



Resources for Health Care Professionals

Medical and Clinical Web Sites

National Down Syndrome Society (NDSS)

Website: www.ndss.org

The NDSS site is the most comprehensive on-line resource on Down syndrome. The site includes a number of health and medical-related articles and links.

Down Syndrome Health Issues

Website: www.ds-health.com

This comprehensive Web site covers topics related to health care issues and Down syndrome. The site contains numerous articles and links to other resources.

Down Syndrome Growth Charts and Head Circumference Charts

Website: <http://www.growthcharts.com>

The Down Syndrome Growth Charts and Down Syndrome Circumference Charts are available on this site for various ages and developmental stages.

National Organizations

National Down Syndrome Society (NDSS)

666 Broadway, Suite 810, New York, NY 10012

Tel.: (800) 221-4602 or (212) 460-9330; Fax: (212) 979-2873

Website: www.ndss.org; E-mail: info@ndss.org

Through education, research and advocacy, NDSS seeks to improve the lives of individuals with Down syndrome and their families.

Association of University Centers on Disabilities

1010 Wayne Avenue, Suite 920, Silver Spring, MD 20910

Tel.: (301) 588-8252; Website: www.aucd.org

AUCD has 67 UCEDDs with at least one found in every state and territory in the U.S. Each is affiliated with a major research university.

American Association on Intellectual and Developmental Disability (AAID)

American Association on Mental Retardation (AAMR)

444 North Capitol Street, NW, Suite 846, Washington, D.C. 20001-1512

Tel.: (202) 387-1968 or (800) 424-3688; Fax: (202) 387-2193; Website: www.aamr.org

AAMR promotes policies, research, effective practices, and universal human rights for people with intellectual disabilities.

National Information Center for Children and Youth with Disabilities (NICHCY)

P.O. Box 1492, Washington, D.C. 20013

Tel.: (800) 695-0285; E-mail: nichcy@aed.org; Website: www.nichcy.org

An information clearinghouse, providing free information on disability-related issues, ages birth to 22.

The Arc

1010 Wayne Avenue, Suite 650, Silver Spring, MD 20910

Tel.: (800) 433-5255; Website: www.thearc.org

The Arc provides advocacy and other services for people with mental retardation and their families.

Subject-Specific Organizations

ADOPTION: National Child Welfare Resource Center for Adoption (NCWRCA)

16250 Northland Drive, Suite 120, Southfield, IN 48075

Tel.: (248) 443-0306; Website: www.nrcadoption.org

Provides training, consultations, and technical assistance towards improving adoption and post-adoption services for children with special needs.

AUTISM: Autism Society of America

7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814

Tel.: (800) 3AUTISM; Fax: (301) 657-0869; Website: www.autism-society.org

The mission of the Autism Society of America is to promote lifelong access and opportunity for all individuals within the autism spectrum, and their families, to be fully participating, included members of their community. This is achieved through education, advocacy, public awareness and research.

BEHAVIOR: Beach Center on Families and Disability

3111 Haworth Hall, University of Kansas, Lawrence, KS 66045

Tel.: (785) 864-7600; Website: www.beachcenter.org

The Beach Center conducts research on the causes of challenging behavior and strategies for positive behavioral support. The Center publishes a newsletter and provides lists of materials and fact sheets.

BENEFITS: Social Security Administration

6401 Security Blvd., Baltimore, MD 21235

Tel.: (800) 772-1213; Website: www.ssa.gov/disability

Information is provided about programs and services, as well as policy, research and other topics.

DENTISTRY: Academy of Dentistry for Persons with Disabilities (Special Care Dentistry)

401 North Michigan Avenue, Suite 2200, Chicago, IL 60611

Tel: (312) 527-6764; Fax: (312) 673-6663; E-mail: SCDA@SCDOnline.org; Website: www.scdonline.org

This professional membership organization provides technical and moral support for clinicians.

