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#### **ABSTRACT**

This reference document lists national organizations that serve as information clearinghouses, referral agencies, or legislative advocates for children, youths, and adults with physical disabilities. Many provide services directly to the individual and include peer and family support, education, and counseling. Some also support research on the cause of specific disorders and their prevention; train professionals; and publish pamphlets, catalogs, monographs, and journals relating to specific disabilities. The resource list is divided into three parts: (1) a list of 59 national organizations and resources, with addresses, telephone numbers, principal publications, and descriptions of the organizations' activities; (2) a list of 16 federal agencies, with similar information; and (3) a select bibliography of 36 items, listing special subject periodicals and directories on advocacy, adaptive equipment, services, and related topics. (JDD)

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# Physical Disabilities: National Organizations and Resources

National Library Service for the Blind and Physically Handicapped The Library of Congress

Washington, DC 20542

Date June 1994

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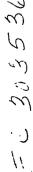
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#### Introduction

This reference circular lists national organizations that serve as information clearinghouses, referral agencies, or legislative advocates for children, youths, and adults with physical disabilities. Many provide services directly to the individual and include peer and family support, education, and counseling. Some also support research on the cause of the disorder and its prevention; train professionals; and publish pamphlets, catalogs, monographs, and journals relating to the specific disability.

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# I. National Organizations and Resources

American Amputee Foundation (AAF)

P.O. Box 250218, Hillcrest Station Little Rock, AR 72225 (501) 666-2523

Principal publication: AAF Newsletter, semiannual

An information clearinghouse and referral center for amputees and their families. Local chapters provide peer counseling to new amputees, publish self-help guides, and assist with low-cost loans for the purchase of prostheses.

#### American Diabetes Association (ADA)

National Center 1660 Duke Street Alexandria, VA 22314 (703) 549-1500 800-232-3472

Principal publications: Diabetes Forecast, bimonthly

Diabetes Advisor, bimonthly

Sponsors educational meetings, in-hospital orientation, and a summer camping program for children. Conducts professional seminars; publishes research journals and a variety of pamphlets, books, and cookbooks; sponsors research into the prevention and cure of diabetes.

## American Epilepsy Society

638 Prospect Avenue Hartford, CT 06105-4298 (203) 232-4825

Principal publication: Epilepsia, quarterly

A professional membership organization that promotes interdisciplinary communication, scientific investigation, and exchange of clinical information about epilepsy; promotes better care; supports peer-review research; funds grants and training fellowships.



# **American Heart Association Stroke Connection**

7272 Greenville Avenue Dallas, TX 75231-4599 (214) 373-6300 800-553-6321

Principal publications: Stroke Connection, bimonthly A Stroke of Luck, 3/year

Provides a forum for the exchange of information and resources through workshops and seminars for stroke survivors, their families, and professionals who work with them. Provides peer counseling through its outreach program; operates Courage Training Center in Minnesota; and publishes pamphlets, books, and videos for public and professional use. Topics include types and aspects of stroke, survival skills, and needs related to living with a stroke.

# American Paralysis Association (APA)

500 Morris Avenue Springfield, NJ 07081 (201) 379-2690 800-225-0292 800-526-3456 (hotline)

Principal publication: Progress in Research, semiannual

Funds research to find a cure for paralysis caused by spinal cord injury, head injury, or stroke. Supports a peer support network through the **Spinal Cord Injury hotline.** Local chapters provide information and act as referral services to persons with spinal cord injuries, their families, and professionals.

# American Parkinson Disease Association (APDA)

60 Bay Street Staten Island, NY 10301 (212) 732-9550 800-223-2732

Provides information about Parkinson's disease and related disorders, treatment centers, and self-help groups across the country to patients and their families; raises funds for research of new drug therapies; and publishes informational pamphlets.



American Spinal Injury Association (ASIA)

250 East Superior Street, Room 619 Chicago, IL 60611 (312) 908-3425

Principal publication: ASIA Bulletin, semiannual

A professional membership organization that provides a forum for the exchange of information through workshops and seminars; maintains a national database of educational materials related to spinal cord injury.

Amyotrophic Lateral Sclerosis Association (ALSA)

21021 Ventura Boulevard, Suite 321 Woodland Hills, CA 91364 (818) 340-7500 800-782-4747 (patient hotline)

Principal publication: Link, quarterly

A clearinghouse of information on the management of Amyotrophic Lateral Sclerosis, also known as Lou Gehrig's disease, and a referral center to ALS patients and their families. Publishes pamphlets on assistive devices, emergency treatment and support systems, and related topics. Pamphlets include Home Care for the Patient with Amyotrophic Lateral Sclerosis, which is also available in Spanish.

#### **Arthritis Foundation**

1314 Spring Street NW Atlanta, GA 30309 (404) 872-7100 800-283-7800 (hotline)

Principal publication: Arthritis Today, bimonthly

Disseminates information about new drugs and therapies to professionals, supports scientific research, and trains specialists. Publishes pamphlets for lay and professionals, some available in Spanish. Also produces <u>Guide to Independent Living</u>. Sponsors the **American Juvenile Arthritis**Organization. Local chapters provide information, education, support groups, arthritis clinics, home care programs, and rehabilitation services to individuals with rheumatic diseases.



