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#### ABSTRACT

This directory, compiled as a reference tool for information and service providers, lists and briefly describes national level organizations which provide information about disabilities and direct services to disabled individuals. Organizations are categorized as: advocacy, consumer, and voluntary health organizations (124); information/data banks/research (86); data base vendors (3); federal government other than information\_ units (25); professional and trade organizations (71); facilities, schools, clinics (19); service organizations (29); and international organizations (7). Appendices include a list of religious organizations serving disabled persons (13); a list of sports organizations by and for disabled persons (29); a list of pertinent databases (50); a list of national directories of services and resources for disabled persons (51); and an index which lists all organizations by handicapping conditions and by areas (such as architectural barriers, mobility, etc.). Each entry provides information on the handicapping condition served, users served, organization (brief description), and information services provided. (CB)



U.S. DEPARTMENT OF EDUCATION
Office of Special Education and Rehabilitative Services
National Institute of Handicapped Research

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# Directory of National Information Sources on Handicapping Conditions and Related Services



# U.S. Department of Education

# Office of Special Education and Rehabilitative Services

National Institute of Handicapped Research

# INFORMATION SOURCES ON HANDICAPPING CONDITIONS AND RELATED SERVICES

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#### PREFACE

This is the fourth edition of what has become a standard reference work for information providers and service organizations concerned with disabled persons. Earlier editions, produced by the Clearinghouse on the Handicapped, have identified and described an ever increasing array of organizations which provide disability-related information, and, occasionally, direct services, on a national basis.

This edition, prepared by Harold Russell Associates, Inc. under contract to the National Institute of Handicapped Research, offers approximately 45 "new" organizations (not described in previous editions), including groups serving specific disabilities, sources of information on technology, and organizations with a focus on independent living.

The assistance of the Clearinghouse on the Handicapped and the National Rehabilitation Information Center in identifying new organizations is gratefully acknowledged. Thanks are also due to the staffs of the organizations in the Directory; many individuals took much time to insure that their services were accurately described.

As always, we welcome your feedback on the content and format of the Directory.

National Institute of Handicapped Research
Office of Special Education and Rehabilitative Services
U.S. Department of Education



# THE DIRECTORY: WHAT IT IS, HOW TO USE IT

# Purpose Of The Directory

The Directory has been compiled as the major reference tool for information and service providers. We hope that it will also work to enhance networking, and facilitate the exchange of information. Comments on earlier editions cited the usefulness of the Directory and urged that it be kept updated. Some users have asked that regional or local organizations be included, a request we are not able to accommodate, since the Directory would then become unwieldy in size. Also, our awareness of local operations is quite fragmentary.

# Organizations Included In The Directory

For the Directory, NIHR has attempted to identify and collect information on national level organizations which respond to inquiries from all parts of the nation on a variety of topics.

The organizations listed in the Directory are information and direct service providers. Because our focus is on information sources, we emphasize the information components of each organization and have included material on data base vendors (commercial companies which offer information seekers access to many computerized data bases). A few organizations listed are direct service providers but operate without geographical limitation on clientele.

In many instances, national level organizations dispense information and services through state or local enapters or affiliates. We have listed only the national address after determining that an inquirer would be referred by the national office to it appropriate counterpart on the state or local level. Addresses of local chapters generally can be found in the telephone directory.

Sports and religious organizations are listed in the appendices. We have also included a listing of pertinent data bases available through organizations described in the Directory or through the commercial data base vendors.

# How The Directory Is Organized

To provide the user of the Directory with an understanding of the basic purpose of the organizations listed, we have grouped them in various categories. A brief description of the type of organization found in each category along with the general kinds of information or services offered accompanies each alphabetical listing, to assist you in determining which organization(s) can best provide the information you are seeking. Some organizations could fit into more than one category. For example, many voluntary health organizations are also direct service providers. Our assignment to a category tends to reflect the primary focus of the organization or the activity which has the greatest potential for providing information nationwide.



Also, we have attempted to identify the most easily accessible place for obtaining consumer information on a particular topic. The National Institutes of Health, for example, have been placed in the section on information providers, not because their basic purpose it providing information, but because they have substantial information operations which are the most direct points of access to the Institutes.

The section on internationally oriented organizations has been expanded to reflect increased interest in communication about disabilities between different countries. Organizations having international chapters but a national orientation are generally included in a different category.

The alphabetical list of organizations will help you locate the information you are seeking irrespective of our attempt to group organizations. Federal agencies have been identified in the list by an asterisk. (Information providers funded by the Federal government but operated on a grant or contract basis have not been identified by an asterisk.)

# How The Data Was Gathered

All organizations included in the 1982 edition were asked to review the description of their services and make any necessary changes. New information providers were contacted by mail and telephone for information necessary to prepare the abstract:

#### The Index

Please take the time and effort to read the introduction to the index. It contains some important guidelines which will facilitate your use of the Directory.



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# ORGANIZATIONS AND FEDERAL AGENCIES

This is the alphabetical listing of all organizations and Federal agencies that appear in the Directory. The codes show the chapter where the organization or agency appears:

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- I = Information/Data Banks
- G = Federal Government Other Than Information Units
- P = Professional and Trade Organizations
- F = Facilities, Schools, Clinics
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- AR = Appendix Religious
- AS = Appendix Sports

All Federal agencies are marked with an asterisk for easy identification.

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# ADVOCACY, CONSUMER, VOLUNTARY HEALTH ORGANIZATIONS

These organizations generally focus on a particular disability or condition or a group of related conditions. The information and services they provide vary widely, from distribution of basic fact sheets to sponsorship of research facilities. Most of these organizations use numerous approaches to information dissemination and direct their activities toward a diverse audience. Following are examples of some activities and services provided by these groups: information clearinghouse; legislative monitoring; procounseling; medical referrals; sponsorship of self-help groups; provision of educational materials; sponsorship of conferences, workshops and seminars; and reports on research projects.

# ADVOCACY, CONSUMER, VOLUNTARY HEALTH ORGANIZATIONS

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Vision Foundation, Inc
Wilson's Disease Association



Adaptive Environments Center Massachusetts College of Art 621 Huntington Avenue Boston, MA 02115 (617) 739-0088 (Voice and TTY)

Handicapping Conditions Served: Physical, mental, and emotional disabilities.

Users Served: Disabled persons, parents, teachers, occupational therapists, caseworkers, physicians.

The Organization: The Adaptive Environments Center, a nonprofit organization, offers consultation, workshops, courses, conferences, and resource materials on adaptive design. The Center's library contains a comprehensive collection of materials on adaptive design. The Center is funded through public and private contracts, donations and memberships.

Information Services: The Center provides free information and referral service on adaptive design. The Center's publications, for which there is a charge, include <u>Humanizing Environments</u>, A Primer; <u>Design Tools for Adapting Environments</u>; and <u>The Picture Book of Adaptive Environments</u>. A newsletter, <u>Accessful Reports</u>, is published semiannually. A variety of audio-visual products may be rented or purchased. The library is open to the public. Only members can circulate library materials; others may use materials on site. Fees vary according to the type of service and type of client, except for the library and information, which are free.

Affiliated Leadership League of and for the Plind of America (ALL)
2025 I Street, NW
Suite 405
Washington, DC 20006
(202) 775-8262

Handicapping Conditions Served: Blindness and visual impairment.

Users Served: Disabled persons, parents, professionals.

The Organization: The Affiliated Leadership League of and for the Blind of America (ALL) is a coalition of over 70 national and local membership organizations which serve the blind. The primary function of the coalition is advocacy; it testifies before congressional committees and advises Federal agencies and national private organizations on the needs and rights of blind persons. ALL's main concerns are human and civil rights, and the utilization of qualified blind people in management positions.

Information Services: ALL publishes a bimonthly newsletter which reports on pending legislation, current hearings, new publications for the blind and new technology. A national delegate assembly is held annually which contains seminars on pertinent information to the blind.



# Alexander Graham Bell Association for the Deaf 3417 Volta Place, NW Washington, DC 20007 (202) 337-5220 (Voice/TDD)

Handicapping Conditions Served: Deafness and hearing impairments.

Users Served: Disabled persons and their families, professionals, general public.

The Organization: The Alexander Graham Bell Association for the Deaf, founded in 1890, is committed to the idea that hearing-impaired children should be afforded the opportunity to develop spoken communication through the effective use of amplified residual hearing and speechreading skills. The Association's Children's Rights Program advocates educational options for deaf children and provides consultant services for families pursuing their legal rights. Through this program, volunteers throughout the country serve as knowledgeable local resources for hearing-impaired children and their families. Special divisions within the Association's membership are: Oral Deaf Adults Section, International Parent's Organization, and International Organization for the Education of the Hearing Impaired.

Information Services: The Association publishes a journal, Volta Review, an annual monograph, and a newsletter. It also publishes a variety of books and audio-visual materials concerning the psychological, social, and educational implications of hearing loss. The Association sponsors regional conferences and a biennial convention.

The Association maintains a library of works of both historical and current importance in the field of deafness. A lending library of current materials is available to members.

The Association disseminates printed materials and answers inquiries from hearing-impaired persons, their families, professionals, and the general public.

Alzheimer's Disease and Related Disorders
Association, Inc. (ADRDA)
70 Lake Street
Chicago, IL 60601
(312) 853-3060
(800) 621-0379 (Outside Illinois)
(800) 572-6037 (In Illinois)

Hanc icapping Conditions Served: Alzheimer's disease and related disorders.

Users Served: Disabled persons and their families, health care professionals, general public.

The Organization: The Alzheimer's Disease and Related Disorders Association (ADRDA) was founded in 1980 to heighten public awareness of this degenerative brain disorder, provide support for patients and their families, and aid research efforts. Currently, the ADRDA network includes over 140 chapters and affiliates across the country, representing over 500 Family Support Groups. ADRDA's board of directors is comprised of business leaders, health professionals and family members. Additionally, ADRDA's Medical and Scientific Advisory Board consults and monitors issues related to Alzheimer's disease.



The major goals of ADRDA include: (1) supporting research into causes, treatment, cures and prevention; (2) providing family support through local chapters, affiliates and family support groups; (3) stimulating education and public awareness for both professionals and the general public on Alzheimer's disease; and (4) advocating for legislation that responds to the needs of patients and family members at Federal, state and local levels. In addition to its public awareness and advocacy activities, the national office administers a research grant program to initiate new investigations into the cause(s), treatment and cure of Alzheimer's disease.

Information Services: ADRDA serves as a clearinghouse for information on Alzheimer's disease. The Association publishes a quarterly newsletter which covers organizational news at the national and chapter/affiliate level, research developments, medical issues, and other items of general interest. As part of its education efforts, ADRDA sponsors a month-long public awareness campaign for National Alzheimer's Disease Awareness Month each November, utilizing radio, television and print media.

The ADRDA chapters, affiliates and support groups offer the most direct link to assistance for patients and families. Support groups are moderated by health care professionals and experienced caregivers and provide a forum for sharing information, answering questions, giving recommendations for patient care options and offering a sympathetic ear to family problems. Major chapter/affiliate activities include family help programs, such as information-sharing meetings, telephone "helplines" and public awareness campaigns. Many chapters and affiliates publish literature aimed at particular caregiving issues and serve as the local resources for national ADRDA information. Some also provide speakers' bureaus.

A nation wide 24-hour hot line provides information and links families who need assistance with nearby chapters and affiliates.

### American Amputee Foundation, Inc. (AAF) Box 55218 \_\_\_\_\_\_\_ Little Rock, AR 72225 (501) 666-2523

Handicapping Conditions Served: Amputations.

Users Served: Disabled persons, parents, attorneys, physical therapists, occupational therapists, prosthetists.

The Organization: The American Amputee Foundation, Inc. (AAF) provides peer support to amputees and their families. Through chapters in 31 states, AAF offers counseling, information and referral, direct financial aid in the form of grants and low interest loans, rehabilitation coordination and hospital visitation. The Foundation distributes educational and self-help material to amputee consumers. AAF has developed a 3 1/2 day peer counseling training program, certified by the University of Arkansas.

Information Services: AAF provides a variety of publications for amputees and their families including self-help guides, a quarterly newsletter, Ability magazine, and a medical data directory on services for amputees throughout the United States. A videotape, "One Step at a Time", is also available. Referrals are made for services for amputees nationwide, including recreation, rehabilitation, medical facilities and prosthetics, for which a computerized system of equipment and certified prosthetists has been developed. AAF provides technical assistance in developing outreach chapters in other states, including local affiliates.



American Brittle Bone Society (ABBS) 1256 Merrill Drive Marshallton West Chester, PA 19380 (215) 692-6248

Handicapping Conditions Served: Osteogenesis imperfecta and osteoporosis.

Users Served: Disabled persons and their families, general public.

The Organization: The American Brittle Bone Society (ABBS) was established in 1975 to support and encourage research and education on osteogenesis imperfects and osteoporosis.

Information Services: ABBS provides free information about osteogenesis imperfecta and osteoporosis. A 16 mm educational film on osteogenesis imperfecta is available to groups upon request. The organization has a 24-hour a day counseling and referral service for families and other interested persons.

American Cancer Society (ACS) 90 Park Avenue New York, NY 10016 (212) 599-8200

Handicapping Conditions Served: Cancer.

Users Served: Disabled persons, parents, professionals, and the general public.

The Organization: The American Cancer Society supports research into the causes and detection of cancer and educates primary care physicians and the public to recognize the signs of cancer. ACS offers a variety of research project grants to institutions and personnel in every aspect of cancer research. The Society's public education programs emphasize the value of periodic checkups and cancer's seven warning signals and are carried out by ACS volunteers in homes, places of employment, community meetings, and through the media. Professional education programs, offered through literature and conferences, are designed to motivate the medical and allied professions to use the latest and best possible cancer detection, diagnostic, and patient management techniques.

ACS provides direct services to the cancer patient. These services include Information and Guidance - providing referral to Society services, community resources and specific information about cancer; Home Care Items - supplying patients with a wide range of equipment, supplies and gifts to enhance their care, comfort and recreation; Transportation - assisting patients with the task of getting to and from medical and therapy appointments; Rehabilitation - assisting patients to return to their families, communities and occupations through trained visitor and group programs such as:

- (1) International Association of Laryngectomees, which offers speech training and moral support to the laryngectomy patient (see separate entry);
- (2) Reach to Recovery which provides support to women with breast cancer;
- (3) Ostomy rehabilitation program which gives support to those patients who have an ostomy;



(4) CanSurmount which provides support to cancer patients and families not covered by other specific programs.

All rehabilitation programs are medically directed and supervised.

Patient Education helps patients to better understand the disease and its management through group education programs like "I Can Cope" along with pamphlets, booklets and audio-visual presentations.

Information Services: The ACS medical library functions as a repository and clearinghouse of information on all aspects of cancer for physicians, nurses, and researchers. Printed materials on cancer safeguards, cancer detection, smoking, statistical information, and information on unproven methods of cancer detection and treatment are available for the lay public. The Society publishes a variety of professional journals and publications. All materials are provided free of charge, and some information is available in Spanish. The ACS divisions and units provide general information services and referrals to area physicians and hospitals.

# American Cleft Palate Educational Foundation (ACPEF) 331 Salk Hall University of Pittsburgh Pittsburgh, PA 15261 (412) 681-9620

Handicapping Conditions Served: Cleft lip and palate.

Users Served: Parents, health care professionals.

The Organization: The American Cleft Palate Educational Foundation (ACPEF) is the teaching arm of the American Cleft Palate Association (see separate entry).

Information Services: ACPEF makes available a series of pamphlets written especially for parents of children with cleft lip/palate. Single copies of these publications are free; there is a charge for bulk orders. A newsletter for parents, published three times a year, discusses activities of parent groups across the country, and announces items of interest such as publications and conferences. A computer-generated topical index is provided on a subscription basis to professionals.

The Foundation also refers parents to sources of services and, if possible, puts them in touch with other parents of children with clefts in their area.

American Coalition of Citizens with Disabilities (ACCD) 1012 14th Street, NW Suite 901 Washington, DC 20005 (202) 628-3470 (Voice and TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons.



The Organization: The American Coalition of Citizens with Disabilities (ACCD) is con.prised of 150 member agencies which represent specific handicapping conditions. The ACCD acts as a unified voice of its member organizations to support legislation for disabled people.

Information Services: ACCD answers inquiries from the public about services and about the legal rights of persons with disabilities, and offers referrals to appropriate agencies. ACCD publishes a newsletter, ACCD NewsNet, and ACCD Action alerts on important issues as they arise. In addition, ACCD has a publication list of over 20 books and pamphlets concerning disability issues.

American Council of the Blind (ACB) Suite 1100 1010 Vermont Avenue, NW Washington, DC 20005 (202) 393-3666 (800) 424-8666

Handicapping Conditions Served: Blindness, visual impairment, and deaf-blindness.

Users Served: Disabled persons, parents, teachers, professionals.

The Organization: The American Council of the Blind (ACB) advocates legislation for the blind and other handicapped persons. Priority areas of advocacy include civil rights, social security and supplemental security income, national health insurance, rehabilitation, eye research, technology and others. The Council has 17 special interest affiliates. These include the Randolph Sheppard Vendors of America, a parents' organization for visually impaired parents and parents of visually impaired children, an organization of guide dog users, and vocationally oriented organizations for professionals (e.g., blind lawyers, blind secretaries, and blind computer programmers). ACB's 52 state chapters monitor state laws affecting the blind. The national office offers free direct legal assistance to groups in discrimination and benefits cases and to individuals in precedent cases. The Council operates "The Washington Connection," a legislative hot line offering updated information toll-free at (800) 424-8666 during non-working hours. ACB also awards scholarships to blind postsecondary students.

Information Services: ACB holds periodic workshops for the blind on advocacy and leadership training. The organization has information about agencies and schools for the blind, scholarships, electronic aids, legislation, and legal rights. It can often give advice about specific legal problems over the phone. If ACB is unable to give legal assistance, it will provide referrals to other possible sources. The Braille Forum, a free monthly magazine updating developments in legislation, education, technology, leisure activities and employment is available in large print, braille, or cassette, and in Spanish. Affiliates and chapters also have newsletters.

American Diabetes Association Inc. (ADA) National Service Center P.O. Box 25757 Alexandria, VA 22313 (800) 232-3472

Handicapping Conditions Served: Diabetes mellitus.



Users Served: Persons with diabetes, physicians, dieticians, diabetes educators.

The Organization: The American Diabetes Association (ADA) Inc. is a national membership organization for professionals and lay persons, with 58 affiliates (state and large city) and 750 local chapters. The twofold mission of ADA is to promote the search for a preventive or cure for diabetes and to improve the well-being of all people with diabetes and their families. Through its extensive research program, which supplements the Established Research Investigators Program of the National Institutes of Health (NIH), ADA attracts scientists starting careers in diabetes research and provides researchers an opportunity to develop new and innovative ideas essential in procuring long-term support from NIH.

Information: ADA conducts professional seminars, scientific meetings and postgraduate courses for physicians and other health professionals. It publishes a monthly research journal for researchers, and a bimonthly clinical care journal and newsletter for the clinician. For persons with diabetes, it publishes a variety of pamphlets, books and cookbooks. The bimonthly magazine and quarterly newsletter include articles on recent research, nutrition information, recipes and hints for 'iving with diabetes. Affiliates and chapters sponsor monthly educational meetings, in-hospital orientation, weekend retreats, and a summer camping program for children. They also serve as a referral source to appropriate direct care agencies. ADA offers a free information package for persons with diabetes; there is a charge for periodicals:

American Foundation for the Blind (AFB) 15 West 16th Street - New York, NY 10011 (212) 620-2000

Handicapping Conditions Served: Blindness, visual impairments, and deaf-blindness.

Users Served: Disabled persons and their ramilies, professionals, local agencies and organizations, general public.

The Organization: The American Foundation for the Blind (AFB) was established in 1921 to help the blind and visually impaired acquire improved rehabilitation services and educational and employment opportunities, and to aid those persons in daily living activities. Through its national, regional, and legislative offices, AFB provides legislative consultation to government agencies, and advisory services to local agencies and schools involved in direct services. AFB conducts national and local surveys on psychosocial needs of the blind, and technological research leading to the design of a variety of devices which help the blind person to lead an independent life. The Foundation manufactures (or adapts) and sells more than 400 such devices, including braille watches, measuring instruments, shop tools, and braille games for adults and children. AFB records and manufactures about 500 talking books per year for the Library of Congress, National Library Service for the Blind and Physically Handicapped (see separate entry).

AFB's six regional offices provide a link between consumers and providers of services. They are located in Atlanta, Chicago, Dallas, New York, San Francisco and Washington, DC.

Information Services: AFB publishes a variety of general interest pamphlets and films about blindness, deaf-blindness, visual impairments, eye disorders, braille, assisting the blind, activities of daily living, travel, rehabilitation, education, devices, dog guides, aging,



recreation and leisure, technology, employment, and careers for people who wish to work with the blind. Single copies of these public education materials are free in print form; films may be rented or purchased. Priced publications are mainly for professionals, and include materials on research, clinical practice, and instructional techniques in the areas of blindness, visual impairments, deaf-blindness, and other multihandicapped disabilities involving blindness. Listings of services such as The Directory of Agencies Serving the Visually Handicapped in the United States and the International Guide to Aids and Appliances for Blind and Visually Impaired Persons are also published by the Foundation. A few publications are available in Spanish; some are available in large print, braille and cassette.

The Journal of Visual Impairment and Blindness covers research and practice reports, book reviews, and legislative and organizational news, and is published in print, braille, and recorded form. Other regular publications include the Washington Report, Long Cane News, a newsletter for orientation and mobility specialists, and a quarterly newsletter.

AFB's M. C. Migel Memorial Library contains more than 37,000 books, periodicals, and other publications on blindness. Its services are available to lay and professional people, who may borrow materials in person or by mail.

Requests for information are responded to with the organization's publications or with individual letters when required. AFB makes referrals to service facilities, local agencies, and other institutions, as appropriate.

# American Heart Association (AHA) 7320 Greenville Avenue Dallas, TX 75231 (214) 750-5300

Handicapping Conditions Served: Cardiovascular disorders and stroke, aphasia.

Users Served: Persons with cardiovascular disorders, stroke patients, health care professionals.

The Organization: The primary concern of the American Heart Association is the reduction of premature death and disability due to cardiovascular diseases. To this end, the AHA: (1) funds research on cardiovascular function and disease and stroke; (2) gathers information on all aspects of cardiovascular disease and stroke; and (3) disseminates the information to professionals and lay persons through its publications and the media.

Information Services: AHA's 2000 local affiliates act as information and referral centers. Public education and community programs focus on the early recognition, diagnosis and treatment of cardiovascular diseases. Topics include risk factors, early warning signs of heart attack and stroke, control of high blood pressure, rheumatic fever prevention, and cardiac and stroke rehabilitation. Also available to lay persons are directories of cardiac rehabilitation units. Professionals can obtain printed materials on successful rehabilitation programs and facilities, exercise testing and training, and standards for testing laboratories. Journals are published for physicians and researchers, and three cardiovascular disease newsletters are printed for physicians and nurses. Publications are available from local affiliates (from the national office for foreign requestors). There is a nominal charge for materials ordered in bulk. Some information is available in Spanish. AHA holds professional continuing education seminars nationwide. Each AHA affiliate acts as a referral agency to direct services available in its locality, such as cardiac and stroke



rehabilitation centers, dieticians, smoking cessation classes and dieting workshops. For information, centact a local AHA office.

### American Lung Association (ALA) 1740 Broadway New York, NY 10019 (212) 315-8700

Handicapping Conditions Served: Respiratory conditions.

Users Served: Disabled persons, physicians, health care professionals.

The Organization: The American Lung Association (ALA) seeks the eradication and control of tuberculosis and chronic obstructive pulmonary diseases, including chronic bronchitis, asthma, and emphysema. It develops materials and programs of professional and public education and research in four major areas: (1) occupational health; (2) clean air conservation; (3) smoking and health; and (4) pulmonary disease. The medical arm of the ALA, the American Thoracic Association, conducts specific research and acts as a medical advisor to the ALA and its 82 affiliates and 59 constituent (state and large city) lung associations. These offer some direct services, such as smoking cessation clinics and breathing improvement classes. ALA provides seed grants to young researchers, and fellowships and grants to universities.

Information Services: Printed materials, films and resource materials on emphysema, chronic bronchitis, air pollution, smoking and health, tuberculosis and other lung diseases are available free to lay and medical persons. Several pamphlets are available in Spanish. The American Thoracic Society publishes a monthly professional journal and is a source of information on pulmonary rehabilitation centers, smoking cessation clinics, and Federal and national facilities and services. Local and constituent lung associations maintain local directories of facilities and direct care providers, and act as lung information and referral centers. For information, contact the ALA at the above address or a local lung association listed in the telephone book.

# The American Narcolepsy Association (ANA) Box 5846-0122 Stanford, CA 94305

Handicapping Conditions Served: Narcolepsy and other chronic sleep disorders.

Users Served: Disabled persons, health care professionals, general public.

The Organization: ANA was established as a non-profit organization in 1975 to help solve the many problems associated with narcolepsy and other chronic sleep disorders. Incorrect diagnosis, inappropriate and sometimes even dangerous treatment are common for this disorder. Narcolepsy exerts a crippling effect on learning, memory, attention and motivation. The cause of narcolepsy is not clearly understood; it can strike anyone at any age and is estimated to afflict more than 250,000 persons, many undiagnosed. Members of ANA form self-help groups and hold meetings for mutual support.

Information Services: ANA distributes information about narcolepsy to members, the medical profession and the general public. Available are: Narcolepsy: A Non-Medical



Presentation; Sleep Apnea: A Non-Medical Presentation; Narcolepsy, Care and Treatment, A Guide for the Primary Care Physician Whose Patient is Afflicted by Narcolepsy; and a 27-minute, 16 mm educational film about narcolepsy entitled "Keep Us Awake."

American Parkinson Disease Association (APDA) 116 John Street New York, NY 10038 (212) 732-9550 (800) 223-2732 (Outside New York)

Handicapping Conditions Served: Parkinson's disease.

Users Served: Disabled persons and their families, health care professionals, researchers.

The Organization: The American Parkinson Disease Association (APDA) was founded for the purpose of providing information about the various services available to patients with Parkinson's disease and for making funds available for research in new drug therapies. It subsidizes Parkinson's Disease Information and Referral Centers in 30 locations throughout the United States which provide treatment and act as local referral sources. The APDA awards research grants to universities and hospitals. In addition, each year a \$50,000 Senior Research Fellowship is awarded to an outstanding medical researcher for a three year period, to aid in finding a cure for Parkinson's disease.

Information Services: APDA publishes four pamphlets and a twice yearly newsletter for Parkinson patients and their families. The four pamphlets are: (1) The Parkinson's Disease Handbook: A Guide for Patients and Their Families; (2) Aids, Equipment and Suggestions to Help the Patient with Parkinson's Disease in the Activities of Daily Living; (3) Speech Problems in Parkinson's Disease; and, (4) Home Exercises for Patients with Parkinson's Disease.

The newsletter provides up-to-date information about new treatments, medications, and research. The national APDA keeps updated lists of treatment centers and self-help groups across the country. For patients in the New York City area, the national APDA office can refer to local physicians, equipment sources, home health care services, and transportation services.

American Society for Deaf Children (ASDC) 814 Thayer Avenue Silver Spring, MD 20910 (301) 585-5400

Handicapping Conditions Served: Deafness, hearing impairments.

Users Served: Parents and professionals.

The Organization: The American Society for Deaf Children (ASDC) is a membership organization. It acts as a clearinghouse for the exchange of information among parents of the deaf and between parents of the deaf and professionals. A "Key Network" of parents across the country contact and motivate others when action must be taken on important



issues such as legislation. ASDC has 95 affiliated groups in the U.S.; Canada, and other countries.