EARLY INTERVENTION: National Early Childhood Technical Assistance Center (NECTAC)

Campus Box 8040, UNC-CH, Campus Box 8040, UNC-CH

Tel.: (919) 962-2001; Website: www.nectac.org

The Center provides a national directory of programs and information about early intervention services as required by the Individuals with Disabilities Education Act (IDEA) for children with disabilities.

EDUCATION: The ERIC Clearinghouse on Disabilities and Gifted Education (ERIC EC)

The Council for Exceptional Children, 1920 Association Drive, Reston, VA 20191

Tel.: (800) 328-0272 or (703) 264-9449; Website: www.ericec.org; E-mail: ericec@cec.sped.org

ERIC EC gathers and disseminates literature, information, and resources on the education and development of individuals of all ages who have disabilities and/or who are gifted.

EMPLOYMENT: Virginia Commonwealth University Rehabilitative Research and Training Center

1314 West Main Street, P.O. Box 842011, Richmond, VA 23284-2011

Tel.: (804) 828-1851; Website: www.worksupport.com

A gateway to information, resources, and services regarding the employment of people with disabilities.

FATHERHOOD: National Fathers Network

Kindering Center, 16120 NE Eighth Street, Bellevue, WA 98008-3937

Tel.: (425) 653-4286; Website: www.fathersnetwork.org

The network celebrates and supports fathers and families raising children with special health care needs and developmental disabilities.

FEEDING: LaLeche League International

1400 North Meacham Road, Schaumburg, IL 60173

Tel.: (800) LALECHE or (847) 519-7730; Website: www.lalecheleague.org

LaLeche League provides information and resources to assist mothers with breastfeeding their babies, including information specific to breastfeeding a baby with Down syndrome.

LIFE PLANNING: National Family Caregivers Association

9621 East Bexhill Drive, Kensington, MD 20895-3104

Tel.: (301) 942-6430

This association is a not-for-profit membership organization dedicated to improving the quality of life for family caregivers by providing services through research, information and education, support validation, respite care and advocacy. They operate a 24-hour help line.

MENTAL HEALTH: National Association for the Dually Diagnosed (NADD)

132 Fair Street, Kingston, NY 12401

Tel.: (914) 331-4336 or (800) 331-5362; Fax: (914) 331-4569; Website: www.thenadd.org

NADD advocates for appropriate services and training concerning persons who have mental retardation and mental illness. The association also provides information and referral services, distributes educational materials, hosts conferences, publishes a newsletter and publications.

PARENT SUPPORT: Parent Training and Information Centers

Technical Assistance Alliance for Parent Centers, 4826 Chicago Avenue South, Minneapolis, MN 55417

Tel.: (612) 827-2966; Website: www.taalliance.org; E-mail: alliance@taalliance.org

Parent Training and Information Centers are funded by the Office of Special Education Programs of the U.S. Department of Education. The centers, located in each state, provide training and information to parents to help them meet the educational needs of their children.

POST-SECONDARY EDUCATION: HEATH Resource Center

American Council on Education, One Dupont Circle, Suite 800, Washington, DC 20036

Tel.: (800) 544-3284 or (202) 939-9320; Fax: (202) 833-4760

Website: www.heath-resource-center.org; E-mail: heath@ace.nche.edu

The HEATH Center is the national clearinghouse on post-secondary education for individuals with disabilities. Supported by the U.S. Department of Education, the Center serves as an information exchange about educational support services, policies, procedures, adaptations, and opportunities.

PROTECTION/ADVOCACY: National Association of Protection and Advocacy Systems

900 2nd Street NE, Suite 211, Washington, DC 20002

Tel.: (202) 408-9514; Website: www.narpa.org

The Protection and Advocacy (P&A) System is a nationwide network of congressionally mandated, legally-based disability rights agencies. P&A agencies provide legal representation and other advocacy services, under all federal and state laws, to all people with disabilities.