Association for Persons with Severe Handicaps (TASH)

7010 Roosevelt Way NE Seattle, WA 98115 (206) 523-8446 (206) 524-6198 TDD

Principal publications: Journal of the Association for Persons with Severe

Handicaps, quarterly
Tash Newsletter, monthly
DC Update, bimonthly

Supports quality education and independent living for individuals with severe and profound disabilities from birth through adulthood; disseminates information on solutions to problems, research findings, trends, and practices relevant to people with severe disabilities. Publishes bibliographies on vocational training, curricula, and self-help skills development. Local chapters provide referral service to schools, clinics, and vocational rehabilitation centers, and sponsor parental support and advocacy groups.

Association for the Advancement of Rehabilitation Technology (RESNA)

1700 North Moore Street, Suite 1540 Arlington, VA 22209 (703) 524-6686 (703) 524-6639 TDD

Principal publications: <u>Assistive Technology</u>, quarterly <u>RESNA Newsletter</u>, bimonthly

An interdisciplinary group of rehabilitation engineers, occupational and physical therapists, and others in the rehabilitation field concerned with providing modern technology to persons with disabilities. Publishes monographs on assistive devices.



#### Association of Specialized and Cooperative Library Agencies (ASCLA)

American Library Association 50 Huron Street Chicago, IL 60611 (312) 944-6780

Principal publication: Interface, quarterly

Promotes library services for persons with physical, visual, health, and behavioral problems; furthers development of standards for materials, services, and personnel; encourages cooperation among agencies and organizations in publicizing and implementing library service to people with disabilities.

#### Association on Higher Education and Disability (AHEAD)

P.O. Box 21192 Columbus, OH 43221-0192 (614) 488-4972 voice and TDD

Principal publication: <u>Bulletin of the Association on Handicapped</u>
<u>Student Service Program</u>, quarterly

Formerly the Association of Handicapped Student Service Programs in Postsecondary Education (AHSSPE), its goals are to promote the full participation of students with disabilities in higher education, to upgrade quality of services available, and to make institutions accessible to postsecondary students with disabilities.

# **Breaking New Ground Resource Center**

Purdue University 1146 Agricultural Engineering Building West Lafayette, IN 47907-1146 (317) 494-5088 voice and TDD 800-825-4264

Principal publication: Breaking New Ground, quarterly

Provides disabled farmers and ranchers with technical assistance on work site modifications; researches, evaluates, and modifies farm equipment to ensure safety to the user; part of the National AgrAbility Project.



Center for Accessible Housing

North Carolina State University School of Design, Box 8613 Raleigh, NC 27695-8613 (919) 515-3082 voice and TDD

Principal publication: News, quarterly

Technical assistance related to housing needs of individuals with disabilities. Includes planning, construction, renovation, financing, and marketing for individuals and organizations. Maintains a design consultation service and publishes pamphlets on modified house design and related accessibility needs.

#### Center for Children with Chronic Illness and Disability

University of Minnesota Box 721 420 Delaware Street SE Minneapolis, MN 55455 (612) 62J-4032 (612) 624-3939 TDD

Principal publications: Children's Health Briefs, irregular

Children's Health Issues, 2-3 issues/year

Springboard, 3 issues/year

A rehabilitation, research, and training center dedicated to the study and promotion of psychological and social well-being of children with chronic health conditions and their families. Affiliated with the National Center for Youth with Disabilities.

## Council for Exceptional Children (CEC)

1920 Association Drive Reston, VA 22091 (703) 620-3660 voice and TDD 800-328-0272

Principal publications: Exceptional Children, bimonthly

Teaching Exceptional Children, quarterly

Disseminates educational information and publications on children and youth with disabilities and giftedness and operates the Clearinghouse on Disabilities and Gifted Education, which is part of the nationwide Educational Resources Information Center (ERIC) network.



DIRECT Link for the Disabled, Inc.

P.O. Box 1036 Solvang, CA 93464 (805) 688-1603 voice and TDD

Principal publication: Direct Connect, quarterly

A telephone referral service that uses its automated database Link Up to locate local affiliates of national organizations and community agencies offering direct services to individuals with disabilities and their families.

Disability Rights Education and Defense Fund (DREDF)

2212 Sixth Street
Berkeley, CA 94710
(510) 644-2555
(510) 644-2629 TDD
800-466-4232 voice and TDD

Principal publication: Disability Rights News, 3/year

Acts as a law and policy center dedicated to furthering the civil rights of people with disabilities. Trains individuals, educators, legislators, and others on disability rights laws and policies. Provides direct legal representation, information and referral services, and technical assistance to community leaders about the Americans with Disabilities Act Titles II and III, which deal with local governments and public accommodations.

Disabled American Veterans (DAV)

807 Maine Avenue SW Washington, DC 20024 (202) 554-3501

Principal publication: <u>DAV Magazine</u>, monthly

A self-help group of veterans with service-connected disabilities. Has state and local chapters. Monitors legislation concerned with the entire range of benefits for veterans. Provides counseling and claims representation to veterans and their families at no cost and functions as attorney-in-fact; provides disaster and emergency relief for disabled veterans; provides scholarships for children of needy disabled veterans. Advocates for local employment programs and removal of architectural and other barriers in the home and workplace.