Information Services: ASDC provides general information about deafness and raising deaf children to all inquirers. It refers new inquirers to other parents of deaf children in their own geographical areas, so that they can share their concerns and experiences. ASDC provides speakers to its affiliated groups for workshops and seminars. The organization also publishes a bimonthly newsletter, available to members, which includes information about developments in education, legislation, and aids for deaf children.

### American Tinnitus Association (ATA) P.O. Box 5 Portland, OR 97207 (503) 248-9985

Handicapping Conditions Served: Tinnitus.

Users Served: Disabled persons, health care professionals.

The Organization: The American Tinnitus Association (ATA) was founded to conduct and support research and educational activities relating to the cure of tinnitus and other defects or diseases of the ear. Tinnitus is the subjective experience of hearing a sound, a ringing, of a noise when no such external physical sound is present. The ATA provides information and referral and counseling services to persons affected with tinnitus. Additionally, information and research support is provided for professionals in the field of tinnitus. While the ATA has no official chapters, it offers information and assistance to about 140 tinnitus self-help groups across the country.

Information Services: The ATA has available several brochures about tinnitus and the Association. The ATA NEWSLETTER, a quarterly publication, includes timely articles and research reports about tinnitus. Also available for sale is Tinnitus: Proceedings of the 2nd International Tinnitus Seminar, a compilation of scientific papers. The ATA can provide a bibliography on tinnitus and statistical data on tinnitus patient characteristics, as well as public service announcements about this condition. Some material is available in Spanish; occasionally materials can be translated upon request. There is a nominal fee for most services and products.

Referrals for patients seeking help for tinnitus can be made to about 700 professionals in the United States and Canada. The ATA also sponsors workshop courses for hearing professionals.

American Veterans of World War II, Korea, and Vietnam (AMVETS): 4647 Forbes Boulevard Lanham, MD 20706 (301) 459-9600

Handicapping Conditions Served: All handicaps.



Users Served: Veterans with all types of disabilities.

The Organization: AMVETS is a service organization for veterans, including handicapped veterans. The organization operates at national, state and local levels with 1400 local posts across the country. Its main concerns for handicapped veterans are veterans benefits-education, rehabilitation and employment--and legislation affecting the handicapped. A legislative staff in Washington keeps abreast of all new legislation affecting veterans and the handicapped, and maintains a close liaison with Congress. Individual advocacy is provided nationwide through a network of service offices located at regional offices of the Veterans Administration (VA).

Information Services: Although AMVETS is a membership organization, information and direct services are available to any veteran or dependents of veterans. AMVETS' primary effort is at the state and local levels, through service officers and accredited representatives. The officers and representatives offer counsel, information and referrals in the areas of education, rehabilitation and employment. They act as the veteran's initial contact in obtaining these benefits, and they refer him or her to the appropriate government agency. They will appeal individual cases before an agency such as the VA if a veteran fails to get his or her rightful benefits. At the post level, AMVETS members visit hospitalized veterans to provide whatever lay assistance they can for the patient's rehabilitation. Professional referrals and information about aids, equipment and prosthetic devices can be obtained from most service officers and post representatives, but the emphasis of each local service varies. The AMVETS newsletter includes reports on newly enacted and pending relevant legislation. For information, contact AMVETS at the above address, or an AMVETS service office at a regional VA office.

The Amyotrophic Lateral Sclerosis Association (ALSA) 15300 Ventura Boulevard Suite 315 Sherman Oaks, CA 91403

185 Madison Avenue New York, NY 10016 (212) 679-4016

Handicapping Conditions Served: Amyotrophic lateral sclerosis (ALS), Lou Gehrig's disease.

Users Served: Disabled persons, physicians, physical therapists, speech therapists, neurological specialists.

The Organization: The Amyotrophic Lateral Sclerosis Association (ALSA) was established in 1984 through the merger of the former National ALS Foundation and the ALS Society of America. ALSA was formed to help ALS families live with the disease more effectively, to educate the public about the nature of ALS and to foster medical research on its cause and cure. ALS is a progressive, usually fatal disorder that attacks the body's nerves and muscles. ALSA carries on an extensive public information program nationwide to locate ALS patients and provide helpful information. Ten chapters nationwide support the psychological needs of families through peer counseling and make referrals to medical facilities for treatment and therapy for ALS patients. The Association supports four ALS Clinical Services Centers in New York, Chicago, Miami and Philadelphia, where diagnosis, outpatient and follow-up care are provided. ALSA has funded over \$6 million in ALS research since 1975. In addition, the organization is actively involved in advocacy, working with other



organizations concerned with neurological disorders to increase government sponsored research.

Information Services: Publications include Home Care for the Patient With Amyotrophic Lateral Sclerosis, also available in Spanish, and Why Didn't Somebody Tell Me About These Things?, a directory of information, aids and other topics of interest to the ALS patient. A wide range of pamphlets includes information on patient-family services, health insurance plans, breathing exercises, communication systems and devices, emergency treatment and support systems, as well as reports and evaluations of current research. A quarterly publication, The ALS Association Newsletter, reports on current experimental research developments, patient news, and activities of ALSA and its chapters. News bulietins are issued to members, if particularly newsworthy events occur between issues of the newsletter. Professionals in the field, as well as patients and their families, are encouraged to use ALSA as a clearinghouse of information on the management of ALS. There is no charge for information; ALS clinics may charge patients for specific services.

Arthritis Foundation 1314 Spring Street, NW Atlanta, GA 30309 (404) 872-7100

Handicapping Conditions Served: Arthritis, rheumatic diseases.

Users Served: Persons with rheumatic diseases and their families, health care professionals.

The Organization: The Arthritis Foundation is a national voluntary health association committed to finding the cause, prevention and cure for arthritis and other rheumatic diseases. Its programs include support for scientific research, training specialists, public information and education, and help within the community for people who have rheumatic diseases. The 71 local chapters and divisions of the Foundation provide basic information as well as assistance in locating treatment specialists, clinics and other agencies to help with physical, financial and emotional problems caused by arthritis. The chapters support a variety of local services, including information and education programs, support groups, arthritis clinics, home care programs and rehabilitation services.

Information Services: The Foundation disseminates information about new drugs and therapies to its chapters and to professionals in the arthritis treatment field. A variety of lay and professional pamphlets are available from the Foundation's local chapters, including information on specific forms of arthritis, various treatments, and solutions to physical and emotional problems associated with arthritis. Some materials are available in Spanish. Chapters maintain lists of medical and community services and make referrals upon request. The Foundation holds national and regional scientific meetings and continuing community education programs to advise local physicians of the latest clinical advances.



Association for Children and Adults with Learning Disabilities (ACLD) 4156 Library Road Pittsburgh, PA 15234 (412) 341-1515 (412) 341-8077

Handicapping Conditions Served: All learning disabilities.

Users Served: Disabled persons, parents, teachers.

The Organization: The Association for Children and Adults with Learning Disabilities is a membership organization for professionals, adults with learning disabilities, and parents of children with learning disabilities. The national ACLD office provides general information about learning disabilities, while the 800 local chapters provide referrals to physicians and treatment centers. One of the prime functions of the national ACLD is the advocacy of educational and rehabilitative legislation affecting learning disabled persons. The ACLD conducts its own research into the link between juvenile delinquency and learning disabilities. With its state affiliates, ACLD works directly with school systems on early identification and diagnosis, as well as remediation in resource and special classroom situations. Direct services, such as parent counseling, nursery school, and day camps are provided by many of the local chapters; no direct services are available at the national level.

Information Services: Through state and national conferences, the ACLD distributes information on new technology for teaching learning disabled persons. For these meetings, ACLD gathers outstanding professionals to speak and answer questions concerning the nature of learning disabilities and the education available to learning disabled persons. Pamphlets and scientific reprints are available at no cost. National lists of colleges, private schools, and summer camps with facilities for learning disabled persons are compiled and updated by the national organization. The ACLD newsletter covers clinical advancements and legislative developments affecting learning disabled persons. A bibliography of more than 400 professional and lay publications on learning disabilities is available.

# Association for Persons with Severe Handicaps (TASH) 7010 Roosevelt Way, NE Seattle, WA 98115 (206) 523-8446

Handicapping Conditions Served: Severe physical handicaps and profound mental retardation.

Users Served: Parents, administrators, teachers, medical personnel, researchers, speech pathologists, occupational and physical therapists.

The Organization: Formerly the American Association for the Education of the Severely/Profoundly Handicapped, the organization was founded in 1974 to respond to changes in legislation affecting persons with handicaps as well as to address the need for quality education and services for individuals experiencing severe and profound handicapping conditions. As reflected in the name change, the organization has expanded its range of concerns to include all services to individuals with severe and profound handicaps and is no longer limited to education. An international membership of over 6000 includes parents and professionals. TASH advocates comprehensive, high quality, integrated education and habilitative services; disseminates research findings and practical applications



for education and habilitation; encourages effective use and sharing of experience and expertise; and supports those actively making the promise of quality education and services a reality.

TASH chapters are being chartered at local levels to facilitate increased involvement in local concerns. TASH has chartered or is developing chapters in 33 states. TASH chapters are also located in several Canadian provinces. New TASH chapters are continually being formed. A membership fee is charged.

Information Service: TASH publishes a monthly Newsletter and a quarterly Journal containing articles on new research trends and practices in services to individuals experiencing severe and profound handicapping conditions. Additional publications include four volumes of Teaching the Severely Handicapped, which reports on current research and innovations, and Methods of Instruction with Severely H. adicapped Students. Books, papers, reprints from past issues of the Journal and bibliographies are available on subjects such as vocational training, curricula, and working with families. A bibliography of special interest to parents of children with severe handicaps is available from TASH and includes reference materials on advocacy, recreation, and self-help skills development. Ongoing surveys include those on integrated public schools and parent needs. A publications and price list can be requested. TASH has a parent-to-parent network of communication. By maintaining lists of parents whose children experience severe and profound handicaps and who are involved in local parent support and advocacy groups, TASH is able to put inquirers in touch with parents with similar concerns. TASH also maintains a register of professional contact people who are available for assistance on specific problems of education, training of personnel, etc. Referrals to direct service providers, including schools, clinics and vocational rehabilitation services, are made by letter or phone. TASH also holds an annual conference.

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Handicapping Conditions Served: Mental retardation.

Users Served: Disabled persons, parents, teachers, professionals.

The Organization: The goals of the Association for Retarded Citizens (ARC) are to prevent mental retardation, find cures, assist mentally retarded persons in their daily living, and provide support for their families. ARC's Research and Program Services Department conducts and sponsors projects to improve conditions for persons with mental retardation. Areas of concern include: (1) research studies on prevention and cure; (2) training volunteers who work with mentally retarded persons; (3) developing demonstration models for educational, training, and residential facilities; (4) developing effective advocacy systems; and (5) furthering employment opportunities for mentally retarded persons.

ARC's 1300 state and local units provide a variety of direct services to mentally retarded persons including day care centers, sheltered workshops, preschool programs and transportation services. ARC works on the national, state, and local levels to communicate and interpret the needs of persons with mental retardation to the public and to government agencies.



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Information Services: ARC answers lay and professional inquiries about mental retardation through publications or by letter. The Association maintains a file of professional and lay articles, which it uses to research specific questions or to compile bibliographies. ARC's own publications are extensive and include pamphlets, monographs, books, handbooks and audio-visuals related to parenting, child development, citizen advocacy, civil rights, education, recreation, vocational rehabilitation, progress in research on prevention and cures, prevention methods, and statistics. General pamphlets about mental retardation, Down's Syndrome, and the Association and its activities are also available. The Association piblishes newsletters devoted to local ARC projects, research and legislative activities. It rovides technical assistance through a Bio-engineering Program and On-the-Job Training Program. ARC also provides access to ARCNET, an electronic mail network. A few of ARC's publications are available in Spanish. There is a nominal fee for publications. Information about direct services may be obtained by contacting a state or local ARC unit.

### Association of Birth Defect Children (ABDC) 3526 Emerywood Lane Orlando, FL 32806 (305) 859-2821

Handicapping Conditions Served: Birth defects of all kinds, especially those caused by environmental agents.

Users Served: Disabled persons, parents, teachers, and health care professionals.

The Organization: The Association of Birth Defect Children (ABDC), formerly the Association of Bendectin Children, was established in 1980 to provide information and support to families of children with birth defects of a nongenetic nature, caused by the mother's exposure to drugs, chemicals, radiation, and other environmental agents. Families of children with genetically caused birth defects are not excluded from membership. ABDC is developing a birth defects registry, which contains demographic and medical history data from member families throughout the United States and Canada.

Information Services: The Association's inquiry response service is geared primarily to parents and people in the medical and health related professions. It makes referrals to organizations working with specific birth defects. The Association also publishes a quarterly newsletter.

Asthma & Allergy Foundation of America (AAFA) 1835 K Street, NW Suite P-900 Washington, DC 20006 (202) 293-2950

Handicapping Conditions Served: Asthma and allergic diseases.

Users Served: Disabled persons, parents, teachers, allergists, primary care physicians, nurses, respiratory therapists.

The Organization: The main goal of the Asthma & Allergy Foundation of America (AAFA) is to cure asthma and allergic diseases. In pursuing its goal, AAFA seeks new and more effective controls for these widespread diseases and better health choices for over 35 million



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American children and adults who suffer from these diseases. Programs include support for developing investigators in immunology, postdoctoral clinical training fellowships in allergy and immunology, patient-family education courses and conferences, publications and audiovisual aids, and national awareness programs. Asthma Care Training for Kids (ACT), a self-management education course for children 7-11 and parents is offered by over 50 certified local groups. Health fairs, free community conferences and workshops are presented by the 4 state chapters and 19 local chapters of AAFA. Local volunteers and medical advisors offer support and referral services via the chapters. AAFA also sponsors the Asthma Athlete of the Year competition, awarding six college scholarships from \$1000 to \$10,000 to outstanding high school seniors who excel in academics and athletics.

Information Services: AAFA responds to mail inquiries for general advice and resources. Pamphlets for patients and the public are available on asthma, hay fever, mold allergy, drug allergy, sinusitis, allergy in children, insect allergy, exercise and asthma, and the immune system. The Foundation publishes the bimonthly national newspaper, The Asthma & Allergy ADVANCE; Consumer Information Bulletins, as new facts become available; and the Allergy Encyclopedia, a complete medical guide in paperback. Audio-visual materials include: "Conquering Asthma and Allergies" (15-minute color documentary film about active teenagers with asthma and allergic diseases) and "Running Hard, Breathing Easy" (15-minute color documentary film about asthmatic Olympic sprinter Jeanette Bolden). These films are available to groups on free loan. There is no charge for general information but there is a nominal fee for newspaper subscription and for pamphlets.

#### Blinded Veterans Association (BVA) 1735 DeSales Street, NW Washington, DC 20036 (202) 347-4010

Handicapping Conditions Served: Blindness.

Users Served: Disabled persons, physicians, physical therapists.

The Organization: The Blinded Veterans Association is a membership organization for veterans blinded during or after their military service. Advocacy, assistance, and fellowship are the goals of the organization. Direct services are based on the one-to-one principle that a blind veteran can most effectively motivate another blind veteran. BVA's Field Service Program, partially funded by the Veteran's Administration (VA), is carried out by field representatives, themselves blind, who visit blind veterans who have not been rehabilitated. They recommend rehabilitation centers, offer counseling in the areas of compensation, pensions, schooling, and the use of prosthetic aids and equipment, and counsel the veteran's family. BVA's Outreach Employment Program, partially funded by the Department of Labor, tries to convince employers, through public service advertising and direct contact, to give job opportunities to the blind veteran. BVA representatives assist the blind veteran by contacting prospective employers, and helping him to prepare resumes and jou applications. They also offer counscing in job discrimination cases. BVA has 40 state groups whose volunteer members help to provide the organization's direct services.

Information Services: BVA publishes a bimonthly newsletter, BVA BULLETIN, which is sent free to all blinded veterans for whom current addresses are available, whether or not they are BVA members. It is also sent to many professionals in the field of blindness. A sounds leet version of the BULLETIN is sent to all members and associate members. The newsletter contains news of association activities, legislative developments, human interest



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stories about blind veterans and information about new aids and appliances. Pamphlets describing the BVA and its principal programs are available at no cost.

The Candlelighters Childhood Cancer Foundation 2025 Eye Street, NW Suite 1011 Washington, DC 20006 (202) 659-5136

Handicapping Conditions Served: Childhood/adolescent cancer.

Users Served: Parents, teachers, medical and social professionals who treat children/adolescents with cancer.

The Organization: The Candlelighters Foundation is an international organization of groups of parents who have or have had children with cancer. Believing that "it is better to light one candle than to curse the darkness," the organization works through its more than 225 chapters throughout the world to provide a variety of support services to families with a child cancer patient, including crisis lines, a parent-to-parent buddy system, and self-help groups. Individual chapters offer other services, which vary from group to group. The Foundation helps new chapters form and links existing chapters. Membership in Candlelighters is open to anyone interested in the control and cure of childhood cancer and in meeting the needs of families of children who have cancer, including professionals in the medical and social services fields.

Registered lobbyists at the metropolitan Washington, DC chapter testify at congressional hearings and coordinate the legislative action programs of local parent groups.

Information Services: The Foundation distributes bibliographies in the following areas: childhood cancer in general, materials for parents, and books for children at various age levels covering cancer and dying. An organization and information handbook is available to parents who want to start a new group. Candlelighters also sponsors conferences for parents, publishes a quarterly newsletter and a newsletter for teens, and serves as a clearinghouse on state and federal programs. Newsletters are free; there is a nominal charge for other publications. The Foundation operates on a grant from the National Office of the American Cancer Society, Inc. and tax exempt donations.

Center on Human Policy Syracuse University 406 Huntington Hall Syracuse, NY 13210 (315) 423-3851

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, parents, professionals.

The Organization: The Center on Human Policy is an advocacy and research organization committed to the rights of people with disabilities to integrated educational, vocational, rehabilitative, and residential services. The Center holds local, regional, and national workshops on rights, advocacy strategies, deinstitutionalization, and attitude change towards



disabled students for regular classroom teachers. The Center also offers advice and backup assistance to individual consumers and advocacy groups.

Information Services: Through the Human Policy Press, the Center publishes books, slides, and posters related to advocacy, teaching resources, institutional treatment of disabled persons, and integration. A catalog of publications is available free upon request. The Center provides consumers with information regarding legal rights and strategies for change. It provides consultation to public schools and other agencies on the integration of handicapped persons into the community.

Consumers Organization for the Hearing Impaired, Inc. (COHI) c/o National Association for Hearing and Speech Action 10801 Rockville Pike Rockville, MD 20852 (800) 638-8255

Handicapping Conditions Served: Hearing impairments.

Users Served: Disabled persons.

The Organization: The Consumers Organization for the Hearing Impaired (COHI) was formed in December 1977 by the Washington Area Group for Hard of Hearing and the Organization for Use of the Telephone. Its purpose is to organize the diverse groups of hearing impaired people--workers, students, professionals, homemakers, parents--to act as the national voice of the hard of hearing on consumer issues. One of the immediate objectives of the organization is to assure the presence of amplification systems in such facilities as auditoriums, university classrooms, theaters, movies and meeting rooms in public and private buildings. Long-range goals include promoting: (1) the modification of all public telephones for hearing aid wearers; (2) research in the fields of hearing disorders and hearing aids and devices; and (3) Federal and state financial assistance for rehabilitation services and aids for the hearing impaired.

Information Services: COHI has organizational, membership information and detailed information sheets explaining how consumers can assemble their own personal communications systems, how organizations can establish Assistive Listening Devices Centers and related material, available free upon request.

Cooley's Anemia Foundation, Inc. 105 East 22nd Street Suite 911 New York, NY 10010 (212) 598-0911 (800) 221-3571 (800) 522-7222 (NY)

Handicapping Conditions Served: Cooley's anemia (thalassemia).

Users Served: All interested persons.

The Organization: The Foundation is committed to the eradication of this genetic blood disease which was once thought to occur only in those of Mediterranean heritage, and is



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now found in ethnic groups from 22 other countries. In the fatal form, it is identifiable almost at birth.

The Foundation operates a patient service program and offers medical supplies at no cost which include: drugs, infusion pumps and batteries. They also offer genetic counseling and can direct interested parties to free testing centers. An ongoing public education program alerts the at-risk population to the dangers of Cooley's nemia. The Foundation funds research projects here and abroad and conducts worldwide symposia on the disorder.

Information Services: The Foundation has a variety of printed materials on the disorder and on how to deal with it (films and audio-visuals, and a newsletter). It publishes materials from the symposia it sponsors and articles on the research progress of grant recipients. The Foundation also maintains a speakers' bureau.

### Cornelia de Lange Syndrome Foundation (CdLS Foundation) 60 Dyer Avenue Collingsville, CT 06022 (203) 693-0159

Handicapping Conditions Served: Cornelia deLange syndrome (CdLS).

Users Served: Disabled persons, parents, teachers, anyone interested in CdLS.

The Organization: Established in 1977, the Cornelia deLange Syndrome Foundation's purpose is to increase awareness about CdLS to encourage accurate and early diagnosis and to enable families and professionals to make responsible decisions about planning for present and future care of affected children. CdLS is a collection of specific medical signs and symptoms of unknown cause resulting in mental retardation, distinctive physical characteristics, delayed psychomotor development and feeding and behavior problems. The Foundation serves as a support system for children affected by CdLS and their families. Support for research on CdLS is a continuing focus of the Foundation.

Information Services: The Foundation publishes a directory of parents and interested persons and a pamphlet "Facts About CdLS." Reaching Out, a bimonthly newsletter for families and friends of peop'e with CdLS, reports on Foundation activities, members' research developments and treatment programs. A Spanish translation of the fact sheet is available.

## Council of Citizens with Low Vision (CCLV) 1315 Greenwood Avenue Kalamazoo, MI 49007 (616) 381-9566

Handicapping Conditions Served: Visual impairment.

Users Served: Disabled persons, parents.

The Organization: The Council of Citizens with Low Vision (CCLV) was founded in 1978 to meet the particular needs of partially sighted persons. The basic purpose of the organization is to help partially sighted persons to be more independent and thus less dependent on costly public and private services. Toward that goal, the objectives of CCLV



include: (1) establishing the right of partially sighted persons to fully utilize remaining eyesight through aids, services and technology; (2) providing a mechanism for individual expression of needs, preferences and interests of partially sighted persons; (3) educating the public, professionals and persons with low vision themselves as to their capabilities and special needs; (4) establishing outreach programs to ensure accessibility to services; (5) promoting research in various fields aimed at improving the lives of persons with usable residual vision; and (6) supporting the development of pre-service professional training programs to establish and expand low vision services. The five state chapters and one local chapter of CCLV conduct local programs based on specific needs in their respective areas. In addition to its annual conference with educational programs, CCLV actively promotes relevant legislation, statewide and nationally, and advocates for adequate signs on public facilities. The Council also provides scholarships for professionals who work in the field of low vision. CCLV is an affiliate of the American Council of the Blind (see separate entry).

Information Services: CCLV offers several pamphlets describing the organization and its mission and a bibliography, Understanding Low Vision. A quarterly newsletter reports on resources, new developments, research, chapter news and conferences. Materials are available in large print. A nominal membership fee is charged, which includes the newsletter subscription and a free subscription to the American Council of the Blind's magazine, The Braille Forum. CCLV makes referrals to low vision services in local areas.

Cystic Fibrosis Foundation (CFF) 6000 Executive Boulevard Rockville, MD 20852 (301) 881-9130 (800) FIGHT CF

Handicapping Conditions Served: Cystic fibrosis (CF), chronic disease affecting pulmonary and digestive systems.

Users Served: Disabled persons, parents, teachers, researchers, doctors, nurses, therapists, caregivers.

The Organization: The Foundation was established in 1955 to find the means for prevention, control, and effective treatment of this chronic degenerative disease involving the lungs, digestive organs, and other major organs of the body. Since there is yet no cure or long term control of this most common genetic killer of children, CFF works through its 59 chapters to alert the general public to symptoms of the disease so early diagnosis and treatment may prolong life of victims. The Foundation helps fund 126 treatment centers, and makes grants to scientists, medical centers, and other organizations involved in research. Annual conferences are held for professionals in the field to present current research and to plan future projects and guidelines for treatment. CFF belongs to the International Cystic Fibrosis (Mucoviscidosis) Association which includes organizations from 26 countries. Advocacy and public awareness campaigns are conducted locally as well as nationally; local seminars and meetings for patients and their families are held periodically. Because of progress in diagnosis and treatment, many CF patients are living into adulthood. As a result, there is a widespread growth of young adult groups through which patients share their experiences in coping with the disease.

Information Services: For professionals, publications include a Guide to Diagnosis and Management of Cystic Fibrosis, Medical Information, Guidelines for Health Personnel, and A Teacher's Guide to Cystic Fibrosis. A number of other materials have been prepared for teachers, parents and the general public. News of local group activities as well as articles



dealing with national programs and questions of higher education, marriage and family planning, and vocational training are available in the Foundation's quarterly publication, Commitment. Lists of publications, audio-visual and teaching materials, medical centers, and local chapters are available on request. Most information is available at no cost.

Deaf Communications Institute (DCI) P.O. Box 247 Fayville, MA 01745 (617) 872-9406 (Voice and TDD)

Handicapping Conditions Served: Deafness, hearing impairment, deaf-blindness.

Users Served: Disabled persons, parents, teachers, professionals working with hearing impaired persons, organizations of deaf persons and those serving deaf and hearing-impaired persons.

The Organization: Founded in 1980, Deaf Communications Institute (DCI) is a nonprofit organization for improved communications services for hearing-impaired persons. According to its by-laws, at least 51% of DCI's Board of Directors must be deaf. Through an international electronic mail service for deaf people called DCI Deafnet, the organization serves a group of deaf users, schools with programs for deaf students, and hearing people who have an interest in the deaf community. This service makes use of Telemail, a commercial electronic mail service owned by Telenet, a division of GTE (General Telephone and Electronics Corporation). International Communications Limited provides the administration and management service of DCI Deafnet on GTE Telemail. Services offered by DCI Deafnet include electronic mail communications to individuals or groups of people, bulletin boards accessible to the entire membership which give announcements and news of interest to the deaf community, opportunities to meet others, and a forum for discussion. Electronic mail is a fast and efficient communication method, saving money on direct calls to individual members and convenient for picking up and sending messages, particularly when different time zones are involved.

DCI also operates the <u>DEAF MESSENGER</u> in the Boston community which is an experimental TDD-compatible electronic bulletin board accessed by TDD.

Information Services: Brochures are available describing the DCI organization and services offered. Anyone can join the DCI Deafnet electronic message service on GTE Telemail by completing the application form and paying an annual membership fee. Membership is open to any interested person. Rate sheets are available from International Communications Limited (the billing agent) through DCI Deafnet. Interested individuals can join DCI without joining DCI Deafnet or Telemail.

DCI also provides technical consultation on telecommunications to groups of deaf people and gives testimony at government hearings.



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Deafpride, Inc.
P.O. Box 10176
Washington, DC 20018
(202) 635-2050 (Voice and TDD)
(202) 635-2433 (Voice and TDD)
(202) 636-8330 (Voice and TDD)
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Handicapping Conditions Served: Deafness and hearing impairment.

Users Served: Disabled persons, parents, hospital administrators and staff, other health care professionals.

The Organization: Deafpride, Inc. is a nonprofit organization which works for the human rights of deaf people and their families by bringing together deaf and hearing persons, and providing opportunities for them to develop their potential as advocates. Deafpride assists groups to organize and work for change, in the District of Columbia and throughout the United States. Deafpride offers activities and programs in leadership/advocacy development; family life; bilingual studies/deaf culture; health services access; technical assistance, information and referral; and sign language programs. The organization also provides interpreting services and conducts workshops and in-service training for health services consumers and providers. Deafpride can design programs, conferences or workshops to meet the specific needs of a group or institution and can provide speakers and panelists from the deaf community.