RECREATION: Special Olympics, Inc.

1325 G Street, NW, Suite 500, Washington, DC 20005

Tel.: (202) 628-3630; Fax: (202) 824-0200; Website: www.specialolympics.org

Special Olympics is an international program of year-round sports training and athletic competition for more than one million children and adults with mental retardation.

RESEARCH: National Institute of Child Health and Human Development (NICHD)

NIH, Bldg 31, Room 2A32, MSC 2425, 31 Center Drive, Bethesda, MD 20892-2425

Tel.: (800) 370-2943; Website: www.nichd.nih.gov

NICHD supports and conducts research on various health-related topics in Down syndrome.

RESPIRE CARE: National Respite Locator Service

800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514

Tel.: (800) 773-5433; Website: www.respitelocator.org

The service helps parents, caregivers, and professionals find respite services in their state and local area.

SEXUALITY: Sexuality Information and Education Council of the United States (SIECUS)

130 West 42nd Street, Suite 350, New York, NY 10036

Tel.: (212) 819-9770; Website: www.siecus.org

SIECUS provides resources on sexuality-related issues and sex education for people with developmental disabilities. A comprehensive bibliography of resources is available.

SIBLINGS: Sibling Support Project

Kindering Center, 6512 23rd Ave NW, #213, Seattle, WA 98117

Tel.: (206) 297-6368; Website: <http://www.siblingsupport.org>

The Sibling Support Project is a national program dedicated to the interests of brothers and sisters of people with special health and developmental needs.

Publications

American Journal on Mental Retardation

AAMR, 444 North Capital Street, NW, Suite 846, Washington, D.C. 20001-1512

Tel.: (800) 424-3688; Web site: www.aamr.org

This bi-monthly publication for professionals features reports on current research in the biological, behavioral and educational sciences. Articles include various topics related to developmental disabilities including prevention, health risks, aging, bio-medics, behavior and clinical interventions.

Babies with Down Syndrome: A New Parents' Guide (2nd edition).

Stray-Gundersen, K. (Ed.) (1995). Bethesda, MD: Woodbine House; 6510 Bells Mill Road, Bethesda, MD 20817; Tel.: (800) 843-7323; Web site: www.woodbinehouse.com.

Parents and professionals contribute chapters on the medical, emotional, educational and social issues concerning the development of the child and the family. A first book for anyone wishing to learn more about Down syndrome, especially new parents.

Disability Solutions

Published through Creating Solutions, PMB 179, 9220 SW Barbur Blvd #119, Portland, OR 97219

Tel.: (503) 244-7662; Website: <http://www.disabilitysolutions.org>

Disability Solutions is a free bi-monthly publication designed to be a resource for families and others interested in Down syndrome and related disabilities, sponsored by the Enoch-Gelbard Foundation.

Down Syndrome Quarterly

Down Syndrome Research Foundation, 1409 Sperling Avenue, Burnaby, BC V5B 4J8

Tel: (604) 444-3773; <http://www.dsrf.org>

Down Syndrome Quarterly is an interdisciplinary journal devoted to advancing the state of knowledge on Down syndrome and will cover all areas of medical, behavioral, and social scientific research. It is published in March, June, September, and December and is distributed by subscription to individuals, organizations, and libraries.

Medical & Surgical Care for Children with Down Syndrome: A Guide for Parents. Van Dyke, D., Mattheis, P., Eberly, S., Williams, J. (Eds.) (1995). Bethesda, MD: Woodbine House; 6510 Bells Mill Road, Bethesda, MD 20817; Tel.: (800) 843-7323; Web site: www.woodbinehouse.com.

The book covers medical conditions and treatments commonly seen in individuals with Down syndrome, including heart disease, thyroid problems, skin conditions, gastrointestinal problems, leukemia, reproductive issues, recurrent infections, eye problems, ear, nose, and throat problems, orthopedic conditions, facial and dental concerns and neurological problems.