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#### Dole Foundation for Employment of People with Disabilities

1819 H Street NW, Suite 340 Washington, DC 20006 (202) 457-0318

Sponsors and supports legislation promoting economic independence, social integration, and civil rights of individuals with disabilities; sponsors seminars on public policy and funds job training and placement programs in local communities.

## Eastern Paralyzed Veterans Association (EPVA)

75-20 Astoria Boulevard Jackson Heights, NY 11370-1178 (718) 803-3782 800-444-0120

Principal publication: EPVA Action, monthly

A regional chapter of the **Paralyzed Veterans of America** for spinal cord injured veterans in New York, New Jersey, eastern Pennsylvania, and Connecticut. Publishes pamphlets on air travel, fire safety for wheelchair users, and wheelchair-accessible house designs. Some material available in Spanish.

# **Electronic Industries Foundation (EIF)**

1901 Pennsylvania Avenue NW, Suite 700 Washington, DC 20006 (202) 955-5810 (202) 955-5836 TDD

Operates the Rehabilitation Engineering Center that promotes commercial availability of assistive devices. Publishes funding guides and monographs on assistive devices for daily living.



#### **Epilepsy Foundation of America (EFA)**

4351 Garden City Drive, Suite 406 Landover, MD 20785 (301) 459-3700 voice and TDD 800-332-1000

An information and referral resource center with local chapters. Works to improve the lives of those with epilepsy through educational and advocacy programs for patients, their families, physicians, and other professionals in the field. Provides materials to improve the school environment for children with epilepsy. Some publications available in Spanish.

## Gazette International Networking Institute (GINI)

5100 Oakland Avenue #206 St. Louis, MO 63110 (314) 534-0475

Principal publications: Rehabilitation Gazette, semiannual

International Ventilator Users Network News,

semiannual

Polio Network News, quarterly Post Polio Directory, annual

Disseminates information to polio survivors on ventilator-assisted living, neuromuscular disease, adaptive equipment, and independent living; provides peer support.

#### **HEATH Resource Center**

(Higher Education and Adult Training for Persons with Handicaps)
American Council on Education
One Dupont Circle NW, Suite 800
Washington, DC 20036
(202) 939-9320
800-544-3284 voice and TDD

Principal publication: Information from HEATH, 3 issues/year

A national clearinghouse on postsecondary education for individuals with disabilities. Provides information about education, educational support services, policies, procedures, adaptations, and opportunities at American colleges, vocational-technical schools, and independent living centers. Publishes a resource directory, factsheets, and packets of material for students and schools.



Independent Living Research Utilization Program (ILRU)

ILRU Research and Training Center on Independent Living at TIRR 2323 South Shepherd, Suite 1000 Houston, TX 77019 (713) 520-0232 (713) 520-5136 TDD

Principal publication: ILRU-insights, bimonthly

A center for information, research, technical assistance, and training in independent living; publishes reports and a directory of independent living centers in the United States.

Juvenile Diabetes Foundation International

432 Park Avenue South, 16th floor New York, NY 10016 (212) 889-7575 800-223-1138 (hotline)

Supports and funds research on the treatment and cure of diabetes; disseminates information and brochures on juvenile diabetes. Local chapters provide parent-to-parent counseling and self-help support groups for individuals newly diagnosed with diabetes.

# Mainstream, Inc.

3 Bethesda Metro Center, Suite 830 Bethesda, MD 20814 (301) 654-2400 voice and TDD

Principal publication: In the Mainstream, bimonthly

Provides information, training, and technical assistance to private organizations and public agencies on issues affecting persons with disabilities in the workplace.



#### March of Dimes Birth Defects Foundation (MOD)

1275 Mamaroneck Avenue White Plains, NY 10605 (914) 428-7100

Provides educational materials such as films and filmstrips to schools, churches, hospitals, and other institutions to inform prospective parents and the general public on ways to protect maternal and newborn health and to prevent birth defects; funds research programs.

#### Multiple Sclerosis Association of America

601-05 House Pike Oaklyn, NJ 08107 (609) 858-3211 800-833-4672

A self-help support group that provides peer counseling, patient education, and referral services. Also supplies therapeutic equipment to its MS care centers.

#### Muscular Dystrophy Association (MDA)

3300 East Sunrise Drive Tucson, AZ 85718-3208 (602) 529-2000

Principal publication: MDA Reports, quarterly

Sponsors recreational activities such as summer camps, and organizes self-help support groups. Publishes pamphlets and audiovisual materials on neuromuscular diseases. Local chapters and clinics provide diagnostic services and rehabilitative follow-up care to individuals with neuromuscular disorders.

# Myasthenia Gravis Foundation

53 West Jackson, Suite 660 Chicago, Il 50604 (312) 427-6252 800-541-5454

Funds research into the detection, treatment, and search for a cure; publishes professional papers. Local chapters provide diagnostic services and treatment, peer support, referral, and medication program.



National Amputation Foundation (NAF)

73 Church Street Malvern, NY 11565 (516) 887-3600

Principal publication: The AMP, bimonthly

Operates a prosthetic center for the manufacture and repair of artificial limbs and provides training in the use of prosthetic devices. Provides legal counseling, vocational guidance and placement, and peer support. Publishes pamphlets on the use of and adjustment to prostheses.