Information Services: Deafpride has produced a brochure describing its services and a booklet on access to medical services for deaf patients. The Advocate is Deafpride's quarterly newsletter which covers news of the organization's activities and projects, conferences, resources, and other items of interest. Deafpride also publishes Perspectives and Options, a collection of position papers, as well as other policy/concept papers. There is a membership charge (includes newsletter subscription) and fees for training sessions, sign language classes and interpreting services.

Disability Rights Center Suite 1124 1346 Connecticut Avenue, NW Washington, DC 20036 (202) 223-3304

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, attorneys.

The Organization: The Disability Rights Center was established in 1976 to advocate for the rights of all disabled persons. At present, the Center is primarily involved in monitoring and seeking ways to strengthen the Federal agencies' affirmative action programs for the employment of disabled persons, as required by Section 501 of the Rehabilitation Act of 1973 and Section 403 of the Vietnam Era Veterans' Readjustment Assistance Act of 1974.

Information Services: The Center disseminates copies of research reports and proposals for change. Research into medical devices resulted in two publications: Medical Devices and Equipment for the Disabled and Consumer Warranty Law: Your Rights and How to Enforce Them. The Center has prepared a guide on how to enforce rights under Section 501 which deals with employment of handicapped individuals in the Federal civil service. It is



primarily for Federal employees and applicants and secondarily for their attorneys. Other publications focus on understanding disability, employment discrimination against disabled persons, a discussion of telethons, and methods for readers to appraise and improve their daily newspapers. A price list for these publications can be obtained from the Center.

# Disability Rights Education and Defense Fund, Inc. (DREDF) 2212 6th Street Berkeley, CA 94710 (415) 644-2555 (Voice) (415) 644-2629 (TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons and their families, organizations concerned with disabled persons, attorneys, legislators.

The Organization: DREDF, founded in 1979, is a national nonprofit organization run primarily by disabled persons to achieve the goals of the disability rights movement. It monitors legislative and educational efforts and conducts training and research programs. DREDF has been very active in the training of disabled persons and their families in the application of their rights under Section 504 of the Rehabilitation Act of 1973. Recently it organized a national effort to prevent deregulation of Section 504. DREDF conducted a study on the educational experiences of disabled females. More than 185,000 disabled women, girls and their parents were contacted to ascertain the level of treatment in education, employment, health, and social services. An executive summary of the study is available free of charge from the above address.

Information Services: DREDF offers concise and up-to-date information on civil rights of disabled persons to attorneys, federal agencies, legislators and their staffs. The <u>Disability Rights Review</u>, the organization's free quarterly newsletter, reports on legislative and judicial activities affecting disability rights. The review is distributed to disabled people, parents, concerned organizations, attorneys and legislators.

#### Disabled American Veterans (DAV) P.O. Box 14301 Cincinnati, OH 45214 (606) 441-7300

Handicapping Conditions Served: Service-connected disabilities of veterans of all wars, as well as special readjustment needs among Vietnam era veterans.

Users Served: Disabled persons, VA health care personnel.

The Organization: The DAV was formed following World War I as a self-help group for veterans with service-connected disabilities. The 1,000,000-member nonprofit association exists solely to serve disabled veterans and their families. There are 51 state departments, 2,760 local chapters and 1850 auxiliary units across the country. The DAV advocates and monitors legislation affecting the entire range of benefits for service-connected disabled veterans, including disability compensation, health care, pension, employment, vocational rehabilitation, death benefits, etc. Expert counseling and claims representation is provided to disabled veterans and their families at no cost by 270 DAV National Service Officers



(NSOs) located in 67 cities in 49 states and Puerto Rico. DAV NSO's act as attorneys-infact, representing clients before the VA, Social Security Administration, Labor Department, HHS, and other government agencies. Since 1973, the DAV has sent Field Service Units to rural and suburban areas to serve veterans and families living some distance from a DAV office. The DAV has several programs aimed at unique problems in specific groups of veterans. These include Veterans of the Vietnam era, aging veterans, Native Americans and incarcerated veterans and others. The DAV provides disaster and emergency relief for disabled veterans and scholarships for children of needy disabled veterans. It also advocates local employment programs and removal of architectural and other barriers to the handicapped.

Information Services: A monthly news magazine covers veterans' benefits, including VA health care and veterans' legislation. It is also available on cassette. General inquiries concerning rights and benefits earned by disabled veterans should be sent to the above address. Requests for assistance with benefit claims should be sent to DAV National Service Department, 807 Maine Avenue, SW, Washington, DC 20024. DAV services are provided at no cost to veterans and their families.

Dysautonomia Foundation 370 Lexington Avenue New York, NY 10017 (212) 889-5222

Handicapping Conditions Served: Familial dysautonomia.

Users Served: Parents, physicians.

The Organization: Established in 1951 by parents of affected children, the Foundation now has 16 chapters in the U.S., Canada, Great Britain and Israel which raise funds for research into dysautonomia and provide information on this genetic disorder to the medical community and patients' families. The condition affects the autonomic (involuntary) nervous system and to a lesser extent the central nervous system, with a variety of symptoms. Confined to children of Eastern European Jewish ancestry, familial dysautonomia is a rare and often misdiagnosed disease; therefore education of pediatricians and parents in early detection and care is a primary concern. The Foundation maintains a Dysautonomia Treatment and Evaluation Center at New York University Medical Center for the benefit of patients and their physicians. A national medical symposium on the disorder is held annually for research scientists, clinicians and health care professionals.

Information Services: A variety of printed material is available without cost, including handbooks on nursing and family care of patients, reprints of articles from both professional and lay publicions, bibliographies, fact sheets and brochures on the disease. Lists of local chapters, schools and camps familiar with the disorder, and names of physicians experienced in treating patients with the disorder can also be requested.



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Dystrophic Epidermolysis Bullosa Research Association of America (D.E.B.R.A.)
Kings County Hospital Center
451 Clarkson Avenue
Building E
6th Floor
Room E6-101
Brooklyn, NY 11203
(718) 774-8700

Handicapping Conditions Served: All forms of epidermolysis bullosa (EB).

Users Served: Parents, physicians, nurses, social workers, geneticists.

The Organization: D.E.B.R.A. was established in 1979 by a small number of parents of children with EB to provide an information and support network for patients and their families. One of D.E.B.R.A.'s primary goals is to encourage and support research into the causes, treatment, and cure of this little understood genetic skin disorder, which leads to localized or widespread blistering. Referrals are made to physicians, surgeons and other affected individuals.

Information Services: The Association responds to inquiries from patients, their families, and the general public, with information packers on the nature of EB, research information, and Association activities. D.E.B.R.A.'s periodic newsletter (samples are free upon request) reports on research findings, local conferences and workshops, and gives practical problem-solving advice for patients and their family members. There is a suggested membership fee, but any donation is acceptable. Most materials are free. The Association assists families in locating local sources of medical, social, and genetic counseling. D.E.B.R.A. maintains files of medical information provided to physicians and other health professionals concerning EB and its treatment, and is in the process of establishing a registry of EB patients. The organization also sponsors seminars and workshops for EB families and health professionals.

Epilepsy Foundation of America (EFA) 4351 Garden City Drive Suite 406 \_\_\_\_\_\_\_ Eandover, MD 20785 (301) 459-3700

Handicapping Conditions Served: Epilepsy and seizure disorders.

Users Served: Disabled persons and their families, teachers, health care professionals.

The Organization: The Epilepsy Foundation of America (EFA) is a national, voluntary organization dedicated to the prevention and control of epilepsy and its consequences, and to helping persons with epilepsy, their families and other concerned individuals overcome the problems associated with this condition. EFA and its 84 affiliated local groups provide a variety of services and programs for the person with epilepsy. EFA sponsors a number of special projects, such as: (1) School Alert, designed to improve school environments for children with epilepsy by providing materials to help students, teachers and other school personnel understand the condition better; (2) National Epilepsy Library and Resource Center, which provides computer access to major medical collections and a wide range of information resources; (3) Training and Placement Service, which provides job training and placement to people with epilepsy in 13 cities; (4) Seed Grant Support and Training,



designed to get promising research projects started and promising young scientists into the field of epilepsy research.

Information Services: EFA provides information on epilepsy and its consequences to any person or group requesting it. Areas include: (1) information on epilepsy for the patient, his family and friends: (2) educational material to individuals and groups dealing with people with scizure disorders; (3) information on employment, including vocational rehabilitation and training, rights, hiring and insurance regulations, special programs, and the particular needs of some people with epilepsy whose seizures are not fully controlled; (4) specific information on the rights of persons with epilepsy as guaranteed by Federal and state statutes; (5) housing information (mostly about discrimination and alternative living arrangements, such as group homes); (6) transportation information, including Federal and state driving regulations; (7) health service information, including prevention, diagnosis, treatment, rehabilitation, and maintenance; (8) information on economic, social and psychological services, such as disability benefits and supplemental security income, recreational services, and individual and group counseling programs: (9) information on the latest research into the causes, treatment and prevention of seizures; and (10) information on Federal and state programs that affect people with epilepsy. Many local affiliates offer similar information services. Some are affiliated with epilepsy clinics or work closely with them. Information on local epilepsy clinics is available from EFA. EFA publishes pamphlets, bibliographies, reprints, books, cassettes, slides, films and a newsletter. The newsletter, National Spokesman, is published ten times per year, covering news and developments in research, legal issues, affiliate activities, national news and self-help. Single copies of literature are provided free; there is a charge for bulk orders and rentals and sales charges for films and audio-visuals. A limited number of brochures have been prepared in braille. A few general brochures are available in Spanish; some affiliates offer materials in other languages as well.

### The Family Survival Project (FSP) 1736 Divisadero Street San Francisco, CA 94115 (415) 921-5400

Handicapping Conditions Served: Adults with chronic brain disorder.

Users Served: Disabled persons, family caregivers, teachers and professionals.

The Organization: The Family Survival Project is a nonprofit organization founded to assist families of adults who have been stricken with chronic or progressive brain disorders (stroke, head injury, Alzheimer's disease, senile dementia, etc.). Its goals include public advocacy for those suffering financial and emotional distress, direct services to families (mostly in California), and the national distribution of information on the care of brain-damaged persons. Through its publications and national conferences, the FSP coordinates and provides specialized training for professionals, primary care givers, and other interested persons to help them understand current research activities and treatment approaches.

Information Services: Information for families and professionals is available on FSP study results, workshop materials, and on adult brain disorders. Information on stroke and Alzheimer's disease is available in Spanish. Available publications include Family Survival Handbook: A Guide to the Financial Legal, and Social Problems of Brain-Damaged Adults, single copies free; and FSP Training Packet: Learning to Survive, for which there is a fee. This packet provides a comprehensive discussion of the various medical, psychological, social, financial, and other factors affecting the brain-damaged person.



Information about new training activities, new publications, and other services is contained in Update, the FSP's quarterly newsletter. The FSP offers training workshops on patient management, diagnosis and treatment, long-term care, legal and financial issues, and other topics upon request on a fee basis.

The Project also maintains a speakers' bureau for media interviews, community groups, public hearings, etc. Technical assistance in establishing support groups, developing programs, and writing social policy is available to groups and organizations on a fee basis.

Foundation for Children with Learning Disabilities (FCLD) P.O. Box 2929
Grand Central Station
New York, NY 10163
(212) 687-7211

Handicapping Conditions Served: Learning disabilities.

Users Served: Disabled persons, parents, teachers, pediatricians, therapists, psychologists, legislators.

The Organization: The Foundation for Children with Learning Disabilities (FCLD), established in 1977, is primarily a public awareness and funding organization. Increased public awareness is accomplished through distribution of Foundation publications and by public service radio and television spots.

The Foundation funds innovative programs in the learning disabilities area which have limited or no access to support from alternative means of funding. Projects which are community based and can serve as demonstration models receive high priority, as do programs that emphasize volunteer involvement. Approximately one million dollars has been given to model programs which help LD children in schools, camps, recreation/day care, museums, and for parent/teacher training. Through recent grants, FCLD has launched national efforts to: (1) encourage public library systems to become resource centers for learning disabled children; and (2) increase public awareness of judiciary and probation personnel, attorneys, and the police about the now established link between undetected learning disabilities and juvenile delinquent behavior.

Information Services: FCLD has two publications which are a public service and available for only postage and handling charges. Their World is an annual magazine which tells real life stories for and about families with learning disabled children. It is the only comprehensive publication for lay persons in the LD field. The FCLD Guide for Parents of Children with Learning Disabilities contains state-by-state listings of schools, institutions and agencies which assist LD children. The Foundation will provide ordering information upon request.

Friedreich's: Ataxia Group in America, Inc. (FAGA) P.O. Box 11116 - - -Oakland, CA 94611 (415) 655-0833

Handicapping Conditions Served: Friedreich's ataxia, and other ataxias.



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Users Served: Disabled persons, teachers, health care professionals.

The Organization: The Friedreich's Ataxia Group in America, Inc. (FAGA) is a nonprofit organization founded in 1969 by people who have this genetic disorder. Friedreich's ataxia is characterized by a slow, progressive loss of function of those parts of the nervous system that control coordination, curvatures of the feet and spine, and heart abnormalities. Diabetes and problems with vision and hearing may also develop. FAGA focuses on the physical and emotional well-being of individuals and their families, support of research into the cause and treatment of FA and education about this disorder. Information and support is provided through 22 state chapters.

Information Services: FAGA publishes a newsletter three times a year to share information about members, chapter activities, research developments, legislation and related topics. The group also publishes a brochure explaining FA. Referrals are made to the Muscular Dystrophy Association, which offers free clinical services for people with FA, including the provision of orthopedic aids. Membership information (no dues) may be obtained by writing to the organization.

Gaucher's Disease Registry (GDR) 4418 E Chapman No. 139 \_\_\_\_\_ Orange, CA 92669 (714) 532-2212

Handicapping Conditions Served: Gaucher's disease (all types).

Users Served: Disabled persons, parents, physicians, geneticists.

The Organization: Gaucher's Disease Registry (GDR) is a self-help group established in 1980 to locate affected persons and to disseminate information about this genetic disease which causes enlargement of the liver and spleen and deterioration of the bones.

Information Services: GDR acts as a clearinghouse of information on research, symptoms, and day-to-day management of the disease. A bimonthly newsletter, Gaucher's Disease Registry Newsletter, is sent to all members and interested persons. It contains material relevant to GD, such as health news, disability aids, research developments and activities of support groups. Fact sheets and general materials are available to anyone requesting information. GDR can make referrals to physicians and genetics clinics.

Gazette International Networking Institute (G.I.N.I.) 4502 Maryland Avenue St. Louis, MO =63108 (314) 361-0475

Handicapping Conditions Served: Physical disabilities.

Users Served: Disabled persons, physicians, physical therapists, occupational therapists, respiratory therapists, social workers, nurses, rehabilitation counselors.



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The Organization: Gazette International Networking Institute (G.I.N.I.) was created in 1983 as an umbrella agency to continue the publication of the Rehabilitation Gazette, an international journal for people with severe disabilities. Other objectives of the organization are to reach, inform, encourage and dignify people with disabilities and to promote a positive attitude toward disabled individuals. G.I.N.I. maintains an international clearinghouse for dissemination of information to disabled individuals and health care professionals, with special emphasis on polio survivors, ventilator-assisted living, spinal cordinjury, adaptive equipment and independent living. Computerization of clearinghouse information is anticipated. G.I.N.I. also convenes international conferences on post-polio problems and independent living which bring together physicians and disabled individuals on an equal basis. Membership is also available in the International Polio Network through G.I.N.I. for an annual fee. Membership includes a subscription to Polio Network News.

Information Services: Annually, G.I.N.I. publishes the Rehabilitation Gazette which is written by individuals with physical disabilities and focuses on independent living for physically disabled persons, especially polio survivors, spinal cord injured, ventilator users and others with neuromuscular diseases and disabilities. The Institute has recently begun a newsletter, to be published quarterly, which covers G.I.N.I. activities, polio support groups and items of interest to ventilator users. Other publications include Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors, Proceedings, 2nd International Post-Polio Conference, 1983, and Proceedings, 3rd International Polio Independent Living Conference, 1985. There is a charge for most publications. G.I.N.I. subscribes to journals in French, Spanish, Japanese, Arabic, German and Portuguese and can provide information in these languages, as necessary.

Referrals are made to individuals with the same disability, physicians, hospitals, agencies, independent living centers, and libraries. The G.I.N.I. library contains case histories which provide evidence that ventilator users can live better and more inexpensively at home.

#### Hemochromatosis Research Foundation, Inc. (HRF) P.O. Box 8569—— Albany, NY 12208 (518) 489-0972

Handicapping Conditions Served: Hemochromatosis (hereditary and acquired).

Users Served: Patients with hemochromatosis and their families, physicians and nurses, blood banks and genetic organizations.

The Organization: Hereditary hemochromatosis (HH) is a genetic disorder in which there is an increased absorption of dietary iron above body needs. Since the body has no way of ridding itself of excess iron once absorbed except by blood loss, iron accumulates in the liver, heart, pancreas and other hormonal glands, and joints causing serious complications and, if undiagnosed and untreated, sometimes early death. Acquired hemochromatosis is secondary to a primary medical condition, such as chronic anemia and chronic liver disease. The goals of the Hemochromatosis Research Foundation, Inc. (HRF) include: (1) increasing the awareness of the public and medical community of HH, its commonality, diagnosis and treatment; (2) encouraging routine use of screening tests by physicians; (3) promoting research aimed at identifying the genetic defect(s) causing the increased iron absorption and at understanding the toxic effects of iron; and (4) soliciting funds for screening, prevalence studies and research. HRF refers patients and families to clinics, hospitals and physicians, as necessary. Chapters of HRF are being formed in about 20 states.



Information Services: HRF has produced booklets for patients and the public on the nature of hemochromatosis, frequency, diagnosis, treatment, etc. and booklets for physicians which include additional information on treatment monitoring and a bibliography of medical journals. Booklets are available in braille through the Library of Congress and the physician's booklet is available in Spanish. A quarterly newsletter, Hemochromatosis Awareness, provides an update on hereditary and acquired iron over-load, through case presentation, articles, news of research developments and a question and answer section. Information is free, but requests for booklets should be accompanied by a self-addressed and 39-cent stamped envelope.

Human Growth Foundation (HGF) 4720 Montgomery Lane Bethesda, MD 20814 (301) 656-7540

Handicapping Conditions Served: Growth retardation.

Users Served: Parents, pediatricians, researchers in the field of growth retardation.

The Organization: The members of the Human Growth Foundation (HGF) are parents of children with severe physical growth problems, and physicians and scientists specializing in the field of growth retardation. The Foundation supports research in endocrinology, and working with the National Pituitary Agency, tries to secure pituitary glands through donor pledges. Pituitary glands are the only source of human growth hormone (HGH), which is often used in the treatment of growth retardation. Twenty local chapters of HGF provide opportunities for parents to share problems associated with their short-statured children.

Information Services: The national and local organizations provide parent and public educational materials about growth problems. Pamphlets on specific growth disorders, such as Turner's syndrome and achondroplasia, are available. Also offered are general brochures on problems in parenting a growth-retarded child, scientific developments, Foundation information, and how to become a pituitary gland donor. HGF makes referrals to physicians who specialize in growth retardation.

Huntington's Disease Foundation of America, Inc. (HDFA) 250 West 57th Street Suite 2016 New York, NY 10107 (212) 757-0443

Handicapping Conditions Served: Huntington's disease (HD).

Users Served: Disabled persons and their families, health care professionals, researchers.

The Organization: HDFA (formerly the Committee to Combat Huntington's Disease) has 25 chapters and 15 branches in addition to a network of support groups. Goals are: identification of HD families; education of the HD family, the general public, and the medical professional, with emphasis on increasing consumer awareness of HD; and a patient services program, coordinated with various community services, to assist families in meeting the social, economic and emotional problems resulting from Huntington's disease. HDFA



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promotes Federal and state legislation for the establishment of clinics, genetic counseling and screening centers, and diagnostic and treatment centers for HD patients.

Information Services: The Foundation maintains a roster of HD families and health care professionals interested in HD, which serves as a unique source of data for the researcher. It also cosponsors and supports workshops. Referral services are available for genetic counseling and other needs. A national hot line operates from 9 a.m. to 5 p.m. weekdays, and crisis intervention services are available at these hours. A wide variety of educational materials and reprints are available from HDFA, some of which are offered at no charge. In addition to a lending library of audio-visual materials designed for the professional and the general public, as well as media materials, it also has a lending library of general and scientific displays. Speakers are available, with advance notice, in areas where chapters are located.

Handicapping Conditions Served: Laryngectomy.

Users Served: Disabled persons and their families, professionals.

The Organization: The International Association of Laryngectomees (IAL) (those whose larynxes have been surgically removed) is a coordinating organization of more than 330 laryngectomee clubs located in the U.S. and abroad. It is financially sponsored by the American Cancer Society (see separate entry). IAL club members are laryngectomees, spouses, speech pathologists and speech therapists who provide rehabilitation (esophogeal speech training), motivation and moral support to newly laryngectomized patients on a volunteer basis.

Information Services: IAL publishes brochures and fact sheets about speech training, speech devices, medical, nursing and family care of the laryngectomee, psychological problems of the laryngectomee, first aid and vocational adjustment problems. Reprints and professional papers are available on similar subjects of interest to the patient, his family and professionals. IAL's major publications include: (1) Annual Directory-which lists member clubs, meeting dates and places, availability of speech instruction, and local sources of supplies--from stoma covers, to artificial larynxes to medical, rehabilitation and teaching films; (2) Laryngectomized Speaker's Source Book, which includes information on cancer of the larynx, problems faced by laryngectomees, speech of the laryngectomee, speaking tips, rehabilitation needs, and information about the IAL; and (3) Registry of Laryngectomized Instructors of Esophogeal Speech.

A quarterly newsletter reports on club activities. All materials may be obtained from ACS national or local offices. IAL refers inquirers to speech therapists, but does not make medical referrals. The IAL holds an annual meeting and a speech institute in conjunction with it.



Joseph P. Kennedy, Jr. Foundation 1350 New York Avenue, NW Suite 500 Washington, DC 20005 (202) 393-1250

Handicapping Conditions Served: Mental retardation.

Users Served: Organizations for mentally retarded persons, universities, and the general public.

The Organization: Established in 1946, the Foundation's purpose is to raise public awareness of medical ethical problems and to improve the quality of life for mentally retarded persons. To these ends the Foundation has funded research and clinical treatment centers at nine universities, instituted two centers for the study of medical ethics at Georgetown University and Harvard, underwritten fellowships in medical and nursing education for postgraduate study of medical ethics, and developed recreational programs including internships, family play programs, and the international Special Olympics Program for mentally retarded persons. Proposals for innovative demonstration models from agencies or individuals are considered for funding. Extensive public awareness campaigns are carried on through the media to improve understanding and acceptance at this population.

Information Services: Brochures describing the Special Olympics Program, the Let's Play to Grow Program for families, and the Community of Caring Program for adolescent mothers are available from the Foundation office. Films on the Special Olympics are available for TV or group use. Another group of films produced for education of health and other professionals includes such titles as "The Right to Survive," "The Right to Let Die," "The Right to Reproduce," and "Becky: The Value of a Life." There is a small rental or purchase fee charged for films; other information is free.

Junior National Association of the Deaf (Jr. NAD) 445 N. Pennsylvania Suite 804 Indianapolis, IN 46204 (317) 638–1715 (Voice and TDD)

Handicapping Conditions Served: Deafness

Users Served: Deaf Students.

The Organization: Established in 1960 to develop leaders among young deaf students, Jr. NAD has 90 chapters in schools and programs at secondary and post-secondary levels throughout the country. Local and regional conferences are sponsored annually, while the national conference is sponsored biennially. Summer camp programs for students 8-13 and 14-19 are held every year. Awards for achievement in athletics, scholarship, writing, art and citizenship are given to encourage leadership skills. Membership dues are \$5.00 per year.

Information Services: The <u>Jr. NAD Newsletter</u> is published monthly January through May. Brochures on summer camp and the Jr. NAD are available from the national office.



### Juvenile Diabetes Foundation International (JDF/JDFI) 60 Madison Avenue New York, NY 10010 (212) 889-757

Handicapping Conditions Served: Diabetes mellitus.

Users Served: Disabled persons, parents, teachers, and researchers.

The Organization: This organization's primary objective is to support and fund research on the treatment and cure of diabetes, mainly juvenile diabetes (also called insulin-dependent diabetes), which has its usual onset from infancy to the late thirties. JDF International awards grants and fellowships for specific research projects in diabetes and related areas. It sponsors national media campaigns to inform the public about diabetes and raise funds for research. Its 149 local chapters provide parent to parent counseling and their families. JDF International a so has eight international affiliates.

Information Services: The Organization publishes free pamphlets and fact sheets about diabetes and insulin for the lay person. They include such titles as: What You Should Know About Juvenile Diabetes; Parent to Parent; Babies with Diabetes; Juvenile Diabetes Isn't Just for Kids: Having Children... A Guide for the Diabetic Woman; and What You Should Know About Insulin. A newsletter, Diabetes Countdown, is published for members. Local chapters hold public education meetings, maintain speaker bureaus, and provide referral to medical specialists and educational programs offered by hospitals and health departments. Some chapters have an information hot line.

Leukemia Society of America 733 Third Avenua New York, NY 30017 (212) 573-8484

Handicapping Conditions Served: Leukemia, the lymphomas, multiple myeloma, and Hodgkin's disease.

Users Served: Disatted persons, parents, physicians, nurses, social workers.

The Organization: The objectives of the Leukemia Society of America are 10 find cures for leukemia, the lymphomas, multiple myeloma, and Hodgkir's disease, and to provide supplementary financial assistance to persons afflicted with those diseases. Research funds are provided to individuals investigating aspects of leukemia and related diseases. The Society's 57 chapters administer patient aid programs, whereby outpatients can receive up to \$750 per year for drugs, radiation treatments, transfusions of blood and certain blood components with related services, and transportation.

Information Services: The Society publishes pamphlets about leukemia, Hodgkin's disease, myelomas and the lymphomas. Some information is available in Spanish. Audio-visual materials on what leukemia is and how persons may be affected by it are available to schools and community groups. Video and audio tapes from symposia are available to the professional. They deal with therapy and treatment of leukemia and virology, immunology and differentiation. For the professional, chapters also offer symposia in conjunction with local medical facilities which emphasize new developments in treatment and maintenance.



The Society sponsors a national symposium delivered by leading specialists every year. As a service to the professional and academic community, the Society maintains a bibliography of research conducted by other organizations and has a library of books and journals on leukemia and related diseases. The Society refers inquirers to leukemia centers throughout the world, and chapters provide information on possible sources of local financial aid. A bimonthly newsletter, Society News, reports on activities of the organization.

Little People of America (LPA) Box 633 San Bruno, CA 94066 (415) 589-0695

Handicapping Conditions Served: Dwarfism.

Users Served: Disabled persons, parents, professionals.

The Organization: Little People of America (LPA) was established in 1957 as a nationwide organization for dwarfs and their families to provide fellowship, the interchange of ideas, solutions to the problems unique to the little person, and moral support. A special membership division provides opportunities for information exchange and group support to parents of dwarfed children. Twelve district directors coordinate local activities, regional and local meetings and informal gatherings sponsored by over 30 local chapters throughout the country. LPA conducts national meetings annually. LPA works closely with adoption agencies throughout the U.S., attempting to place dwarfed children in the homes of dwarfed parents. In 1968, LPA established a foundation to raise funds for vocational training of little people and medical and scientific research on the causes and possible treatment of dwarfism.

Information Services: In addition to a bimonthly organizational newsletter, <u>LP Today</u>, <u>LPA</u> distributes printed material on equipment and aids, clothing, and social and vocational adjustment. Some brochures are available in Spanish. <u>My Child is a Dwarf</u> is a pamphlet of special interest to parents. Materials are free to members; there is a mailing charge for nonmembers. <u>LPA's medical board is used as a referral network to respond to medically-related inquiries; general inquiries are sent to district directors for responses.</u>

Lowe's Syndrome Association (LSA) 222 Lincoln Street West Lafayette, IN 47906 (317) 743-3634

Handicapping Conditions Served: Love's syndrome.

