics, including swimming, archery, weightlifting, track and field, table tennis, and air weapons. Publishes a newsletter.

Yoga for the Special Child

<http://www.specialyoga.com>

A comprehensive program of yoga techniques designed to enhance the natural development of children with special needs.

Transition to Adulthood

Fedcap Rehabilitation Services

<http://www.fedcap.org>

Services include vocational training and job placement for adults with severe disabilities and/or other disadvantages.

Going to College

<http://www.going-to-college.org/>

Information for teenagers with disabilities about what college entails and how to plan for it.

Healthy and Ready to Work Information Center

<http://www.hrtw.org>

Network that works with local agencies to ensure that all youth with special health care needs receive the services necessary to make the transition to all aspects of adulthood, including adult health care, employment, and independence.

I'm Determined.org

<http://www.imdetermined.org/>

Lesson plans, brochures, and information about teaching self-determination skills to adolescents with disabilities, with material for parents, youth, and educators.

Institute for Child Health Policy

<http://www.ichp.edu>

Mission is to research, evaluate, formulate, and advance health policies, programs, and systems that promote the health and well-being of children and youth through applied knowledge to health-related systems and outcomes for children and youth.

Job Accommodation Network (JAN)

<http://askjan.org/>

Information and resources to make workplaces accessible to those with disabilities.

National Center on Accessibility

<http://www.ncaonline.org>

Works with departments of parks, recreation, and tourism throughout the United States to improve accessibility. Sponsors several training sessions each year throughout the United States to educate employers on making their workplaces accessible.

National Center on Physical Activity and Disability

<http://www.ncpad.org>

Mission of the National Center on Physical Activity and Disability (NCPAD) is to promote substantial health benefits that can be gained from participating in regular physical activity.

National Council on Independent Living

<http://www.ncil.org>

A national membership association of nonprofit corporations that advances the full inclusion of people with disabilities in society and the development of centers for independent living. Provides members with technical assistance and training, publishes a quarterly newsletter, and sponsors a national conference.

National Gateway to Self Determination

<http://www.aucd.org/ngsd/template/index.cfm>

Federally funded initiative that has established a model for promoting self-determination and compiled a comprehensive searchable database on interventions.

National Health Care Transition Center

<http://www.gottransition.org>

Information and tools for health care professionals, state policy makers, families, and youth to assist youth as they transition to adult health care.

National Home of Your Own Alliance

<http://alliance.unh.edu/nhoyo.html>

This program is dedicated to helping people with disabilities become homeowners and in controlling their homes.

**National Institute on Disability
and Rehabilitation Research (NIDRR)**

<http://www.ed.gov/about/offices/list/osers/nidrr>
Provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities.

**National Rehabilitation
Information Center (NARIC)**

<http://www.naric.com>
Rehabilitation information service and research

library; provides quick-reference and referral information, bibliographic searches, and photocopies of documents. Publishes several directories and resource guides.

Think College!

<http://www.thinkcollege.net>
Information, activities, and tools for teachers, students, and parents about postsecondary education options for youth with intellectual disabilities.



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