National Association of Protection and Advocacy Systems, Inc. (NAPAS) 900 Second Street NE, Suite 211 Washington, DC 20002 (202) 408-9514

Principal publication: Update, quarterly

Established by Congress in 1975 to ensure vigorous advocacy of rights of persons with developmental disabilities, it has broadened its scope to include all disabilities, including mental illness. Provides legal counseling, litigation services to clients, and training seminars to community leaders on compliance with the Americans with Disabilities Act. Publishes material on advocacy, coalition building, fair housing, and vocational rehabilitation.

# National Center for Youth With Disabilities (NCYD)

University of Minnesota Box 721 420 Delaware Street SE Minneapolis, MN 55455 (612) 626-2825 (612) 624-3939 TDD 800-333-6293

Principal publication: Connection, quarterly

An information and referral center on issues that affect adolescents (ages 10-22) with chronic illness and other disabilities. Maintains a research library and online database, and publishes annotated bibliographies on related topics.



#### National Council on Independent Living (NCIL)

211 Wilson Boulevard, Suite 405 Arlington, VA 22201 (703) 525-3406 (703) 525-3407 TDD

Principal publication: NCIL Newsletter, quarterly

A membership organization of independent living centers in the United States. Provides peer counseling, independent living skills training, technical assistance, information, and referrals.

#### National Easter Seal Society (NESS)

230 West Monroe Street, Suite 1800 Chicago, IL 60606 (312) 726-6200 (312) 726-4258 TDD 860-221-6827

Principal publications: <u>National Easter Seal Communicator</u>, quarterly Computer-Disability <u>News</u>, quarterly

Provides rehabilitation services; monitors federal legislation and regulations through state and local societies; works with voluntary and governmental agencies to provide programs that include comprehensive medical or vocational rehabilitation facilities, recreation, public education, and research. Publishes brochures and videos for professionals, parents, and persons with disabilities. Some material available in Spanish.

# National Head Injury Foundation (NHIF)

1140 Connecticut Avenue NW, Suite 812 Washington, DC 20036 (202) 296-6443 800-444-6443

Principal publication: <u>T.B.I. Challenged</u>, quarterly

Disseminates information on resources and facilities for acute, intermediate, and long-term care; sponsors peer and family support groups; advocates for the rights of head-injured persons. Provides bibliographies on general head trauma, coma and rehabilitation, family and pediatric issues, and prevention. Some material available in Spanish.



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

P.O. Box 1492 Washington, DC 20013-1492 (202) 416-0300 voice and TDD 800-695-0285 voice and TDD

Principal publications: News Digest, 3 issues/year Transition Summary, annual

Disseminates information about children and youths with disabilities, special education, and related programs and services. Provides information on local, state, and national advocacy groups to parents and professionals in the field. Has a computerized database, NICHCY. Publishes <u>State Sheets</u>, a listing by state of agencies that provide educational services, vocational training, rehabilitation services, and booklets and information packets on current issues. Some publications available in Spanish.

# National Information Clearinghouse for Infants with Disabilities and Life-Threatening Conditions

Center for Developmental Disabilities
Department of Pediatrics
University of South Carolina School of Medicine
Benson Building
Columbia, SC 29209
(803) 777-4435
800-922-9234 ext. 201 voice and TDD

A joint project of the Center for Developmental Disabilities and the Association for the Care of Children's Health, funded by the National Center on Child Abuse and Neglect, U.S. Department of Health and Human Services. Helps families to find and access services for their infants and children with disabilities and special health needs, and protects the rights of infants with disabilities and life-threatening conditions. Provides technical assistance to Child Protective Service agencies; publishes fact sheets and bibliographies.



#### National Information System for Vietnam Veterans and their Families

Center for Developmental Disabilities University of South Carolina Benson Building Columbia, SC 29208 800-922-9234 ext. 401 voice and TDD

An information, referral, and advocacy center for Vietnam veterans having young children who have disabilities or special health needs. Publishes and disseminates fact sheets on health conditions common to infants and toddlers of Vietnam veterans.

## National Multiple Sclerosis Society (MS)

733 Third Avenue New York, NY 10017 (212) 986-3240 800-532-7667

Principal publication: Inside MS, quarterly

Publishes pamphlets on mental and emotional health and on careers for homebound individuals. Supports federal research funding. Local chapters provide counseling, referral, and diagnostic services and recreational and social support activities.

# National Organization on Disability

910 16th Street NW, Suite 600 Washington, DC 20006 (202) 293-5960 (202) 293-5968 TDD 800-248-2253

Principal publications: <u>National Organization on Disability Report</u>, quarterly

Trains elected officials at community, local, state, and federal levels in developing and implementing programs to ensure equal access for persons with disabilities.



#### **National Parent Network on Disabilities**

c/o Patty Smith 1600 Prince Street #115 Alexandria, VA 22314-2836 (703) 684-6763 voice and TDD

A coalition established to provide a national voice for parents of children and youths with disabilities; acts as an advocacy group for rights of children and youth.

## National Parkinson Foundation, Inc.

1501 Northwest 9th Avenue Bob Hope Road Miami, FL 33136 (305) 547-6666 800-327-4545

Principal publication: Parkinson Report, quarterly

Provides clinical, rehabilitative, and therapeutic treatment to individuals with Parkinson's and related neurological disorders.