Users Serves: Parents and family members, physicians, physical, occupational and vision therapists, genetic counselors, social service professionals.

The Organization: Established in 1983, the Lowe's Syndrome Association (LSA) is an international, voluntary, nonprofit organization composed of parents, medical and educational professionals, friends, relatives and others interested in Lowe's syndrome. This rare genetic condition affects males and results in multiple handicaps, including congenital cataracts, glaucoma, intellectual impairment, poor muscle tone, kidney problems and others.



The goals of the LSA are to: foster communication among affected families, provide medical and educational information, promote a better understanding of this condition and the potential of individuals affected by it, and encourage research.

Information Services: The LSA provides pamphlets about Lowe's syndrome and the Association and a publications list to anyone who inquires. The organization also publishes a newsletter, On the Beam, which is sent to all members three times per year. The newsletter contains letters from parents and pictures of their children, medical and educational articles, recommended resources, news of the association and other items of interest. A membership fee is charged, which includes a subscription to the newsletter.

The LSA will refer parents and medical professionals to doctors who are experienced with Lowe's syndrome.

Lupus Foundation of America, Inc. 4434 Covington Highway Decatur, GA 30035 (404) 289-7453 (800) 558-0121

Handicapping Conditions Served: Systemic lupus erythemotosus.

Users Served: Disabled persons, parents, teachers, professionals.

The Organization: Incorporated in 1977, the Lupus Foundation of America is a federation of 16 state chapters, 78 local chapters, 138 affiliates and 3 foreign associates. Chapters and affiliates vary in size and scope of activities; some offer educational programs to nursing schools, hospital staffs and other organizations, while others fund fellowships and research grants to physicians who specialize in treatment of lupus. Many chapters conduct monthly cpen meetings with physicians, and publish newsletters and articles to alert physicians as well as the public to the symptoms of this often misdiagnosed disease.

Information Services: Bibliographies for professionals and patients, article reprints, and pamphlets explaining the disease are available. Some information is free; a nominal charge is made for selected pamphlets and books. Information is available in French and Spanish and the book The Sun is My Enemy is translated into Chinese. The Kansas City Chapter has a great deal of material in braille, available on request. <u>LUPUS NEWS</u>, a national paper, is published quarterly and includes information about the disease, research developments, and more. All of the large and most small chapters also publish papers six to ten times per year, focusing on information of local concern in addition to the broader topics of medical and research news. The national office has a list of physicians in foreign countries who treat lupus. Many local chapters and affiliates also maintain such lists for their area. Information and lists of local chapters may be requested from the Foundation.

Mainstream, Inc. 1200 15th Street, NW Washington, DC 2005 (202) 833-1136 ( ce and TDD)

Handicapping Conditions Served: All handicaps.



Users Served: Disabled persons, EEO officers, personnel managers, disability service providers.

The Organization: Mainstream, Inc. is a national nonprofit organization founded in 1975. Its purpose is to increase employment opportunities for disabled people by working with employers and the handicapped community to develop cost-effective solutions to problems inherent in the mainstreaming-into-the-workplace process. Mainstream offers information services and technical assistance on a consulting basis, in areas such as the design of affirmative action plans, development of in-house attitude and awareness training programs and evaluation of community-based recruiting sources. Mainstream has conducted numerous regional conferences to train its audience of employers, disabled people, educators, government officials and rehabilitation specialists on a variety of topics, including job analysis, reasonable accommodation, physical accessibility, legal concerns and interviewing and recruiting techniques. Since 1983, Mainstream has operated Project LINK, a national job development and placement model. LINK matches qualified applicants with available jobs in Washington, DC and Dallas, TX. These project sites serve as centralized applicant referral sources for employers.

Information Services: Mainstream has produced and disseminated many publications, including pamphlets on specific disabilities, medical standards in employment, insurance and section 503. Most information is available on cassette. A bimonthly newsletter, In the Mainstream, reports on programs, methods, organizations and resources effective in mainstreaming disabled people into the workplace in addition to analyses of relevant legislative, administrative and judicial activities. The Mainstream Information Network responds to inquiries on all handicap employment issues. Mainstream had also produced a manual for company trainers, Successful Mainstreaming of Disabled People into the Workplace. Publications and services can be purchased individually or on an annual subscription basis.

### March of Dimes Birth Defects Foundation (MOD) 1275 Mamaroneck Avenue White Plains, NY 10605 (914) 428-7100

Handicapping Conditions Served: Congenital defects and genetic disorders.

Users Served: Disabled persons, parents, teachers, and physicians.

The Organization: To achieve its goals of preventing birth defects, the March of Dimes Birth Defects Foundation funds programs in basic and clinical research (including environmental reproductive hazards), medical services, professional and public education, and community services. Medical services have funded 85 clinical centers in the U.S. which practice genetic medicine and punseling. Satellite clinics provide genetic services for areas with limited medical resources. The MOD funds facilities providing intensive care services for sick newborns and follow-up studies of these infants after discharge. Emphasis now is being placed on early diagnosis and treatment of pregnant women with high risk conditions. Outreach clinics are being started in communities where prenatal care is unavailable.

Information Services: The March of Dimes funds programs through schools, churches, hospitals and other institutions to inform and motivate prospective parents and the general public to do all they can to protect maternal and newborn health. Materials include

educational series, curricula, filmstrips, printed materials, films, documentaries for television, and public service announcements.

Through its Professional Education Publications Program, the March of Dimes transmits the latest scientific findings--in original articles and journal reprints--on birth defects to schools of medicine and nursing, university hospitals, medical centers, physicians, nurses and other health professionals. Also included in the publications program are: (1) the International Directory of Genetic Services, a listing of medical centers that provide genetic counseling and analyses of special genetic conditions; (2) the Birth Defects Atlas and Compendium, which standardizes names and descriptions of 1,005 congenital anomalies, in four languages; and (3) Genetics in Practice, a quarterly newsletter for health professionals.

The MOD serves as a clearinghouse for the exchange of incidence data generated in birth defect monitoring programs in 14 countries.

Mental Health Law Project (MHLP) 2021 L Street, NW Suite 800 Washington, DC 20036-4909 (202) 467-5730

Handicapping Conditions Served: Mental and emotional disorders and developmental disabilities.

Users Served: Attorneys, disability organizations (parent/professional/client groups).

The Organization: Formed in 1972 as a nonprofit public organization, the Project is dedicated to law reform advocacy on behalf of people labeled mentally or developmentally disabled. Test case litigation is used to define, establish, and implement the rights of such persons. Landmark judicial decisions are followed with policy advocacy at the Federal level. Priority issues are preventing neglect and abuse of institutionalized mentally disabled people and generating adequate health and mental health care, education, housing, vocational and supportive services for mentally disabled people living in the community. MHLP also devotes some resources to protecting the civil rights of persons subject to civil commitment or procedures (e.g. ECT, psychotropic drugs). Regional training conferences on mental disability law have been cosponsored with the Practicing Law Institute. Advice on legal strategies for clients appearing before administrative agencies and legislative bodies is available; when appropriate, MHLP will represent protection and advocacy organizations before Federal agencies.

Information Services: MHLP offers backup assistance to attorneys and other advocates representing mentally handicapped clients. These services include model pleadings, legal citations and technical references, discussion of strategies, and comments on pleadings, draft legislation/regulations, assistance in using experts, provision of articles, memoranda, bibliographies, etc. In answer to inquiries from professionals and other interested persons, MHLP supplies general information about legal rights and makes referrals to attorneys. Publications include Legal Rights of Mentally Disabled Persons, a three volume course book which includes technical information about mental health and retardation issues, case law and legal analysis; and other books and reprints of articles by staff attorneys. MHLP's UPDATE is a bimonthly newsletter which offers a succinct overview of federal legislative, administrative and judicial developments affecting mentally disabled people. It is sent without charge to nonprofit organizations actively representing mentally disabled people. MHLP's ALERT is a newsletter published occasionally to cover emerging issues which affect



mentally disabled people, sent to all who request inclusion on the mailing list. Also published biennially is the MHLP <u>Summary of inclusion</u> which reports on current litigation and issues of concern. A nominal fee for duplication and mailing costs is charged for legal papers, bibliographies and other information.

Muscular Dystrophy Association (MDA) 810 Seventh Avenue New York, NY 10019 (212) 586-0808

Handicapping Conditions Served: Muscular dystrophy and related neuromuscular disorders.

Users Served: Individuals with neuromuscular diseases and their families.

The Organization: The Muscular Dystrophy Association (MDA) supports research into 40 neuromuscular disorders. It also provides medical care and other direct services to people with neuromuscular disorders through its 240 clinics and some 170 local chapters. MDA clinics provide diagnosis, physical therapy, medical care and counseling. Upon prescription, MDA chapters provide payment for services including: physical, occupational, and respiratory therapies; orthopedic equipment; respiratory equipment; transportation; and fiu shots. The chapters also sponsor recreational activities, such as summer camps, picnics, and outings. Some chapters organize self-help groups for people with neuromuscular diseases.

Information Services: MDA publishes brochures and audio-visual materials about neuromuscular diseases. Its quarterly magazine covers progress in research, legislation, and various MDA supported programs. Publications are free and available from MDA's national office or its chapters, many of which publish additional informative materials. Local chapters hold patient seminars which focus on available community, financial, educational, and psychological programs. They also hold professional seminars on diagnosis, clinical management, and research.

Myasthenia Gravis (MG) Foundation 7-11 South Broadway Suite 304 White Plains, NY 10601 (914) 328-1717

Handicapping Conditions Served: Myasthenia gravis.

Users Served: MG patients and family members, medical and scientific personnel.

The Organization: The Myasthenia Gravis (MG) Foundation is dedicated to the detection, treatment, and search for a cure of MG. In an effort to prevent misdiagnosis, promote public awareness and early detection, and publicize current treatment modalities, the Myasthenia Gravis Foundation offers educational materials to professionals and the public. Research grants and fellowships are awarded annually to medical students and physicians. The Foundation also sponsors annual scientific meetings and quinquennial international symposia for physicians and researchers; proceedings of the symposia (major state-of-the-art documents) are published and distributed to the medical community. Nationwide chapters and branches of the Foundation provide patient meetings, pill banks, hot lines, newsletters, and information and referral services.

Information Services: Direct inquiries are answered and referrals made by the local chapters as well as the Foundation headquarters. Counseling, pamphlets, and information on low-cost drug banks and recent research are available from the chapters. Publications for the patient and general public include Myasthenia Gravis—the Disease and a Case History, Facts About Myasthenia Gravis for Patients and Families, and MG and the MG Foundation. A medical emergency ID card is also available. Slide/sound presentations are loaned by chapters to groups for showings. Materials for medical professionals are available in English or Spanish editions and include a Manual on diagnosis and management for physicians and a companion Manual for nurses.

National Alliance for the Mentally III (National AMI) 1901 N. Ft. Myer Drive #500 Arlington, VA 22209 (703) 524-7600

Handicapping Conditions Served: Mental illness.

Users Served: Disabled persons and their families.

The Organization: The National Alliance for the Mentally III (National AMI) was founded in 1979 at a conference of independent self-help organizations concerned with severe and chronic mentally ill individuals both in institutions and in community-based settings. The organization promotes public education on mental illness; consumer advocacy at the local, state and national levels to enact new and remedial legislation and funding to provide and strengthen services and programs for the chronic mentally ill; and research in the neurosciences and clinical sciences to discover new breakthroughs, understand causes, and help ameliorate mental illnesses. National AMI promotes quality treatment, rehabilitation and support services, and encourages mental health professionals to be more responsive to the chronic mentally ill and their families. Its affiliates offer emotional support, case management, practical guidance, psychosocial rehabilitation, socialization, and employment services. Some affiliates maintain libraries.

Information Services: The national office coordinates and disseminates information and materials to affiliates. Membership applications are available from National AMI. A bimonthly newsletter is published.

Handicapping Conditions Served: Amputation.

Users Served: Amputees.

The Organization: The National Amputation Foundation (NAF) was established to help the amputee adjust to his/her handicap by encouraging integration into the general community. To this end, NAF offers: volunteer assistance to new amputees in hospitals; monthly social meetings focusing on topics of concern to the amputee, such as legal rights, benefits, and



employment; and training in the use of prosthetics. NAF operates its own prosthetic center for the manufacture and repair of artificial limbs.

Information Services: NAF provides information on veterans' benefits and refers the amputee to possible sources of financial aid, legal assistance, and employment services. The Foundation has a reference library on amputation and materials are available for loan to any interested person. A monthly newsletter, The AMP, covers the highlights of NAF meetings.

National Association for Hearing and Speech Action (NAHSA)
10801 Rockville Pike
Rockville, MD 20852
(301) 897-8682 (Voice and TDD)
(30) 638-8255 (Voice and TDD)

Handicapping Conditions Served: Speech, language and hearing impairments.

Users Served: Disabled persons, parents, teachers, physicians, speech-language pathologists, audiologists.

The Organization: The National Association for Hearing and Speech Action is a membership organization of individuals with speech, hearing and language disorders, their families and interested professionals. NAHSA is primarily concerned with advocacy for the rights of the communicatively impaired and with public information activities. Its most recent effort has been a campaign of public service announcements to alert consumers about the need for early identification of communication problems and services available within their states.

Information Services: A Hearing and Speech HELPLINE (800-638-8255) has been set up to handle specific questions about communication problems and how to find professional assistance. The Association distributes organizational brochures and information on communication disorders. NAHSA also publishes a bimonthly newsletter NAHSA News. Some information is available in Spanish.

National Association for Sickle Cell Disease, Inc. (NASCD) 4221 Wilshire Boulevard Suite 360 Los Angeles, CA 90010 (213) 936-7205 (800) 421-8453

Handicapping Conditions Served: Sickle cell disease (including sickle cell anemia, hemoglobin C, and thalassemia).

Users Served: Disabled persons, parents, teachers, physicians, nurses, social workers, students.

The Organization: The National Association for Sickle Cell Disease (NASCD) is an organization of 86 community sickle cell programs located throughout the U.S. and Canada. The national office has an extensive public and professional education program about sickle cell disease, its variants, and sickle cell trait. The Organization provides leadership on a



national level to create awareness in all circles of the negative impact of sickle cell anemia on the health, economic, social and educational well-being of the individual and his/her family, and to create awareness of the requirements for resolution of the problem.

NASCD provides technical assistance to its affiliates and to groups interested in setting up community sickle cell programs. Affiliates conduct a variety of services, depending on the particular needs of the communities they serve. Services may include: sickle cell screening, counseling to parents who possess the sickle cell trait and to patients with sickle cell disease, blood banks, tutoring, vocational rehabilitation, transportation services, babysitting, etc. The national office and its affiliates provide training to genetic counselors in how to counsel persons with sickle cell trait.

Information Services: NASCD's information is directed to lay persons, physicians and other professionals, and sickle cell program administrators and volunteers. Lay materials include fact sheets, audio-visuals, color prints and brochures about sickle cell trait and anemia, thalassemia and hemoglobin C. A Home Study Kit for Families includes printed materials, cassettes, games and other learning devices to help parents and other family members cope with the problems of the child or the family members. Professional materials include reprints of articles for pediatricians and genetic counselors, and a variety of manuals on the establishment of sickle cell programs, laboratory procedures for detection of the disease, and guidelines for legislation. NASCD's scientific advisory board contributes news on the latest research developments in sickle cell disease to the organization's newsletter, Sickle Cell News, published quarterly. Materials are available to all persons for a nominal fee and/or free of charge.

National Association for Visually Handicapped (NAVH) 305 East 24th Street 17-C New York, NY 10010 (212) 889-3141

Handicapping Conditions Served: Partial vision.

Users Served: Disabled persons, parents, teachers, professionals, busir as.

The Organization: The National Association for Visually Handicap. (NAVH provides information, referral and direct services. The latter include: (1) printing a service in tributing large print textbooks, educational testing materials, and books for pressure in ling; (2) offering a free loan library of large print books; (3) displaying a veriety of visual aids, some available through NAVH and some through commercial sources; (4) serving as advocate for partially seeing individuals to Federal, state, and local gover, ment agencies; (5) offering youth group programs and adult discussion programs in San Francisco, and adult discussion programs in New York; (6) offering counsel and guidance to adults with partial vision and their families, to families of children with partial vision, and to all professional and paraprofessionals who work with partially seeing persons.

Information Services: NAVH acts as a clearinghouse of information for all services available to partially seeing persons from Federal, state, and local government agencies and from private sources. NAVH publishes materials, not available elsewhere, concerning the problems encountered by partially seeing persons. The organization publishes two newsletters in large print, one for children and one for adults. The national office provides information and referral services to any inquirer outside of the 11 Western States (a San



Francisco Office serves those states). Information on commercially available large print reading material and various visual aids is also disseminated. Most information is provided in large print. Most printed materials are free of charge, although a nominal contribution is requested for some items.

National Association of Patients on Hemodialysis and Transplantation (NAPHT) 150 Nassau Street New York, NY 10038 (212) 619-2727

Handicapping Conditions Served: Kidney diseases.

Users Served: Kidney patients.

The Organization: The National Association of Patients on Hemodialysis and Transplantation is primarily a patient organization with approximately 10,000 members and 30 local chapters. Its purposes are: to inform the public and the patient about kidney disease; to stimulate public awareness of the need for kidney donors; to act as a consumer advocacy group at the Federal and local levels; and to provide a source of moral support to the kidney patient. The chapters function as mutual support groups; activities vary among them, but often include educational meetings with professional speakers, self-help meetings, hospital visitations to new kidney patients, group outings, and community awareness programs. NAPHT is working with vocational rehabilitation specialists to develop specific programs for the kidney patient.

Information Services: The national office supplies information about kidney diseases, treatments and patient rights issues. Publications include free pamphlets, such as Living With Renal Failure. Renal Failure and Diabetes, and a salt-potassium counter. State Renal Programs provides information about benefits available from state agencies. RENALIFE is a quarterly magazine which features exercise and diet suggestions, travel tips and reports on medical developments for the renal patient.

National Association of the Deaf (NAD) 814 Thayer Avenue Silver Spring, MD 20910 (301) 587-1788 (Voice and TDD)

Handicapping Conditions Served: Deafness hearing impairment.

Users Served: Disabled persons, teachers health processionals.

The Organization: The National Association of the Deaf (NAD) is a consume oriented organization for professionals and lay persons. It recommends and promotes legislation on behalf of deaf people in areas of education, rehabilitation, legal rights for the provision of interpreters, and captioned television. It was a consumer sponsors a training program to upgrade instructional skills of tenenes of fight language, develops appropriate curriculum and instructional materials of tenenes, and conducts a professional evaluation and certification program for instructors in a ricus sign systems. NAD servens and evaluates general entertainment motion nice tenenes and evaluates general entertainment motion nice tenenes.



by the Conference of Educational Administrators Serving the Deaf under contract with the Department of Education. NAD has 50 state affiliates.

Information Services: NAD has information on where to find programs and services for the deaf, including: schools, camps, interpreters, homes for the aged deaf, devices to assist deaf persons, hearing-ear dogs, and individual professional providers from medical specialists to speech therapists. NAD compiled statistical information about the deaf in a 1974 National Census of the Deaf. Information regarding legislation and legal rights of the deaf is also available.

The organization offers a series of workshops (most held at its biennial conference, but some offered at local meetings nationwide) for professionals and lay persons on such topics as legal concerns of the deaf, orientation to deafness, leadership training for deaf persons, and need for and implementation of mental health services for the deaf. A wide variety of books, audio-visual materials, and merchandise (stationery, bumper stickers, etc.) relating to deafness and sign language is available for sale from the NAD Publishing Division. NAD publishes three periodicals for general audiences: The Deaf American, a quarterly magazine highlighting the achievements of deaf individuals; The Broadcaster, a monthly newspaper covering legislative and legal issues; and The Interstate, a newsletter focusing on state issues and news. General information is available free from the organization. NAD has an extensive library of more than 15,000 books and other materials related to deafness. Any interested person may have access to the NAD collection.

National Ataxia Foundation (NAF) 600 Twelve Oaks Center 15500 Wayzata Boulevard Wayzata, MN 55391 (612) 473-7666

Handicapping Conditions Served: Hereditary ataxia and related conditions.

Users Served: Disabled persons, parents, health care professionals.

The Organization: The Foundation was established in 1957 to serve patients, identify persons at risk, educate the public and the medical community, and stimulate research. Eleven chapters throughout the country offer genetic counseling and moral support to affected families, make referrals to medical and other direct service providers, and raise funds for research grants. Semiannual free clinics are offered in Minneapolis and elsewhere in the country where diagnosis and other information services are available from professionals experienced in work with this neurological disorder.

Information Services: Free booklets, brochures, and fact sheets are available on hereditary ataxia, spastic paraplegia, Charcot-Marie-Tooth disease, hereditary tremor, and Friedreich's ataxia. A quarterly newsletter, Generations, contains reports on NAF activities, chapters, research, advice for patients and information on additional resources. It is free to members. Also available is a 22-minute slide/tape presentation on hereditary ataxia. Membership information and special publications for physicians may also be requested.

National Council on Alcoholism, Inc. (NCA)
12 West 21st Street
7th Floor
New York, NY 10010
(212) 206-6770

Handicapping Conditions Served: Alceholism.

Users Served: Disabled persons, parents, teachers, physicians, law enforcement personnel, TV and radio researchers.

The Organization: The National Council on Alcoholism, Inc. (NCA) is a voluntary health agency founded to combat the disease of alcoholism and to fight the stigma associated with this treatable disease. NCA's major areas of activity are prevention and education, public policy advocacy, publications, community services and public information programs. NCA conducts the National Alcoholism Forum, which brings together volunteers and professionals in the field. Each of NCA's 184 affiliates has its own volunteer Board of Directors and operates within the general policies of NCA. The National Council maintains a public policy office in Washington, DC.

Information Services: The Council stocks and distributes more than 200 books and pamphlets related to alcoholism, including titles of interest to clergy, courts, families, youth and women, as well as pamphlets by Alcoholics Anonymous. A number of these materials are available in Spanish editions. There is a nominal charge for most pamphlets and books.

National Council On Stuttering (NCOS) P.O. Box 8171 Grand Rapids, MI 49508 (616) 241-2372

Handicapping Conditions Served: Stuttering.

Users Served: Disabled persons.

The Organization: The National Council on Stuttering was established to help form local stuttering councils nationwide. There are ten local member councils in the United States, self-help groups which offer stutterers opportunities to share and learn in an atmosphere of understanding and fellowship.

Information Services: NCOS provides materials and suggestions to any group of stutterers interested in starting a local council. It refers stutterers to local self-help groups, and to local accredited therapy services. NCOS, in conjunction with the Speech Foundation of America, has produced a number of films on stuttering, self-help, and prevention of stuttering in children. These films are available on a loan or rental basis from the distributor, Seven Oaks Productions, 9145 Sligo Creek Parkway, Silver Springs, MD 20901, (301) 587-0330. NCOS publishes a quarterly journal covering local council news, informe ion, and articles of interest on stuttering.



National Council on the Aging, Inc. (NCOA) 600 Maryland Avenue, SW West Wing 100 Washington, DC 20024 (202) 479-1200

Handicapping Conditions Served: The aging population, including the aging disabled.

Users Served: All those who work with or are concerned about older people.

The Organization: The National Council on the Aging (NCOA), founded in 1950, is a national nonprofit membership organization for professionals and volunteers, and is involved in all matters affecting the quality of life of older persons. NCOA conducts research, undertakes demonstration programs, sets standards, and promotes the development of a continuum of opportunities and services for aging people, coordinating efforts with profit and nonprofit organizations. Its regional offices are located in New York City, San Francisco, and Los Angeles. NCOA's membership includes individuals, voluntary agencies and associations, business organizations, and labor unions.

Information Services: Principally through its seven constituent units, affiliation with which is open to all NCOA members, the Council provides technical assistance, consultation, and information dissemination. All of these program units serve as resources and respond to inquiries in their area of concern. Each publishes a newsletter as a means of giving technical assistance to members. Several of the programs are described below.

National Voluntary Organizations for Independent Living for the Aging (NVOILA), composed of more than 200 national voluntary, professional, service and for-profit organizations, works to promote self determination and independent living for older persons NVOILA's recently published Directory of National Voluntary Organizations describes the efforts, resources and direct services of member groups. Other NVOILA publications include Continuum of Services: Long-Term Care of the ging (1980), an annotated bibliography; and Long-Term Care for the Elderly: A Voluntary Sector Perspective (1981), a report of NVOILA's 1981 White House Conference on Aging Task Force, which defines the components of a continuum-of-services system and discusses key issues of planning and implementing a comprehensive system. While membership in NVOILA is open only to national organizations (an exception to the Council's policy regarding membership in constituent organizations), its newsletter is free to any interested person upon request.

The National Institute on Adult Daycare (NI/D) advocates daycare as a viable option in community-based services for disabled older persons. The Institute includes in the concept of adult daycare the following: day treatment, day health care, and partial hospitalization. NIAD makes available a brochure on adult daycare, and numerous NCOA publications.

The National Institute of Senior Centers (NISC) provides assistance to senior centers and to organizations and communities seeking to develop new centers or to expand existing services. NISC's publications include Senior Centers and the At-Risk Older Person (1980), which reports on the proceedings of a seminar covering needs identification, informal support networks, attitudes, and policy and funding; The Senior Center: A Partner in the Community Care System (1981), a package of technical assistance materials for senior center leaders and community planners; and a brochure on multi-purpose senior centers.

Two recently established programs meet needs in special areas: the National Center on Rural Aging, which advocates for older persons who live in rural areas, and the National Institute of Senior Housing, which is concerned with planning, developing, financing, and managing specially designed housing for independent older persons.



The National Institute of Community-Based Long-Term Care offers a long overdue focal point for all long-term care planners and practitioners. Representing the entire spectrum of public and private agencies serving older persons, this unit encourages a coordinated approach to long-term care at home and in the community. NCOA publishes Perspective on Aging, a bimonthly magazine, which examines the most important issues, programs, and new developments in all areas of gerontology plus features, special reports, regular columns and book reviews concerned with the field of aging. Also available is Current Literature on Aging, an annotated bibliography of the most recent books, articles and periodicals in gerontology. Other bibliographies can be requested on adult daycare; leisure, recreation, culture and aging; education for older adults; volunteerism; and age, work and retirement. In all, NCOA has approximately 140 different books, training materials and specialized bibliographies on all aspects of aging.

A complete list of NCOA programs and constituent units and a catalog of publications are available upon request. In addition, the Council's ibrary of materials on all aspects of aging is open to the public.

National Down Syndrome Congress (NDSC) 1640 W. Roosevelt Road Chicago, IL 60608 (312) 226-0416 (In Illinois) (800) 446-3835 (Outside illinois)

Handicapping Conditions Served: Down syndrome.

Users Served: Disabled persons, parents, teachers, health care professionals.

The Organization: Formed in 1973 by a group of parents and professionals interested in Down syndrome, the NDSC now has more than 500 chapters of volunteers in the United States and around the world. These members share their experiences with other parents and professionals, promoting parent support and public awareness of Down syndrome. An annual convention and various publications keep the membership informed of medical, legislative and educational developments. Services provided by NDSC include: adoption facilitation, advocacy for adolescents and adults with Down syndrome (including their own annual convention), educational guidelines for pre-school and elementary school, textediting, research monitoring and extended family support. NDSC is governed by a 21-member board of directors which is representative of the U.S. geographically, as well as representative of a variety of ages and functional levels of children with Down syndrome.