# National Rehabilitation Association (NRA)

1910 Association Drive, Suite 205 Reston, VA 22091 (703) 715-9090

Principal publication: Journal of Rehabilitation, quarterly

A membership organization that tracks legislation on disability-related issues; promotes awareness through publications, annual training conference, and exhibits.



#### National Rehabilitation Information Center (NARIC)

8455 Colesville Road, Suite 935 Silver Spring, MD 20910-3319 (301) 588-9284 voice and TDD 800-346-2742 voice and TDD

Principal publication: NARIC Quarterly, irregular

A library and information center on disability and rehabilitation; collects and disseminates results of federally funded projects; operates ABLEDATA and REHABDATA, online databases on disability and research.

National Spinal Cord Injury Association (NSCIA)

600 West Cummings Park, Suite 2000 Woburn, MA 01801 (617) 935-2722 800-962-9629 hotline only

Principal publication: Spinal Cord Injury Life, quarterly

Sponsors research into a cure of spinal cord injury; acts as a clearinghouse of information on independent living, rehabilitation programs, self-help devices, equipment, transportation, employment, education, and personal care. Publishes handbooks on nursing, personal care, and nutrition; some titles available in Spanish. Local chapters provide comprehensive health services to individuals with spinal cord dysfunction (paraplegia and quadriplegia) and sponsor person-to-person assistance and peer counseling.

National Stroke Association (NSA) 8480 East Orchard Road, Suite 1000 Englewood, CO 80111-5015 (303) 771-1700 (303) 771-1887 TDD

Principal publication: Be Stroke Smart, quarterly

An information and referral center on cerebral vascular accidents (stroke). Publishes a handbook for stroke survivors and their families, <u>The Road Ahead: A Stroke Recovery Guide</u>, and other publications.



#### Paralyzed Veterans of America (PVA)

801 18th Street NW Washington, DC 20006 (202) 872-1300 800-424-8200

Principa' publications: <u>PN: Paraplegia News</u>, monthly Sports 'n' Spokes, monthly

Acts as an advocate for civil rights, health care, and rehabilitation of veterans and others with a spinal cord dysfunction. Provides services through the U.S. Department of Veterans Affairs (VA) Spinal Cord Injury Centers and VA regional offices. Funds research on treatment, rehabilitation, and regeneration of the spinal cord. A subdivision, **Paralysis Society of America**, sponsors Access to the Skies/ATTS, a program on the needs of the disabled traveler.

#### Parkinson's Disease Foundation (PDF)

William Black Medical Research Building Columbia University Medical Center 650 West 168th Street New York, NY 10032 (212) 923-4700 800-457-6676

Publishes pamphlets on physical exercises for individuals with Parkinson's disease; funds research into the cause and cure of Parkinson's disease.

#### **Rehabilitation International**

25 East 21st Street New York, NY 10010 (212) 420-1500 (212) 420-1752 TDD

Principal publication: International Rehabilitation Review, 3/year

A federation of more than one hundred organizations in eighty-nine countries. Develops and supports programs and lobbies for legislation on issues of disability prevention, rehabilitation, and integration worldwide. Collects, compiles, and disseminates reports on international rehabilitation; sponsors world congresses; works with United Nations agencies and the Organization of American States.



#### Rural Institute on Disabilities

52 Corbin Hall The University of Montana Missoula, MT 59812 (406) 243-5467 (406) 243-4200 TDD 800-732-0323 voice and TDD

Principal publications: The Rural Exchange, quarterly

MSTD, quarterly

MonTECH News, quarterly Child Care Plus, quarterly

Provides information and assistance for individuals with disabilities living in rural areas; facilitates access to existing education, health, and social services within the community. Develops research and training programs, sponsors conferences, and disseminates material.

Spina Bifida Association of America (SBAA)

4590 MacArthur Boulevard NW, Suite 250 Washington, DC 20007-4226 (202) 944-3285 800-621-3141

Principal publication: Insights into Spina Bifida, bimonthly

Acts as a referral center in providing information and support services to individuals with spina bifida and related hydrocephalus and their families; funds research and training programs for the public and for professionals dealing with the care and treatment of spina bifida.

## Spinal Cord Society (SCS)

Wendell Road Fergus Falls, MN 56537 (218) 739-5252

Principal publication: Spinal Cord Society Newsletter, monthly

Maintains a data bank of chronic spinal-cord-injury case histories that is used for patient referral; carries out public awareness and community outreach programs through local chapters; funds medical research on nerve regeneration in the central nervous system.



United Cerebral Palsy Associations, Inc. (UCPA)

1522 K Street NW, Suite 1112 Weshington, DC 20005 (202) 842-1266 800-872-5827

Frincipal publication: The Networker, quarterly

Promotes community awareness and fosters positive public attitudes toward individuals with cerebral palsy; provides education, medical diagnosis and treatment, social and recreation programs to individuals with cerebral palsy through local chapters; advocates legislation; funds research and training of professional personnel. Publishes reports and newsletters.

#### **United Parkinson's Foundation (UPF)**

360 West Superior Street Chicago, IL 60610 (312) 664-2344

A membership organization for Parkinson's disease patients and their families. Disseminates information and pamphlets on coping techniques, exercises, research, and therapies.

# World Institute on Disability

510 16th Street, Suite 100 Oakland, CA 94612-1502 (510) 763-4100

Principal publication: Impact, semiannual

A law and public policy center that conducts research and training on such subjects as employment, family support, independent living, and public education. Offers personal assistance service, conducts research on availability, cost, and quality of programs, and assists leaders in other countries by providing technical assistance and international collaboration. Has an online database, WIDMET.