Information Services: Parents are put in touch with a family support network. NDSC publishes membership brochures, a pamphlet for the lay person on Down syndrome in English, Spanish and Portuguese; Guidelines for Choosing the Preschool or Primary School for Your Child with Down Syndrome; and product availability fliers. A bibliography of materials relating to Down syndrome is being updated. The Congress publishes two newsletters. The Down Syndrome News, published ten times yearly and available only to members, covers pertinent issues covering all aspects of Down syndrome. The Parent Group Bulletin is published as apprepriate when pertinent parent group information is collected and serves as an immediate communication link with persons touched by Down syndrome. NDSC provides resource information on all aspects of Down syndrome, including very technical areas, and makes referrals to local parent groups or professionals. The Congress charges a membership fee (includes newsletter) and there is a nominal charge for other materials.

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National Down Syndrome Society (NDSS) 141 Fifth Avenue New York, NY 10010 (212) 460-9330 (800) 221-4602

Handicapping Conditions Served: Down syndrome.

Users Served: Parents, teachers, physicians, nurses, and physical therapists.

The Organization: The National Down Syndrome Society (NDSS) was established in 1979 to promote better understanding of Down Syndrome and the potential of the individual with Down syndrome. Major goals are to promote basic and applied research in fields related to Down syndrome and to provide information and services to families, professionals and interested persons.

Information Services: NDSS concentrates on disseminating information to new parents of infants with Down syndrome and the professionals who deal with them. NDSS has produced a public information packet including a booklet entitled This Baby Needs You Even More, a bibliography of current reading materials and fact sheets. The booklet and fact sheets are available in Spanish. A list of parent groups and early intervention programs in each state is also available. In addition, a 25-minute video-cassette about the Down syndrome child age 0-6, entitled "Gifts of Love," is offered on a free-loan basis. A newsletter, NDSS Update, is published twice a year. The Directory of Programs and Services for Children with Down Syndrome Ages 0-6, is free to individuals and contains listings of programs, services, and age groups served on a national basis. A materials fee is charged for bulk orders. A 24-hour 800 hot line is available to answer questions and provide referrals to resources.

National Easter Seal Society 2023 West Ogden Availae Chicago, IL 60612 (312) 243-8400 (312) 243-8880 (TDD) (800) 221-6827 (Cails Outside Illinois)

Handicapping Conditions Served: All disabilities.

Users Served: Disabled persons, parents, teachers, allied health personnel, general public.

The Organization: The Society is the nation's largest and oldest (1919) voluntary health agency providing direct rehabilitation services to persons with disabilities. Over 800 member groups, organized on a state and local basis, provide programs which include comprehensive medical or vocational rehabilitation facilities, recreation, housing, transportation, equipment loans, public education, advocacy and other services for the prevention and treatment of disabling conditions.

The National Society, acting as headquarters for the federation of local and state organizations, conducts national public awareness and fund-raising campaigns, disseminates information and sponsors research projects for the treatment and management of disabilities.



Information Services: A bimonthly interdisciplinary journal, Rehabilitation Literature, which has been published for the past 26 years, contains original articles, book reviews, and the current professional literature. The Society has compiled bibliographies from the entries in the journal in subject areas of interest to rehabilitation personnel, persons with disabilities and their families, and Easter Seal staff and volunteers. The Society also publishes the National Easter Seal Communicator for Easter Seal volunteers (3 times per year) and Computer-Disability News for people with disabilities, computer industry officials and rehabilitation professionals (quarterly).

The National Easter Seal Society publishes a variety of books, pamphlets and reprints for professionals, parents and persons with disabilities. Its catalog lists publications related to: (1) awareness, (2) attitudes, (3) computers and rehabilitation, (4) dental care, (5) disabiling conditions, (6) independent living, (7) prevention, (8) psychological aspects of disability, (9) recreation and camping, (10) rehabilitation administration and (11) volunteers. Some material is available in Spanish. For additional information about publications, contact the Publications Department. There is a nominal charge for publications or a small fee for postage and handling only.

The Society provides a full range of automation services for Easter Seal affiliates, and to agencies serving persons with disabilities, through Easter Seal Systems. Available custom software systems include Medical Rehabilitation, Vocational, Early Childhood, and Camping and Recreation, Fund Accounting, Clinic Billing, and Fund-Falsing.

National Federation of the Blind (NFB) 1800 Johnson Street Baltimore, MD: 21230 (301) 659-9314

Handicapping Conditions Served: Blindness.

Users Served: Disabled persons, parents, teachers, professionals.

The Organization: The National Federation of the Blind (NFB) is a membership organization with 51 state and 400 local chapters. NFB keeps up with Federal and state legislation affecting the blind and state services for the blind. It acts as a legislative resource for its chapters and represents the needs of blind people through advocacy and representation in discrimination cases. It attempts to arouse public awareness of the potential and accomplishments of the blind through public service messages. State and local chapters are active in developing local projects to improve conditions for the blind in areas such as mass transit, employment, and library services. Members contact newly blinded persons to help them with problems of adjustment.

Information Services: NFB conducts seminars on services available to the blind and what the law provides for in each state. Its National Blindness Information Center will attempt to answer any questions about blindness and the rights of the blind by phone or mail. More than 50 publications are available from NFB; some are free. NFB publishes a monthly magazine, The Braille Monitor (available in print, disc, and braille), which reports on problems, progress, activities, and new technologies related to blindness. State and local chapters refer inquirers to appropriate direct service providers.



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#### National Foundation for Ectodermal Dysplasias 108 North First Street Suite 311 Mascoutah, IL 62258 (618) 566-2020

Handicapping Continues Served: Persons affected by any of the ectodermal dysplasia syndromes.

Users Served: Parents, professionals.

The Organization: Ectodermal dysplasias are genetic birth defects, the best known of which is Christ-Siemens-Touraine's syndrome or hypohydrotic ectodermal dysplasia. All of these conditions involve at least two abnormalities of derivatives of the skin. Symptoms may include lack of sweat glands, skin olis, hair, tears, and mucous membranes. There are often severe dental problems. There is no known test to determine the genetic carriers of these conditions. The foundation was formed to locate families encountering difficulties with an ED patient and to provide them with whatever support and information may be required. Educational materials and programs are provided to the medical communication and syndrome identification are currently being conducted in conjunction with major research facilities. Annual family conferences provide information, support, and social interaction. A treatment fund has been organized to provide financial assistance.

Information Services: The Foundation presently responds to all inquiries from families of persons with ED or their dentists or doctors. A variety of publications is available from the foundation including a monthly newsletter, A Family Guide to Ectodermal Dysplasias and Charley: The Story of a Child, a family's diary of experience with their son who has ED. Most publications are free or available for a nominal charge. Audio-visual aids are also available on a short-term loan with returnable deposit.

National Fraternal Society of the Deaf (NFSD) 1300 W. Northwest Highway Mt. Prospect, IL 60056 (312) 392-9282 (Voice) (312) 392-1409 (TDD)

Handicapping Conditions Served: Deafness and hearing impairments.

Users Served: Disabled persons, parents.

The Organization: Organized and administered by deaf people, the organization was originally founded to provide life insurance coverage for deaf people who were denied coverage by established companies. Membership, which entails purchase of insurance, is open to all hearing-impaired persons, their relatives and others involved in the field of deafness-between the ages of 0 and 60. NFSD advocates the rights of deaf people to drive and obtain auto insurance and works to eliminate discrimination in employment, education, and legal proceedings. The organization also awards scholastic and athletic achievement, and sponsors local and national social activities.

Information Services: A field force of trained representatives exists to offer detailed information and explanation of a variety of insurance investments and estate planning to deaf and hearing-impaired persons. Information is provided in sign language. Consumer



education is also conducted through chapters in 36 states and Canada and 106 local divisions and through the bimonthly magazine, The Frat, which carries news of the Society's insurance, social, and advocacy activities. The national office maintains an extensive library collection of monographs and pamphlets relating to deafness, which is available to any person or group for reference or research.

National Genetics Found on, Inc. (NGF) 555 West 57th Street New York, NY 10019 (212) 586-5900

Handicapping Conditions Served: All genetic disorders.

Users Served: Physicians and the public.

The Organization: The National Genetics Foundation (NGF) is a nonprofit health agency dedicated to reducing the burden of genetic disease among Americans. NGF was cited by the National Academic of Sciences in 1975 as a model for health delivery.

Information Services. NGF's primary objective is the advancement of medical genetics into health delivery systems of the U.S. As a service to the public, the National Genetics Foundation provides a computerized analysis of an individual's personal family health history through a Family Health Profile questionnaire. The purpose is to pinpoint health problems important to the person. The report of the analysis is sent to the individual's chysician whose name and address must be listed on the form. There is a charge for each form and analysis to help defray the cost of service, handling and mailing.

The Foundation operates a nationwide network clearinghouse staffed by genetic counselors who provide referral to university-based genetic centers for individuals and families who have, or suspect they may have, an inherited disorder. Phone: (212) 586-5800.

#### National Head Injury Foundation P.O. Box 567 Framingham, MA 01701 (617) 879-7473

Handicapping Conditions Served: Traumatic head injuries.

Users Served: Disabled persons, parents, teachers, physicians, psychologists, social workers, rehabilitation counselors, nurses, therapists.

The Organization: Founded in 1980 by families of head-injured people and professionals with an interest in the treatment of this condition, the National Head Injury Foundation assists head-injured persons and their families to seek out needed resources and services. The Foundation facilitates the formation of family emotional support groups, which exist in many locations throughout the country. Chapters of the Foundation are found in 23 states, and are in the process of forming in 7 states. There are also 350 support groups around the country. The Foundation is also concerned with obtaining financial support for patients and the establishment of specialized rehabilitation programs.



Information Services: The Foundation disseminates information on resources and facilities for acute, intermediate, and long term care, and the rights of head injured persons. This service is available to head-injured persons and their families and professionals who work with them. The Foundation publishes a newsletter quarterly. Bibliographies are available on general head trauma information, coma and rehabilitation, family and pediatric issues, prevention, and general information sources. The Foundation also publishes the National Directory of Head Injury Rehabilitation Services, a listing of over 350 facilities and programs that meet the needs of those who have sustained head injuries. There is a nominal charge for written materials and audio-visuals. One publication, What is a Head Injury?, is available in Spanish.

The National Hemophilia Foundation (NHF)
The Soho Building
110 Greene Street
Room 406
New York, NY 10012
(212) 219-8180

Handicapping Conditions Served: Hemophilia, clotting factor deficiencies.

Users Served: Disabled persons and their families, health care professionals, teachers, social workers.

The Organization: The objective of The National Hemophilia Foundation (NHF) and its 48 chapters is to provide programs of research, professional education and training, public education and patient and community services to foster its overall goal of providing a better quality of life for individuals with hemophilia and related bleeding disorders. Chapters provide varying direct services. Some are comprehensive care treatment centers; some are affiliated with treatment centers. Most chapters sponsor scholarships and "camperships" to youths with hemophilia.

Information Services: The NHF provices wide array of educational materials. Publications include general information on hemophilia for patients and their families, such as sources of possible financial assistance and medical care, educational information for employers and schools, and a variety of technical literature on care and treatment. Some professival materials are devoted to specialty areas such as dentistry, orthopedics, surgery, and physical therapy. NHF also provides newsletters, study reports, conference proceedings, bibliographies, and service directories, e.g., the Directory of Hemophilia Treatment Centers. The NHF has compiled a cumulative list of health educational materials related to hemophilia, published by pharmaceutical companies, blood banking organizations, and government agencies. The pamphlet, Your Child and Hemophilia, is available in Spanish. Order forms for all publications can be requested through local chapters.

NHF chapters refer persons with hemophilia and their families to appropriate direct care facilities and to possible sources of financial assistance.

National Huntington's Disease Association (NHDA) 1182 Broadway Suite 402 New York, NY 10001 (212) 684-2781

Handicapping Conditions Served: Huntington's disease (HD).

Users Served: Disabled persons, parents, physicians, physical therapists, social workers.

The Organization: Organized in 1976 by families, professionals, and citizens concerned with HD, the Association now has 17 c. apters and branches and 34 area representatives. The Association offers postdoctoral fellowships in HD and related disorders. NHDA offers patients and families support services and referrals to local facilities and resources for assistance. Public awareness is another important activity of the Association, which works to remove the stigma that has for centuries surrounded victims. HD patients often exhibit symptoms of chorea (dance-like muscular spasms) and pronounced personality charge. The Association also supports medical research by fund raising and collection of autopsy brain tissue for scientists who are working on HD.

Information Services: Brochures explaining the inheritance and effects of the disease, a manual for medical professionals, a manual for social workers and psychologists who wish to lead support groups for HD family members, a booklet on clinical care (for physicians), reprints of articles about HD and the Association, and a list of local chapters and representatives are available on request, along with membership information and a quarterly newsletter. Referrals can also be made to local medical and nursing home facilities.

National Kidney Foundation (NKF) Two Park Avenue ----New York, NY:: 10016 (212) 889-2210

Handicapping Conditions Served: Genitourinary disorders, chronic renal malfunction.

Users Served: Disabled persons. physicians, nurses, technicians, dieticians.

The Organization: Since 1950, the National Kidney Foundation (NKF) has been seeking the total answer to diseases of the kidney and urinary tract - prevention, treatment and cure-through research, patient services, nationwide organ donor programs, professional education and public information. The Organ Donor Program works through 50 affiliates to gather kidneys and other organs for transplant. Support of blood banks for dialysis patients, administration of detection and screening programs, and staffing of information and referral offices along with advocacy and public information activities are among the activities of Foundation affiliates and 200 local chapters. NKF sponsors symposia, conferences and meetings for medical and allied health professionals. Education of professionals is provided by five Councils of the Foundation: Clinical Nephrology, Dialysis and Transplantation, Nephrology Social Workers, Renal Nutrition, Urology and Nephrology Nurses and Technicians.



Information Services: Affiliates and local chapters provide counseling and referrals to local resources for patients and their families. The Foundation provides a number of brochares for patients and families covering general information on kidney and urinary tract disorders, specific diseases, treatment options, diet and rehabilitation. Sample titles are: What Everyone Should Know About Kidneys, Your Kidneys and How to Detect Kidney Disease, and High Blood Pressure and Your Kidneys. Some information is available in Spanish. Publications include a bimonthly newsletter containing up-to-date information on research, legislation, programs and services and learning opportunities; The Kidney, a bimonthly scientific report on single topics of current research and clinical developments in kidney disease; and The American Journal of Kidney Diseases, a monthly journal focusing on human renal and urogenital function in health and disease primarily for physicians and researchers. Audio-visuals are available on the physiology of the kidney, chronic renal failure, treatment and organ donation. Materials are free to patients; a nominal fee is charged for health care professionals.

The National Marfan Foundation (NMF) 54 Irma Avenue Port Washington, NY 11050 (516) 883-8712

Handicapping Conditions Served: Marfan syndrome.

Users Served: Disabled persons and their families, health care professionals.

The Organization: The National Marfan Foundation is an organization founded in 1982 to meet the needs and interests of individuals with the Marfan syndrome. The syndrome is a genetic disorder of the connective tissue that affects many organ systems, including the skeleton, the lungs, the eyes and the heart and blood vessels. While difficult to diagnose, it is estimated that over 20,000 people in the U.S. have the Marfan syndrome.

The National Marfan Foundation has a threefold purpose: (1) to provide accurate and timely information about this condition to patients, family members and physicians; (2) to provide a means for patients and relatives to share experiences, to support one another, and to improve their medical care; and (3) to support and foster research. The NMF is working to provide grants to research scientists in support of their investigations into the causes and treatment of the Marfan syndrome. Fund raising for research and patient service is a major activity. The Foundation is composed of over 10 chapters and community groups across the country.

Information Services: NMF publishes a variety of materials for patients, the public and professionals. Single copies of printed materials are available free from the national office; there is a charge for bulk orders. Publications include The Marfan Syndrome, which provides a comprehensive description of the condition, and How John Was Unique, a picture-coloring book for children with the condition. Fact sheets on the syndrome and NMF are also available. A bimonthly newsletter, Connective Issues, is free to members. Audio-visuals from the NMF biennial meeting and a TV interview show featuring two persons affected by the Marfan syndrome are offered for loan or purchase. Additional materials, including articles, are available upon request.



#### National Mental Health Association (NMHA) 1021 Prince Street Alexandria, VA 22314-2971 (703) 684-7722

Handicapping Conditions Served: Mental and emotional disorders.

Users Served: Disabled persons and their families, professionals.

The Organization: Formerly the National Association for Mental Health, the NMHA adopted it present name in 1976. Primarily an advocacy and public education organization, NMHA and its 650 local chapters work for legislation affecting the rights and treatment of the mentally ill. On occasion it will engage in litigation, where a test case seems warranted, on such issues as regulation of electroconvulsive therapy, patients' rights to refuse drugs, or rights to counsel during commitment hearings. NMHA works for improved community-based treatment facilities to replace outmoded state hospitals, and it carries on public awareness campaigns to effect changes in neighborhood and business community attitudes toward recovered mental patients.

Information Services: An extensive publications list includes such titles for patient and family as Helping the Mental Patient at Home, and What Every Child Needs for Good Mental Health. Of interest to the general public are such publications as How to Deal With Your Tensions, Depression: What You Should Know About It, and When Things Go Wrong, What Can You Do? Information on services, insurance, research, employment, legislation and litigation, careers in mental health, rehabilitation, and citizen activism is also available, as well as NMHA position statements on topics ranging from psychosurgery to the insanity defense. A monthly newsletter, Focus, informs members of news in the mental health field. Films and other educational materials are available for one-day rentals; a catalog will be sent on request. Inquiries and referrals for direct service are handled by local affiliates.

National Multiple Sclerosis Society 205 East 42nd Street New York, NY 10017 (212) 986-3240

Handicapping Conditions Served: Multiple Sclerosis and related diseases.

Users Served: Disabled persons and their families, health care professionals, general public.

The Organization: The National Sclerosis Society provides funding for research, public and professional education, advocacy and the design of rehabilitative and psychosocial programs. Direct services to MS persons are provided through 151 local chapters and branches. A Washington office is active in advocacy for federal legislation affecting MS persons and NIH research funding. Among the programs offered by chapters are a variety of counseling and referral services; many offer group aquatics and other social/recreational support activities. Sixty-seven clinical diagnostic and treatment centers are supported by local chapters in 30 states. The Society is a member of the International Federation of Multiple Sclerosis Societies.

Information Services: Publications for the general public include such pamphlet titles as What Everyone Should Know About Multiple Sclerosis and Living with MS: A Practical Guide. Books entitled Research on Multiple Sclerosis, Maximizing Your Health: A Program of Graded Exercises and Meditation for Persons with Multiple Sclerosis and Therapeutic



Claims in Multiple Sclerosis are also available. Patient information includes pamphlets on mental and emotional health, careers for the homebound and <u>Inside MS</u>, a quarterly membership periodical. Some information is available in Spanish. Professionals may request publications on treatment, nursing care, group counseling, and reprints of journal articles. Referrals, information on technical aids and equipment, and order lists for free publications can be obtained from chapters.

#### National Network of Learning Disabled Adults (NNLDA) P.O. Box 716 Bryn Mawr, PA 19010 (215) 275-7211

Handicapping Conditions Served: Learning disabilities.

Users Served: Disabled persons.

The Organization: The National Netwo k of Learning Disabled Adults (NNLDA) is an organization formed to provide support, assistance and information to learning disabled adults and self-help groups for learning disabled adults nationwide. NNLDA encourages advocacy and provides an informal communication network among members, which it plans to formalize in the future. In addition, NNLDA works to educate the public about learning disabilities and about the abilities of those who have LD. Assistance is provided to LD adults in locating appropriate services. NNLDA has three state chapters.

Information Services: NNLDA publishes a descriptive brochure about the organization. The NNLDA lewsletter, published four times per year, reports on educational programs and resources, legislation, government policies, employment and training opportunities, organizational news and other items of interest. LAUNCH, a member organization, offers a video tape for sale about LD adults. NNLDA provides speakers for organizations and conferences. The Network maintains an electronic bulletin board entitled LD ADULT on Special Net (see National Association of State Directors of Special Education, separate entry) to disseminate information about issues of concern to LD adults. There is no charge for information or services.

National Neurofibromatosis Foundation (NNFF) 141 Fifth Avenue Suite 7-S \_\_\_\_\_\_\_ New York, \$\frac{1}{2}\$\tag{212}\tag{212}\tag{25}

Handicapping Conditions Served: Neurofibromatosis (Von Recklinghausen's disease).

Users Served: Disabled persons, parents, health care professionals.

The Organization: Neurofibromatosis (NF) is an inherited neurological disorder which can affect all areas of the nervous system and the skin. Symptoms of the disorder usually begin in childhood or adolescence when multiple benign tumors appear on the brain, spinal cord and skin; the nerves controlling vision and hearing are often affected. The Foundation was established in 1978 to provide information to NF-affected individuals and their families, physicians, and other professionals and to promote and support scientific research on the cause, prevention and treatment of NF. The Foundation's activities include public



awareness campaigns, conferences on NF for professionals and to tay public, and, through 19 state chapters, support groups for members. It recently consoned along with the New York Academy of Sciences an international Conference on Neurofibromate which hought together a distinguished group of physicians and scientists to focus on the order NNFF also awards research grants and fellowships. NNFF members include ted more interested persons.

Information Services: NNFF publishes a brochure entitled Neurofibrematosis: 'aformation for Patients and Families, a quarterly newsletter, and a research newsletter for professionals. The Foundation assists individuals affected by NF and their fit illies in finding medical, social and genetic counseling. A patient brochure in Spanish is being prepared.

National Organization on Disability (N.O.D.) 2100 Pennsylvania Avenue, NW Suite 234 Washington, DC 20037 (202) 293-5960 (202) 293-5968 (TDD)

Handicapping Conditions Served: All hand caps.

Users Served: Disabled persons, parents, teachers, community-level administrators, national organizations, employers.

The Organization: The privately funded National Organization on Disability, successor organization to the U.S. Council for the International Year of Disabled Persons, works to support community-based efforts to improve the lives of disabled people. Emphasis is placed on the concept of partnership between able-bodied and disabled individuals in developing cooperative programs. The N.O.D. encourages organizations, corporations and others to support local efforts, and offers technical assistance to the growing number of participating communities. To date, there are 50 state chapters and approximately 1700 local chapters. N.O.D. The National Organization sponsors annual programs for Community Partners and National Partner Organizations at which it awards cash prizes for progress made at these levels toward integrating citizens with disabilities into community life.

Information Services: In conjunction with the National Technical Institute for the Deaf, the N.O.D. publishes Organizing Community Partnership Programs, a 30-page guide which discusses community goal-setting, dealing with the media, fund raising, working with elected officials and more. The N.O.D. also publishes a quarterly REPORT which highlights the organization's program activities and current disability trends. REPORT is available to the general public. UPDATE, a bimonthly newsletter is targeted to community partner groups and highlights replicable community projects and available resources. N.O.D. has a clearinghouse which also stores this information. Limited assistance can be provided to individual inquiries. All information is available on cassette tapes.



National Retinitis Pigmentosa Foundation (RP Foundation Fighting Blindness) 1401 Mt. Royal Avenue Fourth Floor Baltimore, MD 21217 (301) 225-9400 (301) 225-9409 (TDD) (800) 638-2300 (Outside Maryland)

Handicapping Conditions Served: Blindness and visual impairments, caused by inherited retinal degenerative diseases.

Users Served: Disabled persons, parents, teachers, rehabilitation workers, ophthalmologists, optometrists, geneticists, mobility specialists, psychologists.

The Organization: The National Retinitis Pigmentosa Foundation funds research in retinitis pigmentosa (RP) and other retinal degenerative diseases. It funds 13 research centers in the U.S. and England, each involved in different but coordinated areas of investigation into retinal degenerative diseases. The RP Foundation maintains a national confidential registry of RP affected persons for statistical and clinical research. In addition the Foundation has initiated an RP Retina Donor Program to assist the researchers' efforts. The organization's 60 affiliates are involved in a variety of activities including information and referral, experience sharing, and fund raising. Furthermore, the National RP Foundation is a part of the International Retinitis Pigmentosa Association, a coalition of 17 countries which coordinate research on a world wide basis.

Information Services: Volunteer Information Resource Centers (VIRC) plus the chapters provide referral services to rehabilitation, psychological, medical, genetic, and vocational counseling agencies. The RP Foundation publishes several fact sheets, an annual report and a quarterly newsletter for the lay reader. The newsletter is available on cassede and one brochure is available in Spanish. There is no charge for single copies of all materials. The RP Foundation holds regional and national educational workshops for volunteers and professionals, where leading speakers in the field of RP are featured.

National Reye's Syndrome Foundation (NRSF) 426 North Lewis Bryan, OH 43506 (419) 636-2679

Handicapping Conditions Served: Reye's syndrome.

Users Served: Physicians, general public.

The Organization: Formed in 1974, NRSF, a nonprofit organization, has grown to over 140 chapters in 41 states. It promotes awareness of Reye's syndrome, which strikes children from infancy to about 19 years of age, most commonly after a viral illness such as flu or chicken pox. If not diagnosed and treated in its early stages, Reye's syndrome can lead to brain damage ranging from light to severe. NRSF provides funds for basic research on the disease, and support and guidance to families of stricken children.

Information Services: NRSF disseminates literature to the lay community and the medical profession, such as brochures, awareness bulletin and emergency room posters. A brochure and an awareness bulletin are available in Spanish; an awareness bulletin can be requested



in Vietnamese. An audio-visual slide/tape on Reye's syndrome is available for the general public. Two additional programs for in-service hospital training sessions are technical in nature and designed for members of the health profession. There is a nominal charge for large quantities of brochures. NRSF publishes the annual <u>Journal of the National Reve's Syndrome Foundation</u> and a biannual newsletter, <u>In The News</u>. The Foundation compiles statistics and data on Reye's syndrome.

The National Society for Children and Adults with Autism (NSAC)
1234 Massachusetts Avenue, NW Suite 1017
Washington, DC 20005-4599
(202) 783-0125

Handicapping Conditions Served: Autism.

Users Served: Parents, teachers, professionals.

The Organization: NSAC, The National Society for Children and Adults with Autism, is an organization of parents, teachers, professionals and interested people who work for legislation, education, and research for the benefit of all children with severe disorders of communication and behavior. Advocacy on the national, state, and local levels, particularly in the area of education, is a primary function of the organization. The 190 local chapters of NSAC support various direct services, such as recreational programs and group homes (residences for 8 to 12 children).

Information Services: The organization publishes general pamphlets defining autism and suggesting management techniques. NSAC's Information and Referral Service, located at the above address, has specific information available, including: (1) names, addresses, and other information above addresses, and other information above addresses, and residential programs and camps which admit children with autism; (2) a facilities which admit autistic adolescents and adults; (3) ways to effectively organize to get community services for children with autism; (4) legislative information at national and state levels; (5) suggestions for sources of funds, public and private; (6) a list of colleges and universities which offer training in the field of autism; (7) income tax information for parents; (8) a list of contacts and societies for children with autism in other countries. The service also keeps an informal list of research projects being conducted in the area of autism.

NSAC publishes a bimonthly newsletter, The Advocate, an advocacy publication geared toward parents and professionals who work with autistic children. NSAC also publishes the annual Proceedings of Society National Conferences, which includes professional papers on a variety of subjects related to autism. Books about autism for the professional and lay reader are selected and distributed by NSAC's bookstore. These include NSAC publications such as How They Grow: A Handbook for Parents of Young Children with Autism and Critical Issues in Educating Autistic Children and Youth, produced in cooperation with the Office of Special Education Programs, U.S. Department of Education.



### National Society to Prevent Blindness (NSPB) 79 Madison Avenue - New York, NY 10016 (212) 684-3505

Handicapping Conditions Served: Prevention of blindness and visual impairments.

Users Served: Parents, teachers, doctors, nurses, and safety professionals.

The Organization: This organization, founded in 1908, works to prevent blindness by sponsoring community screening and testing programs, public and professional education, and research. Community programs, carried on through 26 affiliated volunteer state agencies, concentrate on health education and free screening for the public. These programs aim to detect, control, correct, or prevent glaucoma and cataract blindness; eye problems in children; eye accidents; and blindness caused by hereditary and congenital conditions, diabetes, and macular degeneration. NSPB works for the implementation of laws for eye protection in hazardous environments. It funds research in eye care and disease prevention.