## II. Federal Agencies

#### Clearinghouse on Disability Information

Office of Special Education and Rehabilitative Services (OSERS) U.S. Department of Education Switzer Building, Room 3132 330 C Street SW Washington, DC 20202-2524 (202) 205-8241 voice and TDD

Principal publication: OSERS News in Print, quarterly

Responds to inquiries, provides referrals, and disseminates information on federal funding for programs serving people with disabilities, federal legislation affecting the disability community, and federal programs benefiting people with disabilities.

#### JOB Accommodation Network (JAN)

P.O. Box 468
Morgantown, WV 26506-6080
800-526-7234 voice and TDD
800-526-4698 within WV
800-526-2262 within Canada voice and TDD

Sponsored by the President's Committee on Employment of People with Disabilities, provides businesses with information and consultation on government policies and recommended worksite modifications.

# National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse

P.O. Box AMS 9000 Rockville Pike Bethesda, ML 20892 (301) 495-4484

Provides general bibliographical information to health professionals and the public on the nature, diagnosis, and treatment of rheumatic disorders. Publishes a pamphlet, <u>Spanish language materials for patients: a bibliography on arthritis and musculoskeletal and skin diseases</u>, in Spanish.



#### National Council on Disability (NCD)

1331 F Street NW, Suite 1001 Washington, DC 20004-1107 (202) 267-3846 (202) 267-3232 TDD

Principal publication: Focus, 3/year

An independent federal agency charged with reviewing all government laws, programs, and policies affecting individuals with disabilities. Has a mandated responsibility to address, analyze, and make recommendations on issues of public policy for independent living, community integration, and employment. Formerly the National Council on the Handicapped.

## National Diabetes Information Clearinghouse (NDIC)

P.O. Box NDIC 9000 Rockville Pike Bethesda, MD 20892 (301) 468-2162

Responds to inquiries about diabetes and its care through its online database, NDIC Network; publishes annotated bibliographies of print and nonprint material on diabetes. Some material available in Spanish.

# National Health Information Center (NHIC)

P.O. Box 1133 Washington, DC 20013-1133 (301) 565-4167 800-336-4797

An information clearinghouse and referral center on health-related topics for professionals and the public. Publishes and disseminates bibliographies, directories, manuals, resource guides, posters, and audiovisuals on current health-related topics produced by the Office of Disease Prevention and Health Promotion, Public Health Service, U.S. Department of Health and Human Services. Maintains an online database of health-related organizations, publications, and programs.



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#### National Industries for the Severely Handicapped

2235 Cedar Lane Vienna, VA 22182 (703) 560-6800 (703) 560-6512 TDD

Principal publication: NISH News, monthly

A federally funded agency set up under the Javits-Wagner-O'Day Act to provide employment to individuals with severe disabilities through federal contracts.

## National Institute of Neurological Disorders and Stroke (NINDS)

National Institutes of Health Building 31, Room 8A06 9000 Rockville Pike Bethesda, MD 20892 (301) 496-5751

Conducts and supports fundamental and applied research on human neurological disorders such as Parkinson's disease, epilepsy, multiple sclerosis, muscular dystrophy, head and spinal cord injuries, and stroke; publishes bibliographies, factsheets, professional monographs, pamphlets, and special reports.

National Institute on Disability and Rehabilitation Research (NIDRR) 330 C Street SW Washington, DC 20202 (202) 205-9151

Principal publication: Rehab Brief, monthly

Sponsors research and demonstration projects that highlight ways to improve employment of adults with disabilities.



National Library Service for the Blind and Physically Handicapped (NLS)

Library of Congress Washington, DC 20542 (202) 707-5100 (202) 707-0744 TDD 800-424-8567

Principal publications: Address List: Regional and Subregional Libraries

for the Blind and Physically Handicapped, annual Facts: Books for Blind and Physically Handicapped

Individuals, annual

Administers a national library service that provides braille and recorded books and magazines on free loan to persons who cannot read standard print because of visual or physical disabilities. Reading materials and playback machines are distributed to eligible borrowers through cooperating regional and subregional (local) libraries.

President's Committee on Employment of People with Disabilities (PCEPD)

1331 F Street NW, 3rd floor Washington, DC 20004-1107 (202) 376-6200 (202) 376-6205 TDD

Conducts a program of public education and enlists the support of federal, state, and local officials and professional organizations in providing employment opportunities for persons with physical disabilities, mental retardation, and mental illness. Publishes and distributes pamphlets on accessibility, adaptation of the workplace, education, and employment. Sponsors National Disability Employment Awareness Month.



**Rehabilitation Services Administration (RSA)** 

Office of Special Education and Rehabilitation Services U.S. Department C Education Switzer Building 330 C Street SW Washington, DC 20202-2524 (202) 730-1282

Principal publication: American Rehabilitation, quarterly

Administers the basic grants program for state vocational rehabilitation services and supports job training and client assistance programs. For the **Vocational Rehabilitation Agency** under this program, consult a local telephone directory under the state social service rehabilitation office.