Information Services: NSPB provides answers to specific questions about eye diseases, eye safety, vision defects, and eye checkups when queried by mail. It publishes brochures and pamphlets on various subjects, such as glaucoma, cataracts, sunglasses, and TV and the eyes, providing single copies of most materials at no charge. NSPB publishes a newsletter, three times a year and a quarterly magazine. Low-cost curriculum aids for teachers are also available. A complete catalog of NSPB publications and films may be obtained by writing to NSPB, enclosing a stamped, self-addressed, business sized envelope.

National Spinal Cord Injury Association 149 California Street Neuton, MA 02158 (617) 964-0521

Handicapping Conditions Served: Spinal cord injuries caused by trauma and disease.

Users Served: Disabled persons and their families, physicians, nurses, therapists, social workers, rehabilitation counselors.

The Organization: Founded by the Paralyzed Veterans of America in 1948, the National Paraplegia Foundation in 1979 merged with the New England Spinal Cord Injury Foundation and adopted the present name. Dedicated to programs of research and services. the Association works through its 30 chapters to develop comprehensive systems of quality care for paraplegics and quadriplegics. Care is offered as a direct service by some chapters which give individual case consultations and advise on case management of the newly injured. Other chapters make referrals to direct service providers. All chapters emphasize personal contact between persons with spinal cord injuries and involve them in all aspects of activities. Cure is the goal of the research division which offers fellowships to neuroscientists who are working in the field of repair or regeneration of the spinal cord. Regional seminars and an annual conference give professionals, constituents, and other interested persons an opportunity to exchange and compare new developments in technological, environmental, and medical research. Coping with the disability is facilitated by peer counseling; public awareness; and environmental barrier removal. Some chapters sponsor independent living rehabilitation programs and more of these are being developed for the severely disabled (quadriplegic).



Information Services: The Association functions as a clearinghouse of information for medical and other health care workers. Information on independent living rehabilitation programs, self-help devices, equipment, transportation, employment, education, personal care, and referrals is available from the national office and through chapters. Individual case consultations and case management advice can also be requested; contacts can be arranged for person-to-person assistance and peer counseling, if appropriate. Publications include Spinal Cord Injury Life, a timonthly newsletter; regional and national resource directories; and handbooks on nursing, personal care, and nutrition. Interested persons may also request bibliographies of current and relevant research. In general, there is no charge for services or publications to persons with spinal cord injuries; there is a min.mal charge to others for some publications.

National Stroke Association (NSA) 1420 Ogden Street Denver, CO 80218 (303) 839-1992

Handicapping Conditions Served: Disabilities related to stroke.

Users Served: Stroke survivors and their families, physicians, nurses, physical, occupational and speech therapists, other rehabilitation professionals, rehabilitation centers and community stroke organizations.

The Organization: NSA is the only national organization focusing its efforts solely on cerebral vascular accidents (CVAs or strokes). Its goal is the reduction of stroke incidence and the provision of a strong, visible, nation-wide education, information and referral service for stroke survivors, their families, health professionals and the lay community. NSA also maintains a research program focused on the prevention, treatment and rehabilitation of stroke. The program is guided by the NSA Scientific Advisory Committee, which is composed of nationally recognized, stroke-knowledgeable medical professionals. The NASA was founded in 1984 and its first state chapter office will open in 1986.

Information Services: This Association publishes a quarterly newsletter, Open Channels, as a tool for exchanging stroke-related experiences and other information. All NSA members receive this publication, which contains articles from practitioners, researchers, stroke survivors and their families. The NSA also publishes a series of educational materials entitled Be Stroke Smart. A stroke recovery guide, The Road Back, is available as of December, 1985.

The NSA's clearinghouse is collecting a manage of stroke information and data on available services. The clearinghouse is loping a Stroke Resource Catalog and is collecting audio-visual materials for loan to interested groups. In addition, inquirers are referred to local services and support groups when appropriate.

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#### National Stuttering Project (NSP) 1269 7th Avenue San Francisco. CA 94122 (415) 566-5324

Handicapping Conditions Served: Stuttering.

Users Served: Disabled persons, parents, teachers, speech therapists.

The Organization: Estab-ished in 1977, the NSP is a self-help organization run by and for people who stutter, serving over 2,000 members nationwide. NSP provides information on all aspects of stuttering to people who stutter and the general public. In 35 self-help group chapters, NSP runs biweekly meetings where people who stutter can come, share, learn about themselves, and have fun speaking in a specially designed meeting format. NSP offers consultations in program development and technical assistance to school districts, speech clinics, hospitals, rehabilitation centers, and other agencies involved in speech services.

Information Services: The NSP publishes a monthly newsietter called Letting Go which is available only to members. Publications also include pamphlets and article reprints with such titles as: "What Teachers Can Do to Help the Child Who Stutters" and "A Personal Journey Through Stutte". A tane series, which includes a tape of a chapter meeting, and the handbook, Self The py for Stuttering, are available at nominal cost. NSP has a Speech Pathology Referral Service which provides information on experienced speech therapists. Speakers and slide show presentations may be requested by schools and other organizations.

National Tay-Sachs and Allied Diseases Association, Inc. (NTSAD)
92 Washington Avenue
Cedarhurst, NY 11516
(516) 569-4300

Handicapping Conditions Served: Tay-Sachs and other inborn errors of metabolism.

Users Seried: Parents, physicians.

The Organization: National Tay-Sachs and Allied Diseases Association, Inc. (NTSAD) is an organization that supports research, provides educational literature on Tay-Sachs and the allied disorders, acts as a referral agency for families with afflicted children and encourages screening. Tay-Sachs is an inherited disorder caused by the absence of a vital enzyme, which results in destruction of the nervous system and fatality, usually by age five. NTSAD provides information about screening for possible carriers of the Tay-Sachs gene and can direct interested persons to screening centers and genetic counseling services nationwide. NTSAD supports the Quality Control Program to accredit laboratories doing analysis of samples. To facilitate interaction between parents of children with these disorders, NTSAD has formed a Parent Peer Group Network to provide emotional support and offer practical guidance on a personal level.

Information Services: Brochures for lay and professional persons describe the disease and recommend preventive measures through carrier testing and genetic counseling. A list of Tay-Sachs screening centers in the U.S., Canada and other foreign countries is available to medical professionals. NTSAD publishes a semiannual newsletter, <u>Breakthrough</u>, to report



on legislation, research developme ts, Association activities and chapter news. One pamphlet is available in Russian and some information is offered in French. There is no charge for services or publications.

National Tuberous Scierosis Associacion, Inc. (NTSA) National Headquarters P.O. Box 612 Winfield, IL 60190 (312) 668-0787

Handicapping Conditions Served: Tuberous Sclerosis (TS).

Users Served: Parents, neurologists, pediatricians, de matologists and other medical specialists.

The Organization: The Association was founded in 1975 by parents and concerned physicians of patients with this genetic disorder which results in tumors in any constitutions, including the brain, convulsions, skin lesions, and, in severe cases, mental retaining. Research, accurate diagnosis, anti-convulsant therapy, and early developmental intervention are the goals of the organization. Dissemination of information to the medical profession as well as to parents and the general public, advancement of research by fund raising, and annual meetings for researchers and for the Association's membership of an antional Human Professionals implement these goals. The Association has established a national Human Neurospecimen Bank and a case registry to assist scientists in their research. The members of the Association offer counseling, referral, and support services to other families of TS patients.

Information Services: A parent booklet, an illustrated medical brochure and a clinical brochure listing the location of NTSA state representatives are all free upon request. A 20ute slide presentation is available for loan. A 30-second public service tape can be up ed to any local media. A attends all major medical conventions. NTSA's rly newsletter provides upte information on treatment and research. An annual pership fee includes all mail

Orton yslexia Society (ODS) 724 York Road Baltimore, MD 21204 (301) 296-0232

Handicapping Conditions Served: Dyslexia.

Users Served: Disabled persons, parents, teachers, health care professionals.

he Organization: The Orton Dyslexia Society (ODS) is an international membership organization for professionals and parents of dyslexic children. Its purposes are to disseminate information related to dyslexia, and to guide persons with dyslexia and parents of dyslexic children to available resources for diagnosis, remediation, and tutoring. ODS has 33 volunteer branches which serve the needs of their individual communities by offering guidance, workshops, and semin rs.

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Information Services: ODS can provide some general information to inquirers by phone or by letter; most information requests are met through a variety of ODS publications on dyslexia and ted learning disabilities. There is a charge for books and a nominal fee for most pamphl and article reprints. The ODS Annals of Dyslexia (formerly the ODS Bulletin) is a compilation of scientific papers delivered at its ann conference, containing therapy applications and articles about the state of the art. Additages of individual conference papers are available. ODS also publishes a quarterly newsletter, Perspectives can Dyslexia, containing pertinent local and national information.

Osteogenesis Imperfecta Foundation, Inc. (OIF) P.O. Box 838 Manchester, NH 03105 (603) 623-0934 (Editorial Office) (516) 325-8992 (Administrative Office)

Handicapping Conditions Served: Ostcogenesis imperfecta (brittle bone disease).

Users Served: Disabled persons, parents, teachers, health care professionals.

The Organization: The Foundation was organized in 1970 by parents of children suffering from this genetic defect. Characterized by fragility of bone and often by stunted growth, the condition displays a wide range of severity. Management of the disease and treatment of symptoms, which may include hearing and dental problems as well as frequent fractures, is now available at many hospitals and medical centers. Referral to genetic counselors is another service offered to affected families. Public awareness and fund raising to support research are other activities of the organization. Members are adult patients as well as parents of children with the disease.

Information Services: Information about medical facilities and services, care and management techniques, and equipment is available from the Foundation office or any of the 12 local chapters. Pamphlets describing the disease and its management; a guide to education for children with osteogenesis imperfects; reprints of articles by parents, researchers, and health care professionals; a quarterly newsletter, <u>Breakthyough</u>; and referrals to local chapters and medical facilities are available from the Foundation.

Paralyzed Veterans of America (PVA) 801 Eighteenth Street, NW Washington, DC 20000 (202) 872-1300

Handicapping Conditions Served: Paralysis caused by spinal cord injury or disease.

Users Served: Paralyzed veterans, families, health care professionals, and the broad universe of disabled persons.

The Organization: Paralyzed Veterans of America (PVA) is a national organization for paralyzed veterans with offices in each of the Veterans Administration's (VA) 20 Spinal Cord Injury Centers and many VA regional offices and outpatient clinics. PVA operates as an information and advocacy agency, and supports and funds research on the treatment, rehabilitation, and regeneration of spinal cord dysfunction. A national advocacy program focuses on transportation, architectural barriers, wheelchair design, and employment and



educational opportunities. PVA representatives plead claims for paralyzed veterans before the Veterans Administration. The organization has more than 40 state chapters and 22 subchapters which help the PVA carry out its programs. One of PVA's chapter-oriented programs trains nurses in the care and treatment of spinal cord injury patients. PVA sponsors and supports wheelchair sports and recreation.

Information Services: PVA publishes brochures and other materials on such subjects as architectural barriers, research related to spinal cord injury, veterans benefits, disability-related legislation, and sports. It provides statistical data (e.g., VA health care utilization) and technical assistance materials on architectural barrier removal and adaptive devices. PVA also publishes two magazines, Paraplegia News, and Sports and Spokes.

Parent Care University of Utah Medical Center Suite 2A210 Salt Lake City, UT 84132 (801) 581-5323

Handicapping Conditions Served: Handicaps resulting from premature birth.

Users Served: Perinatal professionals, psychologists, hospital administrators, occupational therapists, behavioral scientists, developmental specialists, social wor':ers, parents, and concerned citizens.

The Organization: Parent Care, formerly Parents of Premature and High-Risk Infants, Inc. (PPHRI), was established in 1982 by a group of parents and professionals to provide a national focal point for information, referral, and support for families of infants who require special care at birth. The goals of the organization are to support families with critically ill newborns, to encourage communication between parents and perinatal professionals, to initiate and support parent support groups, to facilitate networking between parent support groups and health care agencies, and to enhance public awareness of the special needs of families of premature and high-risk infants.

Information Services: Parent Care publishes a quarterly newsletter, <u>Parent-Care Newsbrief</u>, which is free to members. It also publishes a <u>Resource Dire pry</u> which lists support groups throughout the country, and reviews books and other magnials in this field. There is a small charge for most materials (members receive reduced rater).

For information regacting membership, educational materials, and proceedings from the 1984 and 1985 Paren. Care conferences, contact the national headquarters at the above address.

Pediatric Projects, Inc. (1 + 4) P.O. Box 1880 Santa Monica, CA 90406 (213) 459-7710

Handicapping Conditions Served: All handicaps, including emotional disabilities caused by pediatric hospitalization.

Users Served: Children in health care, parents, teachers, professionals.

The Organization: Pediatric Projects, Inc. (PPI) is an international, nonprofit, public benefit corporation which serves as an educational and advocacy group, promoting the mental health of children in health carc. PPI develops and distributes medically-oriented therapeutic toys and books for children and publications for parents and professionals about helping children to cope with illness, disability, treatment and hospitalization. In addition to materials, the organization provides educational sessions and consultations to encourage quality mental health approaches to the physical care of ill or disabled children.

Information Services: Besides brochures about the organization, PPI provides information about preparing children psychologically for treatment and hospitalization, developing therapeutic play programs in medical settings and assisting children and their families in coping with illness. Pediatric Mental Health is a bimonthly newsletter, available by subscription. It includes articles on parenting, play and preparation for treatment and hospitalization, with interviews and reports of research, written in readable style. Issues in rediatric Mental Health is a monograph series, covering gaps in practice and research and providing extensive bibliographies. PPI also publishes books for children, parents and professionals on coping with treatment and hospitalization and extensive series of bibliographies on specific illnesses, disabilities and treatments. Curriculum materials in the form of both fiction and non-fiction books help children understand the disabilities of their friends, neighbors and classmates. Some publications are available in Spanish.

Also available from PPI are two videocassette series. "Growing Up With Cancer' is a two-part series about school re-entry after cancer treatment. A "Mr. Rogers" series for young children discusses going to the hospital, having an operation and having a cast.

All publications, videos and medically-oriented toys are available by mail order for reasonable charges. Catalog requests should be sent to PPI:

Pediatric Projects, Inc. provides technical assistance to medical and nursing staffs in developing new programs and improving existing ones so that attention is given to the mental health and development of children in clinics and hospitals. Consultation, seminars and workshops are available for a see.

People First International P.O. Box 12642 Salem, OR 97309 (503) 378-5143

Handicapping Conditions Served: Mental retardation and developmental disabilities.

Users Served: Disabled persons, parents, teachers, any persons interested in self-advocacy.

The Organizations: People First International is an organization of mentally retarded and developmentally disabled individuals who meet to learn leadership skills and self-advocacy techniques. People First began in Salem, OR in 1973. Since then, more than 50 local chapters have been established across the U.S. and Canada. The national office provides assistance through consultation and information to groups seeking to establish chapters. People First is currently working towards establishing a People First/U.S.A. Network.

Information Services: Information about People First and setting up programs is available from the organization. Materials include a "how-to" booklet, an officer's booklet and several articles about the organization. There is a charge for the information packet. Information



about workshops, a People First film and a book telling the story of "We Are People First" can be obtained from the national office, as well as the location of local chapters. Some local groups publish newsletters about their activities; one Canadian group prints a newsletter in French.

#### The Phoenix Society 11 Rust Hill Road Levittown, PA 19056 (215) 946-4788

Handicapping Conditions Served: Burn victims.

Users Served: Burn victims and their families.

The Organization: A self-help organization established in 1977 for burn victims and their families, the Phoenix Society works to ease the psychosocial adjustment of severely burned persons during and after hospitalization so that they can return to normal lives within their communities. While anyone with an interest in the goals of the Society is free to join, members are in large part recovered burn victims, who volunteer to help patients and their families on a one-to-one basis. Members work under the supervision of attending hospital staff.

Information Services: Burn victims and their families who would like to get in touch with other burn victims for counseling or help may contact the Phoenix Society for referral to the nearest regional coordinator. If there is no coordinator close enough, the Society will make arrangements for a volunteer to contact the inquirer.

The Society publishes a quarterly newsletter, <u>The learus File</u>, which is included with membership. Nonmembers may subscribe for a nominal charge. In addition, a list of audiovisual materials on fire prevention, burn care, true life stories of burn victims, and other topics is available from the Society. Information and/or assistance is available in Spanish; the Society is prepared to make arrangements for other languages as necessary.

Prader-Willi Synu 5515 Malibu Drive Edina, MN 55436 (612) 933-0113 \* Association

Handicapping Conditions Served: Prader-Willi syndrome.

Users Served: Parents, teachers, health care professionals.

The Organization: Prader-Willi syndrome is a rare condition which results from a birth defect. Those with this sporadically occurring disorder suffer obesity, if untreated short stature, poor muscle tone, and mental retardation in 95% of the cases. Association members are parents and professionals, who share knowledge and experience about the syndrome and how to manage it. Parent groups across the country hold informal meetings and often invite professional speakers to address them. There are 14 state chapters of the Association.



Information Services: The Association's bimonthly newsletter contains tips from parents and professionals on management of a Prader-Willi syndrome child; diet is emphasized. Prader-Willi Syndrome: A Handbook for Parents contains information on behavior and learning capacity of the Prader-Willi child as well as tips on management, diet and exercise. Prader-Willi Syndrome, an overview by Suzanne Cassidy, M.D., may also be purchased. There is a nominal charge for mater als. An overview of the syndrome is available in French and Spanish. The Association provides information to parents regarding physicians or hospitals with specific knowledge of the syndrome.

Recovery, Inc.
The Association of Nervous and Former Mental Patients 802 North Dearborn Street Chicago, IL 60610 (312) 337-5661

Handicapping Conditions Served: Emotional disorders and mental illness (after-carc).

Users Served: Disabled persons.

The Organization: Founded in 1937 to provide self-help after care for released patients of psychiatrist Abraham Low, the organization uses Low's techniques of describing and coping with daily problems to prevent relapse or chronicity. All leadership is voluntal, and groups follow procedures established by Dr. Low. Health care profess on als are welcome as observers, but weekly meetings are conducted by members who are ay leaders and former patients. It is not necessary to have been under the treatment of a physician co to have been hospitalized to join Recovery, many members come through personal referrals or publicity as well as professional referral. There are 1,000 chapters in the U.S. Canada, Ireland, the United Kingdom, and Puerto Rico.

Information Services: The techniques on which the organization
the handbook by Dr. Low, Mental Health Through Will Training
and French). Other Low lectures are available on cassettes or .opics range from
"The Fear of Life Ebbing Away" to "The Obsession of Being Cont...ed." Pamphlets on
the organization, a bimonthly nemeletter, reprints of articles describing the organization, a
publications list, and a directory of group meetings can be requested. The organization
prefers to offer demonstration meetings instead of speakers at gatherings of professionals or
for other interested organizations. Contact the headquarters office for information on this
service.

Self Help for Hard of Hearing People (SHHH) 7800 Wisconsin Avenue Bethesda, MD 20814 (301) 657-2248 (Voice) (301) 657-2249 (TDD)

Handicapping Conditions Served: Hearing impairment.

Users Served: Disabled persons, parents, teachers, audiologists, otolaryngologists, rehabilitation agencies.



The Organization: Incorporated in 1979, Self Help for Hard of Hearing People (SHKH) is an international educational organization of hard of hearing persons and others concerned with this disabling condition. SHHH seeks to educate hearing-impaired persons about hearing loss detection, management, and proves the of the loss, and to develop public and professional acceptance of the needs of hard of hearing people. Over 100 chapters have been formed in 33 states. The State cancel Center is being established to promote research into the treatment and provide the state of hard of hearing loss. This Center will function as the grant-making arm of SHHH.

Information Services: SHHH publishes a program; and a newsletter for enapter organizers. The organization also offers information and reference services. Publications are available on a variety of topics including hearing aids, assistive listening devices, communications access systems for groups and large rooms, the psychological effects of hearing loss and assertiveness training for hard of hearing peop's: There is a charge for most publications.

Sensory Aids Foundation (SAF) 399 Sherman Avenue Suite 12 Palo Alto, CA 94306 (415) 329-0430

Handicapping Conditions Served: Blindness and visual impairment, deafness/hearing disorders.

User: Served: Disabled persons, employers, rehabilitation counselors.

The Organization: The Secony Aids Foundation (SAF) is a nonprofit organization in operation since 1972, which introduces employers to the kinds of services and equipment they need in order to employ handicapped persons. Major services provided are: (1) employer orientation to sensory aids equipment and assistive devices used in making jobs accessible for handicapped people; (2) identification of specific jobs which handicapped persons may perform competitively: (3) identification of equipment used by handicapped persons; (4) identification of new areas of employment for handicapped persons; (5) maintenance of C-TEC (Computer Training and Evaluation Center) for hands-on training on computer access equipment; and (6) Vidvox - a research and de clopment program on communication aids for deaf persons.

Information Services: Services are provided to potential employers, rehabilitation counselors, and handicapped persons. SAF publishes the <u>SAF Quarterly</u> journal, <u>Technology Update</u> (a monthly subscription newsletter) and <u>Sensus</u>, a quarterly magazine. Both <u>Sensus</u> and <u>Technology Update</u> are concerned with new equipment, new applications and new techniques to assist visually and hearing-impaired persons.

Sick Kids (N ed) Involved People, Inc. (SKIP)
216 New Drive
Severn MD 21146
(301) 64

Hand J ditions Served: Disabilities in children which require dependency on medical particularly related to home care.



Users Served: Disabled persons, parents and family members, health care professionals.

The Organization: Sick Kids (Need) Involved People. Inc. (SKIP) is a national education, resource and support organization founded to foster and promote the feasibility of specialized pediatric home three for medically fragile children. Assuring the highest possible quality of life obtainable for these children who are dependent on medical technology is the ultimate goal. SKIP has approximately 25 chapters nationwide and is expanding in all areas of the country. Chapters provide information, education and support over the telephone and through group meetings. Professionals such as physicians, social workers, psychologists and counselors particise to in group meetings through educational presentations and as facilitators to encourage parental interaction. Parent networking to offer peer support and mutual aid is an important component of SKIP services.

Information Services: SKIP puts out printed materials and sponsors educational presentations dealing with home care of technology-dependent children. The organization also publishes a newsletter. Donations for individual membership are requested, but are not required.

# Society for the Rehabilitation of the Facially Disfigured 550 First Avenue New York, NY 10016 (212) 340-5400

Handicapping Conditions Served: Facial disfigurement and deformities of the hand and extremities.

Users Served: Disabled persons, parents, physicians.

The Organization: The Society was founded to provide programs of public education and research, to establish new treatment facilities, and to encourage training in reconstructive plastic surgery as a means of siding victims of facial disfigurement. The Society's Institute of Reconstructive Plastic Surgery at the New York University Medical Center functions as a center for clinical services, professional training, and medical research, in association with several plastic surgery clinics in the New York met opolitan area. Research emphasizes three major areas: facial and hand reconstruction, microsurgery, and replantation of amputated fingers, hands, and other parts. A formal residency training program, approved by the AMA, is also offered. Special rehabilitation programs are available for those with congenital facial defects and for hand, eye, and cancer surgery patients. Speech rehabilitation is emphasized, and the services of mental health professionals and vocational consultants are offered to assist with vocational problems.

Information Services: The Society routinely refers those interested in direct services to local plastic surgeons and clinics. Assistance is provided, if needed, in locating help to pay for the rehabilitation. Incividual case reviews and recommendations are sometimes made by teams of specialists from the Institute. If the case is of such a serious nature that only the Institute could help, families are advised of the cost. Fact sheet describing the services of the Institute are available, as well as brochures and pamphlets describing the range of possibilities of such surgery, and giving selected nation histories from the Institute's files. A bibliography of publications by Institute providing is also available. The Society publishes an annual newsletter, SFD News.

Spina Bifida Association of America (SBAA) 343 South Dearborn Street Room 310 Chicago, !L 60604 (312) 663-1562 (800) 621-3141

Handicapping Conditions Served: Spina bifida, with related hydrocephalus.

Users Served: Parents, teachers.

The Organization: Organized in 1974, the SBAA began and continues a many emphasis on local parent and patient support groups. Activities also include pool an action, research, advocacy, and sponsorship of an annual conference for profession is and lay persons on medical, social, educational, and legal issues remains to this disability. A Medical Advisory Board identifies national medical needs and evaluates current medical advances, reporting on these to the membership. The Professional Advisory Board for Education studies current educational programs for children with the National Easter Seal Society and the Opines Birth Defects Foundation, and the American Academy of Pediatrics.

Information Services: Publications and public education materials are available through 100 local chapters in the U.S. and Canada; chapters also sponsor parent, teenage, and young adult support groups. "hications include The Child with Spina Bifida; By, For and With Young Adults with Spina sifida; When Something is Wrong With Your Baby; Straight Talk; The Teacher and the Chi With Spina Bifida; Giant Steps for Steven; Beyond the Family and the Institution; a bimonthly newsletter, Spina Bifida Insights; and manuals for parents and teachers. Material on organizing SBAA chapters, copy for radio spots, publicity and media presentations, and a directory of chapters can be requested. There is a nominal charge; price lists will be mailed. SBAA will make referrals to local chapters and/or Treatment Centers as necessary.

Spinal Cord Society (SCS) 2410 Lakeview Drive F. rgus Falls, MN 56537 (218) 738-5252

Handicapping Conditions Served: Spinal cord injury.

Users Served: Disabled persons and their families, physicians interested in spinal cord treatment, neuroscientists.

The Organization: The Spinal Cord Society (SCS) is an international organization of persons with spinal cord injuries, their families and friends, and dedicated scientists and physicians who are all working toward the ultimate goal of cure through improved treatment methods and research. The SCS raises funds to support a targeted research program aimed at nerve regeneration in the central nervous system. The Society also performs public awareness and community outreach functions. The SCS has over 140 affiliated chapters in the U.S. and Canada.

In addition to its support of reversal-oriented pure and applied medical research, the SCS maintains a data bank of chronic spinal cord injury case histories which are continuously



monitored for improving treatment and guiding research. The case histories are also used for screening patients for referral to other physician of the SCS Spinal Center, based in the University of Minnesota Hospitals and Clinics.

Information Services: Brochures are available describing the activities of the Spinal Cord Society. A newsletter, published monthly, containing p-to-date information on the latest treatments and research. A subscription is included in the annual membership fee. SCS also has a 28-minute film, "The New Epidemic," available to chapters, service clubs and other interested groups: A data and referral service is available to SCS members.

Tourette Syndrome Association (TSA) 1-02 Bell Boulevard payside, NY 11361 (7-8) 224-2999

Ho dicapping Conditions Served: Gilles de la Tourette syndronie (TS).

Users Served: Disabled persons, parents, teachers, physicians, other health care and educational professionals.

The Organization: Established in 1972 by patients and their families, the Association offers information and moral support to others affected by this condition through its more than 100 chapters in the U.S., Canton, and Europe. Tourette Syndrome is a neurological movement disorder, characterized by rapidly repetitive multiple movements called "tics" and involuntary vocalizations. Neuropsychiatric symptoms that characterize this genetic disorder appear in childhood and may be misdiagnosed for an average of 10 years, creating severe psychological damage it the patient and family. For this reason, Association activities emphasize early identification and treatment. Education of professionals as well as the general public is conducted through publications and the media to alert physicians and families to the signs and symptoms of the syndrome. Since the cause and cure are not known, the Association supports medical research by advocacy, fund raising, and solicitation of autopsy brain tissue for the TSA Brain Bank.