U.S. Architectural and Transportation Barriers Compliance Board

1331 F Street NW, Suite 1000 Washington, DC 20004-1111 (202) 272-5434 (202) 272-5449 TDD 800-872-2253

Principal publication: Access America, quarterly

Also called the Access Board, it develops national standards for accessibility and is responsible for enforcing the Architectural Barriers Act (PL 90-480), which requires that most buildings and facilities constructed or leased by the federal government since 1969 be accessible to disabled persons; publishes pamphlets on barrier-free architecture.



## U.S. Department of Justice Office on the Americans with Disabilities Act (ADA) Civil Rights Division

P.O. Box 66118

Washington, DC 20035-6118

(202) 307-2222

(202) 514-0301 or 800-514-0301 ADA hotline

(202) 514-0383 or 800-514-0381 TDD

(202) 514-6193 electronic bulletin board

Enforces federal civil rights laws that prohibit discrimination on basis of race, national origin, religion, sex, or handicap in the areas of voting, education, employment, housing, credit, the use of public facilities, and public accommodations, and in the administration of federally assisted programs. Administers Titles II and III of ADA. The ADA hotline is available between 11 a.m. to 5 p.m. eastern standard time, Monday to Friday.

## U.S. Department of Veterans Affairs (VA)

810 Vermont Avenue NW Washington, DC 20420 (202) 233-2741 800-829-4833 TDD

Provides disabled veterans with rehabilitation programs, medical care, education, and counseling services; also provides adapted housing assistance under PL 96-385, the Veterans Disability Compensation and Housing Benefits Amendments of 1980.

## U.S. Social Security Administration (SSA)

Office of Public Affairs 6401 Security Boulevard Baltimore, MD 21235 (410) 965-7700 voice 800-772-1213 voice hotline 800-325-0778 TDD hotline

Administers the federal retirement, survivors, disability insurance, and supplemental security income (SSI) programs. For information call the local office listed in the telephone directory under SSA. These offices can also provide information on Medicare, the federal health insurance program for the aged and disabled persons.



#### III. Select Bibliography

- This select bibliography lists special-subject periodicals not mentioned in the previous sections, and current directories on advocacy, adaptive equipment, services, and related topics of interest to persons with physical disabilities.
- Accent on living. Quarterly. \$8/year. Cheever Publishing, Inc., P.O. Box 700, Gillum Road and High Drive, Bloomington, IL 61702.
- Batshaw, Mark L., and Yvonne M. Perret. Children with disabilities: a medical primer. 3d ed. Baltimore, MD: Paul H. Brookes Publishing Co., 1992. 664p. \$28.
- Berliss, Jane R., and others. Trace resourcebook: assistive technologies for communication, control, and computer access. Madison, WI: Trace Research and Development Center, University of Wisconsin-Madison, 1993. 937p. \$40. (S-151 Waisman Center, 1500 Highland Avenue 53705).
- Careers and the disABLED. Quarterly. \$8/year. Equal Opportunity Publications Inc., 150 Motor Parkway, Suite 420, Hauppauge, NY 11788-5145.
- Closing the gap. Bimonthly. \$26/year. Closing the Gap, P.O. Box 68, Henderson, MN 56044.
- The complete directory for people with disabilities: products, resources, books, and services. Lakeville, CT: Grey House Publishing, 1992. 580p. \$69.95.
- Directory for exceptional children: a listing of educational training facilities. Biennial. \$45/year. Porter Sargent Publishers, Inc., 11 Beacon Street, Boston, MA 02108.
- Directory of grants for organizations servicing people with disabilities. Annual. Loxahatchee, FL: Research Grants Guides. \$47.50. (Dept 73, P.O. Box 1214 33470).
- Directory of independent living programs. Annual. \$8.50. ILRU Research and Training Center on Independent Living at TIRR, 2323 South Shepherd, Suite 1000, Houston, TX 77019.



- Disability leadership forum directory. Chicago, IL: National Easter Seal Society, 1993. 123p. \$9.95. (230 West Monroe Street, Suite 1800 60606).
- Enders, Alexandra. Funding for assistive technology and related services: an annotated bibliography. Washington: Electronic Industries Foundation, Rehabilitation Engineering Center, 1989. 17p. Free. (1901 Pennsylvania Avenue NW, Suite 700 DC 20036).
- Enders, Alexandra, and Marian Hall, eds. Assistive technology sourcebook. Washington: RESNA Press, 1990. 600p. \$60. (1101 Connecticut Avenue NW, Suite 700 DC 20036).
- The exceptional parent: parenting your child with a disability. 8/year. \$18/year. P.O. Box 3000, Dept. EP, Denville, NJ 07834. Includes annual list of national organizations.
- Geralis, Elaine, ed. Children with cerebral palsy: a parents' guide. Baltimore, MD: Woodbine House, 1991. 434p. \$14.95.
- HEATH Resource directory, 1993-1994. Washington: HEATH Resource Center, 1991. 32p. Free. (One Dupont Circle NW, Suite 800, DC 20036-1193).
- The illustrated directory of disability products. 3d ed. Lawrence, KS: Trio Publications, Inc., 1993. 224p. \$22.95. (3600 West Timber Court 66049).
- Independent living: connecting dealers and people with special needs. Quarterly. \$18/year. Equal Opportunity Publications Inc., 150 Motor Parkway, Suite 420, Hauppauge, NY 11788-5145.
- Kemlage, Brian, ed. Information resources. Washington: Rehabilitation Engineering Center, National Rehabilitation Hospital, 1990. unpaged. Free. (102 Irving Street NW DC 20010-2949).
- Mainstream: magazine of the able-disabled. 10/year. \$24/year. Exploding Myths, Inc., P.O. Box 370598, San Diego, CA 92137-0598.
- Moore, Cory. A reader's guide for parents of children with mental, physical, or emotional disabilities. 3d ed. Rockville, MD: Woodbine House, 1990. 248p. \$14.95.