Information Services: As the only clearinghouse of information on TS, the Association maintains a current referral file of physicians throughout the country who are working with patients. Exhibits are held at medical conventions each year to acquaint more physicians with current research and treatment. The TSA Newsletter reports on medical progress throughout the world as well as on activities of local chapters. Lists of insurance companies, TS chapters, bibliographies and article reprints for professionals and patients, membership information, and public education films, "The Sudden Intruder," and "Stop h! I Can't" are available on request. Recent publications focus on making Tourette Syndrome understandable to the school nurse, the school psychologist, and service providers. A pamphlet is available in Spanish. Publications are free or available for a nominal charge.

United Cerebral Palsy Associations (UCPA) 66 East 34th Street New York, NY 10016 (212) 481-6300

Handicapping Conditions Served: Cerebral palsy and other neuromotor disabilities.

Users Served: Disabled persons and their families, professionals.

The Organization: The United Cerebral Palsy Associations' (UCPA) programs and services are directed toward a two-fold goal-the prevention of cerebral palsy, and meeting the needs of those who are affected by the condition and others who have similar service needs. To fulfill this goal, UCPA: (1) provides funds for research and the training of scientific personnel who work in the fields of prevention and treatment of cerebral palsy; (2) acts as an advocate for the civil rights of disabled persons in the areas of education, employment, independent living, and access to public buildings and public transportation; (3) provides public education programs in schools, hospitals, and community facilities, which emphasize prevention of neuromotor problems; and (4) through its 230 state and local affiliates; provides direct services including: medical diagnosis, evaluation and treatment, special education, career development, social and recreational programs, parent counseling, adapted housing for disabled persons, advocacy, and community education.

Information Services: Through a variety of publications as well as telephone and letter responses to inquiries, UCPA provides extensive information about the nature of cerebral palsy, the means of preventing the condition, the services available to and required by persons with cerebral palsy and their families, and the civil rights of persons with disabilities. Lay publications include: What Everyone hould Know About Cerebral Palsy, a cartoon booklet describing the causes of the condition management techniques, available services, and the outlook for prevention; references are made to appropriate publication lists and materials.

In the professional area, UCPA publications included bibliographies on housing, family life skills, sensorimotor performance, and speech; a dbook on transportation; booklets on marketing employment concepts; guidelines for information, referral and follow-along; a respite care manual; putritional care of the young fild with cerebral palsy; six monographs on infant development programs; organizing inservice training workshop guidelines; concerns on teenage programs; and information on advocacy efforts. UCPA publishes a monthly general interest newsletter and issues a newsletter dealing with governmental reatters of concern to disabled persons. This includes a series of analysis papers on governmental activities affecting persons with disabilities. For professionals and volunteers, the Association publications include materials on child development; testing, management, teatment of cerebral palsy; service needs; Federal assistance programs; and fund the disabilities of professionals which focus on upging the quality of patient services. Progress in the effort to prevent cerebral palsy is reported periodically in the Research Report and Medical Director's Report. Most information is provided free to any inquirer.

United Stomy Associa on (UOA) 2001 W. Beverly Boulevard Los Angeles, CA 90057 (213) 413-5510

Handicapping Conditions Served: Ileostomy, colostomy, and urinary ostomy patients.

Users Served: Persons with ostomies and their families, health care professionals.

The Organization: Formed by an alliance of 28 local chapters in 1962, the Association now has more than 650 chapters in the U.S. and Canada. Volunteers are trained to visit new patients in hospitals and offer the information and moral support that only a fellow estomate can provide. Monthly chapter meetings, as well as regional and national

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demonstrations, workshops, and equipment presentations to educate estomates, their families, and health professionals in the management and care necessary following surgery.

Information Services: publishes educational materials explaining the surgery, postoperative care, and living with an ostomy for patients, doctors and nurses. Public information programs are conducted in an effort to eliminate job and insurance discrimination.

Publications include booklets on surgery, management and care for patients. Fact sheets and catalogs describing insurance, equipment, and suppliers, and a quarterly magazine are available. Special problems children may have in accepting their condition, or that adults may have with personal and sexual relationships or childbearing, are dealt with in other publications, all available at nominal cost from the Association.

# United Parkinson Foundation (UPF) 360 West Superior Street Chicago, IL 60610 (312) 664-2344

Handicapping Conditions Served: Parkinson's disease.

Users Served: Disabled persons and their families, health care professionals.

The Organization: The United Parkinson Foundation (UPF) is a membershy organization for Parkinson's disease patients and their families. UPF assembles information about the disease and disseminates it to members and nonmembers alike. UPF also gives financial assistance to scientists who are studying the disease.

Information Services: Booklets on exercise, research and therapies are available at no cost to Parkinson's disease patients and their families, and the information in the booklets is supplemented and updated by UPF's quarterly newsletter. The organization maintains a national list of diagnostic, treatment and rehabilitation centers for the patient, it can provide the names of retail outlets for obtaining prosthetic devices and special equipment. At the request of the patient, UPF will contact the patient's employer to explain Parkinson's disease and the work limitations, if any, UPF sponsors spicintific symposia on Parkinson's disease for lay audiences. Professionals are permitted on-site use of UPF's collection of reprints of scientific papers.

#### United Scleroderma Foundation (USF) P.O. Box 350 Watsonville, CA 95077-0350 (408) 728-2202

Handicapping Conditions Served: Sclerodernia.

Users Served: Disabled persons and their families, physicians, rheumatologists and dermatologists, other health care professionals.

The Organization: The United Scleroderma Foundation (USF), a nonprofit organization established in 1975, works to educate the public about scleroderma, to promote medical



research toward finding a cure, and to help patients make contact with each other. There are 28 USF chapters nationwide.

Scleroderma literally means hard skin. Localized scleroderma involves the skin and subcutaneous tissues; systemic scleroderma, which is more scrious, can affect the entire body system.

Information Services: The Foundation disseminates pamphlets on scleroderma and its various manifestations, the Scleroderma Handbook for patients, and the Scleroderma Digest. Members receive a quarterly newsletter which reports on medical treatment, research, chapter news, workshop information and helpful hints. Many chapters also publish quarterly or monthly newsletters. Accredited workshops are offered through various chapters nationwide. Membership (dues charged) entitles the donor to a full literature packet and four newsletters; otherwise there is a cominal charge for publications. Two brochures are available in Spanish. USF will refer to lents and their families to physicians in their areas and to a local chapter if available.

United Together (UT) 348 Haworth Hall Lawrence, KS 66045 (913) 864-4950

Handicapping Conditions Served: All disabilities, particularly developmental disabilities.

Users Se. ved: Disabled persons, service providers.

The C-ganization: United Together was formed in March 1980 as the result of a meeting of disabled advocates, many of them developmentally disabled, who felt that there was no national organization representing their needs. The purpose of the organization is self-advocacy and the organizational goals were developed from the members' shared belief that all persons should be able to live as independently as possible. The objectives of United Together include: working to assist in legislative change, increasing the availability and variety of community living situations, encouraging more and equitable employment of disabled persons, and improving community awareness of disabled people. This nonprofit organization is made up completely of volunteers, both disabled and nondisabled. Currently, there are ten regional offices to serve the membership of United Together. There is a membership fee for individuals and for groups.

Information Services: The organi ation publishes a newsletter, the UT Quarterly, devoted to promoting concepts of self-advocacy and informing members about the self-advocacy movement across the country. It is available on cassette tape. UT also publishes a brochure describing the goals and activities of the group and curriculum materials on organizing self-advocacy groups. A movie describing the formation of United Together and its purpose of self-advocacy is also available. Organization members provide technical assistance in starting self-advocacy groups and in advocating for specific disability issues. There is a nominal fee for materials, to cover copying or printing costs.



Very Special Arts (VSA) 1825 Connecticut Avenue, NW Suite 417 Washington, DC 20009 (202) 332-8960 (Voice and TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, parents, teachers, and volunteers.

The Organization: Established in 1974, Very Special Arts (formerly the National Committee, Arts with the Handicapped) is an educational affiliate of the Kennedy Center for the Performing Arts. It disseminates information about curriculum and instruction in the arts for handicapped people and publicizes the need for the benefit of expanded arts epportunities for handicappeu people. VSA sponsors "Very Special Aits Festivals" in 440 sites across the country which offer in-service training to teachers and administrators, workshops and performances by visiting actists, and opportunities for handicapped children to demonstrate or perform in the arts. VSA has conducted research in the areas of model arts programs for the handicapped and in personnel preparation through grants provided by the Department of Education's Special Education Programs office.

Information Services: The Committee has compiled lists of national, state, and local organizations with art programs for the handicapped, model sites and other programs which VSA recognizes for excellence, and sources of financial assistance for establishing programs and conducting research projects. Materials about VSA research and demonstration projects and other publications are available for a nominal charge and include reviews of special projects, curriculum ideas for patents and teachers, resource guides and bibliographies. Brochures emphasizing the importance of art, music, dance, and drama for handicapped persons are also available. The <u>VSA Newsletter</u>, published quarterly, contains information about arts programs for individuals with disabilities around the country.

Handicapping Conditions Served: Blindness, visual impairment.

Users Served: Disabled persons, optometrists, ophthalmologists, social workers.

The Organization: Vision Foundation, Inc. is a self-help organization whose primary 30al is to assist persons with sight loss in adjusting to their disability and receiving services. In addition to the information and referral program described below, support services are available to persons in Massachusetts and neighboring states, through one local chapter and self-help groups.

Information Services: The Foundation operates an information, referral and follow-up center, which handles inquiries on the availability of large print materials and aids and appliances, social security and other benefits and services, travel, housing, employment, recreation, and other areas. The Foundation also distributes materials in large print, braille, and recorded formats, such as catalogs, self-help tapes, and brochures. Vision Views, the Foundation's quarterly newsletter, is a membership benefit available in large print and on



cassette. Coping with Sight Loss: The Vision Resource Book may be purchased in large print and on voice-indexed cassette. A vision resource list, an annual listing of more than 150 brochures, pamphlets and catalogs, is available free of charge; there is a handling fee for items ordered. While the Foundation primarily serves disabled consumers, professionals working with visually impaired persons will find these publications of interest.

Wilson's Disease Association P.O. Box 75324 Washington, DC 20013 (703) 636-3003

Handicapping Conditions Served: Wilson's disease and Menkes' syndrome.

Users Served: Disabled persons, parents, physicians and other health care professionals, genetic counselors, and social workers.

The Organization: The Wilson's Disease Association is a nonprofit self-help and advocacy group whose main purpose is to give aid and support to the families and victims of Wilson's disease and related diseases. Wilson's disease is a rare genetic disorder characterized by excess storage of copper in the body tissues, particularly in the liver, kidneys, brain and corneas of the eyes. The Association fosters research, disseminates information, disburses funds for research and provides direct financial aid to patients.

Information Services: The Association's biannual newsletter contains information on current reservel, pertinent legislation, and advocacy activities. Pamphlets about the symptoms, diagnosis and treatment of Wilson's disease are available free of charge, up to 50 copies. The Association can refer patients to physicians specializing in Wilson's and related diseases and to researchers. The Association also maintains a data base of articles from medical journals and books that deal with various aspects of the disease.



### **INFORMATION/DATA BANKS/RESEARCH**

This group of organizations is involved in collecting, documenting, analyzing, tabulating, storing, abstracting and disseminating information on one or more aspects of disabling conditions. Information organizations and data banks generally serve as literature depositories and clearinghouses, and many operate as computer-based information storage and retrieval systems. Computer searches on a specific topic can produce bibliographies and resource lists. Data banks often stock bibliographical lists, reprints and publications on frequently-requested topics and will do custom searches for specialized requests. Research organizations, in addition to information collection, evaluation and dissemination activities, often sponsor conferences and workshops to share state-of-the-art findings and developments. Many organizations in this category are located at universities and government agencies.



### INFORMATION/DATA BANKS/RESEARCH

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#### Accent On Information (AOI) P.O. Box 700 Broomington, IL 61702 (309) 378-2961

Handicapping Conditions Served: Physical disabilities.

Users Served: Disabled persons, physical therapists.

The Organization: Founded in 1972, Accent on Information (AOI) is a computerized retrieval system containing information on products and devices which assist physically disabled persons and other how-to information in such areas as eating, bathing, grooming, clothing, furniture, home management, toilet care, sexuality, mobility and written and oral communication. The citations in this data base, which number over 6000, give two types of information: (1) references to publications on topics covered, including sources; and, (2) brief descriptions of equipment and devices with addresses of manufacturers marketing the products.

Information Services: For a nominal charge, a search of the ACI system is made on the requestor's topic. The requestor receives up to 50 of the most recent citations for each search.

The <u>Buyer's Guide</u>, which grew out of AOI's information retrieval system, lists equipment and devices which assist disabled persons in daily living activities. Manufacturers which marke, these products are also listed.

Other publications available from AOI include titles on devices and techniques for persons with the use of only one hand, ideas for making your home accessible, clothing, attendant care, sexuality, bowel management for persons with spinal cord injuries, wheelchairs, and accessories, and easy-to-prepare recipes. The Accent On Living magazine, issued quarterly, contains information on products, techniques, and money saving ideas for disabled persons; true life stories; and other practical and inspirational articles.

American Humane Association National Hearing Dog Project 9725 E. Hampden Denver, CO 80231 (303) 695-0811 (Voice and TDD)

Handicapping Conditions Served: Deafness, hearing impairment.

Users Served: Disabled persons, parents, professionals.

The Organization: The American Humane Association's National Hearing Dog Project focuses on the broad needs of all concerned with hearing dogs rather than "hands on" dog training. A hearing dog is a working animal professionally trained to alert its deaf owner to the sounds important for daily home survival, thereby increasing personal safety, independence and mobility. The purpose of the project is to provide the hearing-impaired individual, hearing dog programs, the media, schools, libraries, and the general public with the following resources and services: (1) information and referral; (2) national public awareness and advocacy programs; and (3) resources for program improvement, standardization and networking. An accreditation program for hearing dog training centers is currently under development.



Information Services: The National Hearing Dog Project has produced a number of publications of interest to the hearing-impaired and the general public. Materials available include a directory of hearing dog training centers, a legal rights hand book for hearing-impaired individuals and their dog guides, a hearing dog recipient manual designed to assist hearing dog guide owners with the care and training of their dog, and legal access information. There is a charge for some publications. The Project also provides technical assistance in hearing dog program improvement.

#### American Paralysis Association (APA) P.O. Box 187 Short Hills, NJ 07078 (800) 225-0292

Handicapping Conditions Served: Paralysis due to spinal cord injury and central nervous system disorders.

Users Served: Disabled persons, physicians, physiatrists, researchers.

The Organization: The American Paralysis Association (APA) funds research to cure paralysis caused by brain or spinal cord injury or disease, which affects 3 million Americans. The organization provides funds and information to researchers. On a local level, 20 APA branches provide referrals to physicians for spinal cord injured patients and updates on research developments to the medical community and disabled persons.

Information Services: The APA publishes two brochures which give general descriptions of the type of research in progress, Hope for a Cure and Researching a Cure. The APA also publishes a quarterly newsletter, Progress in Research, which is sent at no charge upon request. This newsletter reports on the latest Association-sponsored tesearch. Central Nervous System Trauma, the Journal of the APA, is published twice per year. A 20-minute, 16mm film, "The Search", will be available after December 1985. There is no charge for most services and products.

### Arthritis Information Clearinghouse P.O. Box 9782 Arlington, VA 22209 (703) 558-8250

Handicapping Conditions Served: Rheumatoid arthritis, osteoarthritis, gout, SLE (systemic lupus erythematosus), and other rheumatic diseases.

Users Served: Health professionals.

The Organization: The Clearinghouse is a service of the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases, U.S. Department of Health and Human Services, and is designed to help health professionals identify materials for professional and patient education. It was established in 1978.

Information Services: The Clearinghouse maintains an on-line computerized data base on the rheumatic diseases available to the public via BRS Information Technologies. Bibliographies, biblio-profiles, and catalogs are compiled and distributed. Information on rheumatic disease education programs currently in operation and those being developed is



offered. The Clearinghouse has a newsletter and acts as a liaison and referral organization for health professionals. Patients and the general public are referred to the Arthritis Foundation (see separate entry) for information.

Artificial Language Laboratory (ALL) 404 Computer Science Michigan State University E. Lansing, MI 43824-1042 (517) 353-5399

Handicapping Conditions Served: Physical disabilities, learning disabilities, speech and language disorders, blindness.

Users Served: Disabled persons, parents, teachers, speech pathologists, physical therapists, occupational therapists.

The Organization: The Artificial Language Laboratory (ALL) is a multidisciplinary research center involved in basic and applied research in computer processing and formal linguistic structures. Applied research matches individuals who have speech or language disabilities and cannot find appropriate commercially available voice output communication aids with lab-built equipment. The Lab is a research facility located at and affiliated with Michigan State University.

Information Services: The Artificial Language Laboratory has pamphlets available which describe and explain technical developments including switches, hardware and software prepared by the Lab. Communication Outlook, a quarterly publication, is available by subscription. It contains information on communication aids, organizations, conferences and articles of general interest. Another publication, Communication Enhancement Bibliography, is updated annually and can be ordered from ALL. It is available on diskette. Videocassette films describing lab-built equipment and applications are for rental. Technical assistance is provided to individuals who require specially built voice output communication aids. There is a charge for evaluations.

Barrier Free Environments, Inc. (BFE) P.O. Box 30634 Water Garden Highway 70 West Raleigh, NC 27622 (919) 782-7823 (Voice and TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, architects, builders, manufacturers, service providers.

The Organization: Barrier Free Environments (BFE) is a design firm specializing exclusively in the design of products and buildings to be usable by elderly and disabled people. Product designers, architects, interior designers, and housing designers in the organization practice "universal design," BFE's term for designing all things to be usable by all people all of the time. BFE provides design and consulting services to individuals, families, corporations, small business and institutions on the following: home and building modifications for accessibility; design or redesign of consumer products and equipment for



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use by disabled and elderly people; appropriate selection of products and equipment for use by disabled and elderly people; market research, advertising literature design, content and media placement; training programs and seminars on access design, home modifications, products and equipment for accessibility; and training as stance on issues relating to design and disability or aging. BFE is affiliated with the Information Development Corporation (see separate entry).

Information Services: BFE has available publications on accessible housing design, accessible arts programming, barrier-free meetings, accessible design and product information. In addition, BFE offers on-site technical advice or design services on any aspect of making buildings and products as usable as possible by disabled and elderly people without increasing costs. Charges for services and products are variable and negotiable.

Breaking New Ground
Department of Agricultural Engineering
Purdue University
West Lafayette, IN 47906
(317) 494-1185

Handicapping Conditions Served: Physical handicaps.

Users Served: Disabled persons, parents, teachers, professionals.

The Organization: The Breaking New Ground project has been established to assist agricultural producers who are physically handicapped and wish to remain active in their operations. The project researches, designs and constructs hand controls and tractor manlifts that provide the greatest versatility and control for the least cost. Ever aware of the potential for accidents, the project is also involved in the evaluation of existing lifts, controls and other modified farm equipment and buildings to determine effectiveness and insure safety. Other activities include development of a comprehensive resource center and assembly of a product information file. The project provides assistance with designing, organizing and conducting state and regional workshops for producers and rehabilitation professionals:

Information Services: Breaking New Ground, a quarterly newsletter, offers ideas on agricultural equipment modification for producers with physical handicaps and contains articles on disabled farmers who are continuing farming. Other publications include a bibliography concerning rural rehabilitation for agricultural producers and a manual on equipment, tools, machinery and buildings adapted for ranchers and farmers with physical handicaps. An audio-visual on rehabilitation technology for agricultural producers is available. Charges for materials and services vary.

The project provides information and referral services in response to specific requests from producers. Technical assistance on agricultural worksite modifications is also offered.

Bureau of the Census U.S. Department of Commerce Washington, DC 20233 (301) 763-4100

Handicapping Conditions Served: All disabilities, as related to work.



Users Served: Government agencies and officials; administrators, planners, and evaluators of economic and social programs; general public.

The Organization: The Bureau is a general purpose statistical agency which collects, tabulates, and publishes a wide variety of statistical data about the people and economy of the United States. This data is utilized by Congress, by the executive branch, and by the public in the development and evaluation of economic and social programs. In addition, the Bureau conducts special censuses at the request and expense of states and local government units, publishes estimates and projections of the population, provides current data on population and housing characteristics, and issues current reports on other subjects.

Information Services: The principal products of the Bureau are its printed reports, computer tapes, and special tabulations. However, it also produces statistical compendia, catalogs, guides, and directories which are useful in locating information on specific subjects. Since 1981, the March supplement to the Current Population Survey has contained questions that can be used to identify persons with a work disability. The survey does not obtain information on type of disabling condition. A report entitled Labor Force Status and Other Characteristics of Persons With a Work Disability: 1982 was issued in July 1983. The report is temporarily out of print but photocopies of tables can be obtained at cost from the Population Division, (301) 763-7946.

The 1980 census long form included a question on disability as related to employment and the use of public transportation. Tables showing the disability status of noninstitutional adults are included in the General Social and Economic Characteristics volumes from the 1980 census. The reports are available for the United States and for each state. Estimates are available for areas within states including SMSAs, counties, and places of 10,000 population and greater. Copies of the reports may be purchased from the U.S. Government Printing Office, Washington, DC 20402. A 1980 census supplementary report Selected Characteristics of Persons With a Work Disability will present data for each state on such characteristics as age, employment, education, earnings, and income. The report is scheduled for publication in late 1985. Reports based on the new Survey of Income and Program Participation (SIPP) show selected characteristics of persons with a work disability. The most recent report available is Economic Characteristics of Households in the United States: Second Quarter, 1984. The 1984 SIPP panel was asked a special supplementary set of questions on disability status. Initial reports based on these questions should be available in early 1986. The supplementary questions included items appropriate to the young and old as well as the working-age population. Information about SIPP disability data can be obtained from the Population Division, (301) 763-7946.

Cancer Information Clearinghouse National Cancer Institute Building 31 Room 10A18 Bethesda, MD 20892 (301) 496-4070

Handicapping Conditions Served: Cancer.

Users Served: Health professionals, organizations.

The Organization: The Clearinghouse is a service of the National Cancer Institute's Office of Cancer Communications (see separate entry). The Clearinghouse finds, documents, stores,



and abstracts cancer education materials for the patient and the public. Also collected are references to the planning, development and management of health education programs. Sources of material number in the thousands.

Information Services: Users of the Clearinghouse are organizations and health professionals engaged in public and patient education. Public contact is not encouraged, since the public is served through these intermediaries. Materials cover screening and detection; cause and prevention; diagnosis and treatment; rehabilitation; and behavior (coping with cancer). The Clearinghouse does not actually disseminate materials but performs reference searches in its collection of about 2,000 materials. Topics include oral cancer, skin cancer, nutrition for the cancer patient, patient education for ostomates, Spanish language materials, asbestos, smoking, breast cancer, coping with cancer, cancer information in the workplace, patient rights, and cancer treatment (patient materials). The Clearinghouse is a medium for exchange of information among the Comprehensive Cancer Centers, all of which provide community information. The Clearinghouse has a file of over 300 cancer education programs and can put professionals in touch with others who have started such programs. There is no charge for any Clearinghouse service.

Center for Residential and Community Services 207 Pattee Hall University of Minnesota 150 Pillsbury Drive, SE Minneapolis, MN 55455 (612) 376-5283

Handicapping Conditions Served: Developmental disabilities.

Users Served: Professionals, Federal and state agency personnel.

The Organization: The Center for Residential and Community Services, located in the Department of Educational Psychology at the University of Minnesota, collects and disseminates national data on residential and related services for handicapped people. The Center has, over the past several years, conducted a wide range of studies primarily related to residential services for developmentally disabled persons and has contributed a major national data base from the results of this research. The Center has operated primarily with funding from the Administration on Developmental Disabilities, the Health Care Financing Administration, and the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services, and from the Office of Special Education Programs, U.S. Department of Education.

Information Services: Information dissemination is primarily done through publications and direct response to requests for information. A complete listing of publications and prices is available upon request.

Center for Special Education Technology 1920 Association Drive Reston, VA 22091 (703) 620-3660 (800) 345-TECH (Limited Hours)

Handicapping Conditions Served: All disabilities.



Users Served: Parents, teachers, administrators, related service personnel.

The Organization: The Center for Special Education Technology collects and exchanges information about using technology in the education of handicapped children and youth. Based at the Council for Exceptional Children (see separate entry), the Center is funded by the U.S. Department of Education. CEC is assisted by JWK International of Annandale, VA and LINC Resources (see separate listing). The broad objectives of the Center are to: (1) provide information on technology advances and applications in special education to interested professionals and others; (2) collect and organize information from a variety of sources on issues that educators and others confront as they use technology in special education; (3) encourage the exchange of information about technology among educators; (4) develop information exchange capabilities that provide easy access to information and resources; and (5) examine the issues in designing and conducting research in the use of educational technology in special education.

The Center reviews many sources to identify technology advances and applications. Examples of advances the Center monitors include voice-response technology, slow-scan TV, audioconferencing, assistive devices, microcomputers and videodiscs. Educational applications are also monitored, such as using technology for instruction, management and communication, and for social and academic learning in the home.

Information Services: The Center collects information on technology, special education issues, companies/vendors, projects, resource organizations and funding sources involved in technological development. The material is organized into a variety of formats, which are used to respond to inquiries.

The Center disseminates information through direct response to individuals and organizations, news releases and information memos, and publication of articles in journals and magazines. The Center also operates two electronic bulletin boards, TECH.LINE and TECH.TALK, on Special Net, a national computerized information network for special education personnel.

The Center has a toll-free hot line, (800) 345-TECH. The hot line is operational Monday through Friday from 1 p.m. to 6 p.m. Eastern Time. At all other times, callers can access the Center's taped message system TECH-TAPES. This audiotex service contains prerecorded messages on resources and uses of technology in special education. To receive a menu for TECH-TAPES, contact the Center.

Clearinghouse on the Handicapped
Office of Special Education and Rehabilitative Services
U.S. Department of Education
Switzer Building
Room 3132
Washington, DC 20202-2319
(202) 732-1241

Handicapping Conditions Served: All handicaps.

Users Served: All interested persons.

The Organization: Created by the Rehabilitation Act of 1973, the Clearinghouse responds to inquiries, and researches and documents information operations serving the handicapped field on the national, state and local levels.

Information Services: The Clearinghouse responds to inquiries on a wide range of topics. Information is especially strong in the areas of Federal funding for programs serving disabled people, Federal legislation affecting the handicapped community, and Federal programs benefiting people with handicapping conditions. The Clearinghouse is knowledgeable about who has information and refers inquirers to appropriate sources.

The Clearinghouse assists the Office of Special Education and Rehabilitative Services (OSERS) in publishing a quarterly newsletter, <u>OSERS News in Print</u>. The newsletter focuses on Federal activities affecting the handicapped and reports on new developments in the information field. All services of the Clearinghouse are provided free of charge.

### The Council for Exceptional Children (CEC) 1920 Association Drive Reston, VA 22091 (703) 620-3660

Handicapping Conditions Served: All handicaps and gifted.

Users Served: Teachers, other professionals, and parents.

The Organization: The Council for Exceptional Children (CEC), a private, nonprofit membership organization, was established in 1922 to advance the education of exceptional children and youth, both handicapped and gifted. CEC Information Services acts as an information broker for teachers, administrators, students, parents, and others, serving as a comprehensive literature depository for English language materials. The ERIC Clearinghouse on Handicapped and Gifted Children, housed at CEC, catalogs, indexes, and abstracts journal articles and research reports for inclusion in the ERIC data base (see separate entry).

CEC has an in-house data base, Exceptional Child Education Resources (ECER), which began in 1969 as an abstract journal. This file contains documents entered into ERIC by the Clearinghouse on Handicapped and Gifted Children (approximately 50 percent of ECER records) and special education materials not appropriate to the ERIC system, such as textbooks and doctoral dissertations in special education. ECER, which contains bibliographic data and abstracts on approximately 60,000 documents, has been searchable online since 1971.