- The national housing directory for people with disabilities. Lakeville, CT: Grey House Publishing, 1992. 1430p. \$185.
- Reisner, Helen, ed. Children with epilepsy: a parents guide. Baltimore, MD: Woodbine House, 1988. 313p. \$12.95.
- Report on disability programs. 26/year. \$273/year. Business Publishers, Inc., 951 Pershing Drive, Silver Spring, MD 20910.
- Resource directory of scientists and engineers with disabilities. Irregular.

  American Association for the Advancement of Science, 1333 H Street NW, Washington, DC 20005.
- Resources for people with disabilities and chronic conditions. Lexington, MA: Resources for Rehabilitation, 1993. 213p. \$44.95. (33 Bedford Street, Suite 19A 02173).
- Rosenfeld, Robert, comp. Listing of organizations working with persons with disabilities in developing countries. 3d ed. Palo Alto, CA: The Hesperian Foundation, 1992. 1v. (unpaged). \$15. (P.O. Box 1692 94302).
- Rubin, Ellen, comp. Bridging the gap: a national directory of services for women and girls with disabilities. New York: Educational Equity Concepts, 1990. 132p. \$15. (114 East 32nd Street, NY 10016).
- Schlacter, Gail Ann, and Richard Weber. Financial aid for the disabled and their families, 1994-1996. San Carlos, CA: Reference Service Press, 1994. 321p. \$38.50. (1100 Industrial Road, Suite 9 94070).
- Shrout, Richard Neil. Resource directory for the disabled. New York, Facts on File, 1991. 392p. \$45.
- Social Security Administration. Social security and SSI benefits for children with disabilities. Baltimore, MD: 1991. 20p. [pamphlet]. Also available in Spanish. (free from local social security offices or write to P.O. Box 17443 21235).
- Spinal network: the total resource for the wheelchair community. Annual. \$35. P.O. Box 4162, Boulder, CO 80306.



- U.S. Department of Education. Office of Special Education and Rehabilitative Services. Clearinghouse on Disability Information. Pocket guide to federal help for individuals with disabilities. Washington: For sale by the Supt. of Docs., U.S. Govt. Print. Off., 1993. 29p. [pamphlet].
- U.S. Department of Education. Office of Special Education and Rehabilitative Services. National Institute on Disability and Rehabilitation Research. Directory of national information sources on disabilities. 5th ed. Washington: For sale by the Supt. of Docs., U.S. Govt. Print. Off., 1991. 555p.
- U.S. Equal Employment Opportunity Commission and U.S. Department of Justice. Americans with Disabilities Act handbook. Washington: For sale by the Supt. of Docs., U.S. Govt. Print. Off., 1991. lv. (unpaged).
- White, Barbara J., and Edward J. Madara, comp. & eds. The self-help sourcebook: finding and forming mutual aid self-help groups. 4th ed. Denville, NJ: American Self-Help Clearinghouse, 1992. 222p. \$10. (Saint Clares-Riverside Medical Center, 25 Pocono Road 07834).
- Wolf, John, et al. Mastering multiple sclerosis: a guide to management. 2d ed. Rutland, VT: Academy Books, 1987. 432p. \$22.95.

Compiled by Ruth Nussbaum Reference Section June 1994



The reference circulars listed below are available free on request from:

Reference Section
National Library Service for the Blind
and Physically Handicapped
Library of Congress
Washington, DC 20542

#### Reference Circulars

Assistive Devices for Reading, 1993

Bibles, Other Scriptures, Liturgies, and Hymnals in Special Media, 1993

Blindness and Visual Impairments: National Information and Advocacy Organizations, 1990

Braille Instruction and Writing Equipment, 1986

Building a Library Collection on Blindness and Physical Disabilities: Basic Materials and Resources, 1990

Deaf-Blindness: National Organizations and Resources, 1993

Guide to Spoken-Word Recordings: Foreign-Language Instruction and Literature, 1988

Guide to Spoken-Word Recordings: Popular Literature, 1987

Information for Handicapped Travelers, 1987

Learning Disabilities: National Information and Advocacy Organizations, 1990

Parents' Guide to the Development of Preschool Children with Disabilities: Resources and Services, 1992

Physical Disabilities: National Organizations and Resources, 1994

Reading Materials in Large Type, 1987

Reference Books in Special Media, 1982; Addendum, 1987



Sources of Braille Reading Materials, 1985

Sports, Outdoor Recreation, and Games for Visually and Physically Impaired Individuals, 1991

# **Bibliographies**

A series of bibliographies is also published by the Reference Section. The following titles are available free on request:

Accessibility: A Selective Bibliography, 1994

Assistive Technology: A Selective Bibliography, 1992

Disability Awareness and Changing Attitudes, 1991

Library and Information Services to Persons with Disabilities, 1989