The CEC Department of Governmental Relations monitors and analyzes policies concerning exceptional children, conducts policy research in this area, and works to encourage policies favorable to the development of exceptional persons.

The CEC Department of Professional Development sponsors an annual convention and numerous topical conferences, academies, symposia, and other training activities.

In addition, CEC's 13 divisions, which focus on particular aspects of special education, are autonomous in developing professional programs and publications geared to meet the needs of division members. These divisions are (periodicals available to nonmembers by subscription are listed in parenthesis): Council of Administrators of Special Education; Council for Children with Behavioral Disorders (Behavioral Disorders); Division on Mental



Retardation (Education and Training of the Mentally Retarded); Council for Educational Diagnostic Services (Diagnostique); Division on Career Development (Career Development for Exceptional Individuals\*); Division for Children with Communication Disorders; Division on Early Childhood; Division on Physically Handicapped; Division for the Visually Handicapped; Association for the Gifted (Journal for the Education of the Gifted); Teacher Education Division (Teacher Education and Special Education); Division for Learning Disabilities; and Technology and Media Division. An asterisk (\*) indicates that subscriptions are available to libraries only.

Information Services: Custom computer searches of the ECER, ERIC and other education oriented data bases are available from EEC for a charge. Reprints of previous searches on selected popular topics may also be ordered.

CEC produces numerous publications on special education, awareness of handicapped people, child abuse, recreation, parent-professional cooperation, career and vocational education, see rely handicapped children, and public policy. Bibliographies on topics of current interest are also available. In addition, subscriptions to the ECER journal, which appears quarterly, may be ordered.

Original documents or microfiche copies of most ECER documents are retained in CEC's library, which also houses over 250 periodicals, the complete ERIC microfiche collection, and many reference materials. The library is open to the public Monday through Friday.

CEC responds to thousands of requests each year from professionals, students, parents, and others. When appropriate, inquirers are referred to other organizations. Users are asked not to direct inquiries to both CEC and the ERIC Clearinghouse on Handicapped and Gifted Children, since the two organizations share staff and resources in responding to requests.

The ECER data base may be accessed directly through BRS Information Technologies and DIALOG (see separate entries).

CRISP
Statistics and Analysis Branch
Division of Research Grants
National Institutes of Health
U.S. Department of Health and Human Services
Bethesda, MD 20892
(301) 496-7543

Handicapping Conditions Served: All handicaps.

Users Served: Health care professionals, researchers, general public.

The Organization: The mission of the Statistics and Analysis Branch in the Division of Research Grants at the National Institutes of Health (NIH) includes the operation of a large computer-based information system, Computer Retrieval of Information on Scientific Projects (CRISP). CRISP was developed to facilitate the rapid dissemination of current scientific information on research projects supported through the various research grants and contracts programs of the Public Health Service or conducted intramurally by NIH and the National Institute of Mental Health. On the basis of applications or progress reports for extramural research and annual reports or project narratives for intramural research, awarded projects are indexed by NIH staff scientists. The file contains approximately 500,000 items, many of which report on research on disabling diseases and conditions,



including the following: cerebral palsy, mental retardation, spina bifida and other congenital abnormalities, blindness, deafness, metabolic disorders, multiple sclerosis and other diseases of the nervous system, spinal cord injuries, amputation, mental illness, and all other major handicapping conditions.

Information Services: CRISP will perform searches of the data base on single specific topics (e.g., sickle cell disease) or generic data (e.g., all research support on cancer). The computer printout includes information on the research area, disease, materials, and methods. For routine searches, there is no charge to government agencies, public interest groups, other nonprofit organizations, and individuals; profit-making organizations must pay for searches.

Deafness Research Foundation (DRF) 55 East 34th Street New York, NY 10016 (212) 684-6556 (TTY)

Handicapping Conditions Served: Deafness and hearing impairments.

Users Served: Researchers in the area of deafness.

The Organization: The Deafness Research Foundation (DRF) was founded in 1958 to find support for new research into the causes, treatment, and prevention of deafness. DRF provides seed grants for ear research projects at hospitals, research laboratories, and universities in the U.S. and Canada. The Centurions of the DRF, an organization of physicians, audiologists, and researchers, contributes its membership dues to meet the basic administrative expenses of the DRF, thus making it possible for all public contributions to go directly into the funding of ear research.

With the endorsement of the American Academy of Otolaryngology and the National Association of the Deaf, the DRF sponsors the National Temporal Bone Banks Program (NTBB) and seeks individual pledges of temporal bones to be used for research and physician training.

Information Services: DRF publishes The Receiver, which reports current research and provides practical tips for dealing with specific ear diseases and hearing problems. Information about NTBB may be obtained from DRF or NTBB regional centers located in Boston, Minneapolis, Houston, and Los Angeles.

Educational Resources Information Center Central ERIC
National Institute of Education
U.S. Department of Education
Washington, DC 20208
(202) 254-5500 (Management)
(202) 254-7934 (Reference)

Handicapping Conditions Served: All handicaps.

Users Served: Teachers, administrators, researchers, students, general public.



The Organization: ERIC is a decentralized nationwide network, sponsored by the National Institute of Education and designed to collect educational documents and to make them available to teachers, administrators, researchers, students, and other interested persons. ERIC is made up of 16 clearinghouses located across the country, each specializing in a particular subject area of education. The exact number of clearinghouses has fluctuated over time in response to the shifting needs of the educational community. Central ERIC provides the funding for the clearinghouses and document processing operations, sets policies, and monitors the overall functioning of the information system.

The clearinghouses are responsible for collecting all relevant unpublished, non-copyrighted, or copyright-released materials of value in their subject areas. These include current research findings, project and technical reports, speeches and unpublished manuscripts, conference proceedings, and professional journal articles. At the clearinghouses, these items are screened according to ERIC selection criteria, abstracted, and indexed. All of this information is entered in a central ERIC computer data base and announced in the ERIC reference publications.

Information Services: All documents entered into the ERIC system are listed in the following periodicals:

- Resources in Education (RIE), a monthly abstract journal announcing recently completed research reports, descriptions of outstanding programs, and other documents of educational significance, indexed by subject, author, and institutional source. Cumulative semiannual indexes are available. RIE may be ordered from the Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402.
- <u>Current Index to Journals in Education (CIJE)</u>, a monthly guide to the periodical literature, with coverage of more than 700 major educational and education-related serial publications. It includes a main entry section with annotations, and is indexed by subject, author, and journal title. Annual cumulative indexes are available. Subscriptions to CIJE are available from Oryx Press, 2214 N. Central Avenue, Phoenix, AZ 85004.

The ERIC Document Reproduction Service (EDRS), operated by Computer Microfilm International Corporation, 3900 Wheeler Avenue, Alexandria, VA 22304, (703) 823-0500, produces microfiche and paper copies of most documents announced in RIE. Over 725 institutions and organizations, including many libraries, receive complete sets of ERIC documents on microfiche. Sources for items included in RIE but not available from EDRS are given in the RIE listing. Copies of articles from a majority of the journals regularly covered in CIJE are available through the reprint service operated by the University Microfilms International (see separate entry).

In addition to searching the ERIC reference publications, which are available in many libraries, researchers may obtain custom searches of the ERIC data base. These are available from each clearinghouse (see entries for the following ERIC Clearinghouses: Adult, Career and Vocational Education; Counseling and Personnel Services; Elementary and Early Childhood Education; Handicapped and Gifted Children; Reading and Communication Skills; and Tests, Measurement, and Evaluation.) (ERIC Clearinghouses with less relevance to special education and therefore not covered in this Directory are listed below.) Searches may also be obtained from one of the libraries, agencies, and other organizations which have access to this file. There are advantages in contacting the ERIC clearinghouse that has responsibility for processing documents in the inquirer's specific area of interest: (1) the information specialists at each clearinghouse are knowledgeable about the contents of the data base in the clearinghouse's subject area, and are therefore able to formulate effective

search strategies; and (2) each clearinghouse has a number of products in its subject area which it disseminates to its users, i.e., short bibliographies, resource lists, and newsletters.

Access points for computerized ERIC searches are listed in the <u>Directory of ERIC Search Services</u>, available at no charge from the ERIC Processing and Reference Facility, 4833 Rugby Avenue, Suite 301, Bethesda, MD 20814. Some of these centers serve only specific user groups; others have no restrictions on clientele. Cost per search and turn-around time vary with each center.

Authors of reports, speeches, papers, etc., who would like to have their materials considered for national dissemination through ERIC may forward their contributions to the ERIC Processing and Reference Facility, 4833 Rugby Avenue, Suite 301, Bethesda, MD 20814. Documents are forwarded to the proper clearinghouse, screened, and if found appropriate, entered into the ERIC system.

The ERIC data base is available commercially through BRS information Technologies, DIALOG, and the System Development Corporation (see separate es).

Other ERIC Clearinghouses:

ERIC Clearinghouse on Educational
Management
University of Oregon
Eugene, OR 97403
(503) 686-5043

ERIC Clearinghouse for Junior Colleges University of California Powell Library, Room 96 Los Angeles, CA 90024 (213) 825-3931

ERIC Clearinghouse on Higher Education George Washington University One Dupont Circle, Suite 630 Washington, DC 20036 (202) 296-2597

ERIC Clearinghouse on Languages
and Linguistics
3520 Prospect Street, NW
Washington, DC 20007
(202) 298-9292

ERIC Clearinghouse on Information Resources
Syracuse University
School of Education
Syracuse, NY 13210
(315) 423-3640

ERIC Clearinghouse for Social Studies/Social Science Education
855 Broadway
Boulder, CO 80302
(303) 492-8434



ERIC Clearinghouse on Rural Education and Small Schools
New Mexico State University
Box 3AP
Las Cruces, NM 88003
(505) 616-2623

ERIC Clearinghouse on Urban Education
Box 40
Teachers College
Columbia University
525 W. 120th Street
New York, NY 10027
(212) 678-3437

ERIC Clearinghouse for Science, Mathematics, and Environmental Education Ohio State University 1200 Chambers Road, Third Floor Columbus, OH 43212 (614) 422-6717

ERIC Clearinghouse on Adult, Career and Vocational Education
National Center for Research in Vocational Education The Ohio State University
1960 Kenny Road
Columbus, OH 43210-1090
(614) 486-3655
(800) 848-4815

Handicapping Conditions Served: All handicaps.

Users Served: Teachers and other educational practitioners.

The Organization: The scope of the ERIC Clearinghouse on Adult, Career, and Vocational Education encompasses the following areas: (1) adult and continuing education-including adult basic education, educational gerontology, community education and development, and professional skill upgrading; (2) career education-including career awareness, exploration and development, prevocational education, career centers, and experience-based career education; (3) vocational and technical aducation-including agricultural education, business and office education, health education, home economics, trade and industrial education, and new vocational and technical fields; and, (4) education and work-including comprehensive employment and training, youth employment, school-to-work transition, job training and placement, and apprenticeships. Information on disabled persons is available in many of these subject areas.

Information Services: The Clearinghouse provides publications and user services, including custom searches of the ERIC data base described above. Bibliographies and resource lists on topics of current interest, including career education and individualized education programs for handicapped students, are additional Clearinghouse services. The Clearinghouse's information analysis series is designed to assist teachers, administrators, researchers, and other educational practitioners by providing reviews, analyses, syntheses, and interpretations of current literature in selected subject areas. A few of the titles in this publication series



are of interest to professionals working with disabled persons. The Clearinghouse also publishes information bulletins on a periodic basis to highlight ERIC materials, products, and activities.

The Clearinghouse staff provides consultation on information search problems and, when appropriate, refers clients to additional educational resources. There is a charge for some services and publications, including computer searches of the ERIC data base.

The ERIC data base is available commercially through BRS Information Technologies, DIALOG, and the System Development Corporation (see separate entries). See separate entry for the National Center for Research in Vocational Education.

ERIC Clearinghouse for Counseling and Personnel Services (CAPS) 2108 School of Education Building University of Michigan Ann Arbor, MI 48109 (313) 764-9492

Handicapping Conditions Served. All handicaps.

Users Served: Professionals in counseling and personnel services.

The Organization: The ERIC Clearinghouse for Counseling and Personnel Services (CAPS) focuses on resource: for the professional. Information relating to the continuing education of helping services personnel includes the following subject areas: counselor training, development, and evaluation; student characteristics and environments; family relationships; career planning; drug education and abuse; and special populations such as women, youth, dropouts, aged, incarcerated, widowed and divorced, and handicapped. (Information on career education for disabled persons is available from the ERIC Clearinghouse on Adult, Career, and Vocational Education; see separate entry).

Information Services: CAPS offers computer searches of the ERIC data base relevant to the counseling and prescribed fields. The cost varies according to the on-line time involved and the number of citations printed.

CAPS puts out a variety of publications, including monographs on specific issues in the helping services, and <u>Searchlights Plus</u>, which are computer-produced bibliographies on topics of current interest. <u>Counseling the Exceptional: Handicapped and Gifted</u>, Searchlight 32+, contains an article on the state-of-the-art in counseling services for handicapped and gifted persons and an annotated listing of over 150 references on the subject. <u>Counseling Exceptional People</u> describes practical counseling techniques to use with specific disabilities and giftedness. There is a nominal charge for CAPS publications.

CAPS conducts national, state, and local workshops on topics of current educational interest. These workshops are also designed to familiarize participants with ERIC tools and materials. The CAPS Learning Resources Center, open to the public, houses the complete ERIC collection, as well as professional books, journals, newsletters, and magazines on helping services.

The ERIC data base is available commercially through BRS Information Technologies, DIALOG, and the System Development Corporation (see separate entries).



ERIC Clearinghouse on Elementary and Early Childhood Education College of Education University of Illinois 805 W. Pennsylvania Avenue Urbana, IL 61801 (217) 333-1386

Handicapping Conditions Served: The Clearinghouse does not focus on information relating to handicaps. Material on mainstreaming does, however, fall within the scope of the Clearinghouse.

Users Served: Teachers and other education professionals, early childhood specialists.

The Organization: The ERIC Clearinghouse on Elementary and Early Childhood Education collects documents about child development and behavior from the prenatal period through age 12, day care, early childhood education, and general aspects of elementary education. Material on mainstreaming falls within the scope of the Clearinghouse. Specific curriculum areas and related fields (such as testing, counseling, and administration) are handled by other ERIC clearinghouses (see separate entries).

Information Services: Searches of the ERIC data base, resource lists, bibliographies, papers on topics of current interest, and a newsletter are available from the Clearinghouse. Referrals are made to other organizations when appropriate. There is a charge for ERIC searches and some publications.

The ERIC data base is available commercially through BRS Information Technologies, DIALOG and the System Development Corporation (see separate entries).

ERIC Clearinghouse on Handicapped and Gifted Children (ERIC/EC)
Council for Exceptional Children (CEC)
1920 Association Drive
Reston, VA 22091
(703) 620-3660

Handicapping Conditions Served: All handicaps.

Users Served: Teachers, professionals, parents.

The Organization: Housed at the Council for Exceptional Children (CEC, see separate entry), the ERIC Clearinghouse on Handicapped and Gifted Children processes documents on research, programs, evaluation methods, administration, services, teacher education, and curricula related to handicapped and gifted children and youth.

Information Services: Searches of the ERIC data base, Exceptional Child Education Resources (an in-house data base developed at CEC and described under the entry for CEC), and other files relevant to education may be ordered from the Clearinghouse. In addition, the Clearinghouse publishes: (1) digests and brief bibliographies on topics of current interest; (2) a newsletter; and, (3) information analysis products, which are books and monographs focusing on emerging trends or research analysis, produced jointly with CEC. There is a charge for computer searches and for most publications. Users are asked not to direct inquiries to both CEC and the Clearinghouse, since they would receive duplicate



responses. The ERIC data base is available commercially through BRS Information Technologies, DIALOG, and the System Development Corporation (see separate entries).

# ERIC Clearinghouse on Reading and Communication Skills National Council of Teachers of English 1111 Kenyon Road Urbana, IL 61801 (217) 328-3870

Handicapping Conditions Served: Communication and language disorders.

Users Served: Teachers, specialists in reading and communication skills.

The Organization: The ERIC Clearinghouse on Reading and Communication Skills collects, analyzes, and disseminates educational information on the language arts and related disciplines. The Clearinghouse is concerned with all dimensions of human communication, especially with the acquisition of functional competence in reading, writing, speaking, and listening at all educational levels and in all social contexts. The placement of handicapped students in regular arts programs and the development of communications skills in learning disabled individuals are areas covered by the Clearinghouse.

Information Services: The Clearinghouse provides searches of the ERIC data base and copies of journal articles, books, reports, booklets, extensive bibliographies, and mini-bibliographies on subjects within the scope of the Clearinghouse. Copies of a mini-bibliography on learning disabilities and reading are available from the Clearinghouse. There is a charge for searches and for most publications. The ERIC data base is available commercially through BRS Information Technologies, DIALOG, and the System Development Corporation (see separate entries).

ERIC Clearinghouse on Tests, Measurement, and Evaluation Educational Testing Service Princeton, NJ 08541 (609) 734-5181

Handicapping Conditions Served: All handicaps.

Users Served: Educational professionals.

The Organization: The ERIC Clearinghouse on Tests, Measurement, and Evaluation processes documents in the following areas of interest: (1) tests or other measurement devices; (2) measurement or evaluation procedures and techniques; (3) research methodology; (4) human development (documents concerned only with infancy and early childhood are not within the scope of the Clearinghouse); and (5) learning theory in general. Documents on subject-referenced learning (i.e., mathematics or language), or learning patterns in specific populations (i.e., handicapped or disadvantaged) are handled by other ERIC clearinghouses (see separate listings).

Information Services: The Clearinghouse staff assists inquirers by providing information on the ERIC system, by assisting in the preparation of search strategies, and by searching the ERIC data base to prepare customized bibliographies. There is a charge for ERIC searches.

The Clearinghouse has produced a number of publications on testing and evaluation, including measuring attitudes toward the handicapped and mainstreaming. There is a charge for bibliographies and for most other Clearinghouse publications.

The ERIC data base is available commercially through BRS Information Technologies, DIALOG, and the System Development Corporation (see separate entries).

Educational Testing Service (ETS) Test Collection Princeton, NJ 08541 (609) 734-5686

Handicapping Conditions Served: Major types of disability.

Users Served: Teachers, therapists, information specialists, graduate students.

The Organization: The Educational Testing Service (ETS) is an educational measurement and research organization providing tests and related services for schools, colleges, and government agencies. The ETS Test Collection, an extensive library of tests and other measurement devices, contains materials on the testing of persons with disabilities.

Information Services: Test Collection bibliographies are available, for a charge, in the following areas: blind and visually handicapped, deaf and hearing impaired, physically handicapped, brain damaged, mentally retarded, identification of learning disabilities, identification of emotionally disturbed persons, and vocational measures for the handicapped. In addition, Test Collection staff respond to specific inquiries. A four-page newsletter is published ten times per year to announce tests recently received, as well as to report on new reference sources in testing.

A data base of 7000 descriptions of tests is available through BRS Information Technologies (see separate entry). There are charges for the newsletter subscription and for computer searches.

The Eterna International Foundation P.O. Box 1344 Oak Brook, IL 60522 (312) 969-0318

Handicapping Conditions Served: All disabilities.

Users Served: Disabled persons, parents, teachers, professionals.



The Organization: The Eterna International Foundation is a nonprofit corporation which places special emphasis on providing services to professionals in the fields of medicine and education with an interest in handicapped persons, particularly children. Eterna is a Latin word meaning "forever." The motivating concept behind Eterna International is the enduring nature of worthwhile efforts directed towards improving the chances for the life, health, education and emotional well-being of children. The Foundation's major activities include: (1) facilitating the collection and dissemination of information helpful to those in the service of handicapped children and families with special needs; (2) facilitating research aimed at benefiting individuals with handicaps and children and families with special needs; and (3) encouraging the adoption of newborns with handicaps and other medical management problems into families willing and able to care for them.

Eterna International seeks to promote understanding between disciplines through a multidisciplinary approach, providing services such as seminars, conferences, publications and media materials. The Foundation sponsors annual conferences on pediatric social work and on parenting the handicapped. Eterna International assists in the facilitation of clinical studies through the production and dissemination of surveys and inventories necessary for the research process.

The work of Eterna International is conducted by hundreds of volunteer professionals from a wide range of fields interested in the welfare, health and education of children with special needs. Professionals participate through editing professional publications, writing abstracts and reviews, translating, representing Eterna in other professional organizations and serving as representatives to facilitate collaborative studies.

Information Services: Eterna International publishes pamphlets on neural tube defects and the legal rights of handicapped newborns. The organization publishes and disseminates numerous periodicals covering a variety of topics including spina bifida, pediatric social work, literature in medicine and psychology as it relates to special education, parenting studies, Down syndrome, the institutionalized child, comparative special education, international child development and international pediatric chronic illness and disabilities. Books are available on spina bifida, sickle cell anemia and childhood cancer. In addition, the Foundation publishes a bibliography and curriculum materials on developmental pediatrics. There is a subscription fee for periodicals and a charge for most publications.

Greater Detroit Society for the Blind (GDSB) 4-Sights Network 16625 Grand River Detroit, MI 48227 (312) 272-3900

Handicapping Conditions Served: Blindness, visual impairment, deaf-blindness.

Users Served: Disabled persons, parents, teachers, physicians, ophthalmologists, optometrists, counselors, rehabilitation personnel.

The Organization: The 4-Sights Network, a division of the Greater Detroit Society for the Blind, is a state-of-the art communication catalyst enabling workers for the blind as well as blind persons themselves to obtain necessary information easily and to apply it effectively toward the common goal of successful rehabilitation. Information is available in areas such as vocational training, education, technology and professional disciplines. The Network provides teleconferencing opportunities, an array of data bases and electronic mail service.



Information Services: A multiple phone hookup enables blind persons and people working with them to communicate quickly and efficiently with one another by computer or touch tone phone. Members contribute as well as receive information. Some categories offer the opportunity for questions and comments, while others are designed as data bases. Information categories currently available in the 4-Sights Network include: Teleconferencing, Bulletin Board, Jobs Available, Positions Wanted, Rehabilitation Resources, Specialized Training Facilities, Multi-Handicapped Services, Technical Aids and Software Descriptions, Technical Aids and Software Reviews, Calendar of Events, Low Vision Conferences, Public Policy Issues, and Occupational Information Library. Access is available to subscribers through telephones, using personal computers or terminals equipped with a modem. Fees are kept to a minimal per-hour use rate that decreases in proportion to on-line time and frequency of use. To best accommodate the needs of all users, 4-Sights data can be accessed readily by either the standard monitor, large print, braille or synthesized speech devices.

Pamphlets are available on teleconferencing, technology, occupational information and rehabilitation issues. Newsletters appear periodically as part of Network presentations.

HEATH Resource Center
National Clearinghouse on Postsecondary Education
for Handicapped Individuals
One Dupont Circle
Suite 670
Washington, DC 20036-1193
(202) 939-9320 (Voice and TDD)
(800) 544-3284 (Voice and TDD, Outside Washington, DC)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, parents, teachers, allied health specialists, psychologists, psychiatrists, counselors, rehabilitation specialists.

The Organization: The HEATH (Higher Education and the Handicapped) Resource Center, which receives funding from Special Education Programs, U.S. Department of Education, is a clearinghouse and information exchange center for resources on postsecondary education programs and handicapped persons. The HEATH Resource Center operates the National Clearinghouse on Postsecondary Education for Handicapped Individuals. Topics covered include educational support services, policies, procedures, adaptations, and opportunities on American campuses, vocational-technical schools, adult education programs, independent living centers and other training entities after high school. The Center is a program of the American Council on Education. Another clearinghouse, National Information Center for Handicapped Children and Youth, handles the concerns of younger disabled persons through secondary school, and those interested in careers in special education and related services (see separate entry).

Information Services: The Center disseminates information on programs, publications and persons with expertise in many areas of concern about education and training after high school for persons with handicaps. Fact sheets and research papers are available on a variety of topics including access, audio-visual materials, computers, counseling, employment, financial aid, hearing impairment, learning disability, severely handicapped, testing in the classroom, and vocational rehabilitation. HEATH publishes a newsletter, Information from HEATH, three times a year which includes information about laws, regulations, court cases, campus highlights, new resources and issues of general interest. An



annual resource directory contains an annotated listing of over 100 national organizations which can provide additional information on postsecondary education and handicapped individuals. There is no charge for HEATH publications and materials. All HEATH publications are available on cassette from the Regional Libraries of the National Library Service for the Blind and Physically Handicapped (see separate entry).

High Blood Pressure Information Center (HBPIC) National High Blood Pressure Education Program 120/89 National Institutes of Health Bethasda, MD 20892 (301) 496-1809

Handicapping Conditions Served: High blood pressure (hypertension).

Users Served: Cardiologists, specialists in internal medicine, family practice nurses, physicians' assistants, health educators, lay public.

The Organization: Coordinated by the National Heart, Lung and Blood Institute, National Institutes of Health, the National High Blood Pressure Education Program (NHBPEP) was begun in 1972 to reduce illness and death from hypertension by educating professionals and the public. The High Blood Pressure Information Center, operated for the Institute by Kappa Systems, Inc., is a major component of NHBPEP's professional and public education effort. The Center serves as a national clearinghouse for the collection, evaluation, and dissemination of information on hypertension.

Information Services: NHBPEP provides technical assistance to national and local agencies and organizations in a variety of ways. The Program works with health care providers to improve professional standards and guidelines for patient care and the education of practitioners. NHBPEP also reviews current patient care practices and hypertension education programs.

Services of the High Blood Pressure Information Center include reference and research assistance to health professionals and the public and the dissemination of fact sheets, reports, bibliographies, catalogs, and educational materials produced by NHBPEP and other federal and private groups. A newsletter, INFOMEMO, on hypertension control is published quarterly. There is no charge for the Center's services or publications. Brochures and pamphlets are available in Spanish; limited quantities in other languages can be requested. Access to HBPIC's data base is available through BRS Information Technologies (see separate entry); it is a part of Combined Health information Database (CHID).

Highway Research Information Service (HRIS) Transportation Research Board 2101 Constitution Avenue, NW Washington, DC 20418 (202) 334-3250

Handicapping Conditions Served: Primarily physical handicaps.

Users Served: Transportation professionals.



The Organization: Developed by the Transportation Research Board (TRB), National Academy of Sciences, with financial support from the state highway and transportation departments and the Federal Highway Administration, the Highway Research Information Service (HRIS) is a computer based information storage and retrieval system. This file contains bibliographic information, including abstracts on articles, books, reports, and summaries of ongoing research projects from more than 1000 U.S. and foreign sources, among which are Engineering Information, Inc., the National Technical Information Service, and the U.S. Department of Transportation. There are more than 110,000 records in the file on administration, planning, design, forecasting, finance, user needs, law, safety, vehicles, and other topics. Material on the transportation of disabled persons includes the design of buses and other vehicles which accommodate handicapped persons, transportation programs for special populations, and street crossing and signal systems.

Information Services: Inquirers may obtain custom searches of the HRIS data base. Only material entered in the file since January, 1970 is searched, unless the requestor asks that older material be included. The TRB staff also supplies referrals and supplemental material, including TRB publications. HRIS current awareness service provides monthly printouts of recent additions to the data base in standard subject areas and on custom-designed topics. In addition, HRIS publishes HRIS Abstracts, a quarterly publication containing informative abstracts of journal articles, research reports, and technical papers and announcements of bibliographies on U.S. and foreign research. There is a charge for HRIS searches and publications.

The HRIS data base and other transportation-related material may be accessed through TRIS, data base number 63, available from DIALOG (see separate entry).

HUD User P.O. Box 280 Germantown, MD 20874 (301) 251-5154

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, housing and community development professionals, general public.

The Organization: Established in 1978, HUD User is an information service operated for the Office of the Assistant Secretary for Policy Development and Research (PD&R), Department of Housing and Urban Development, by Aspen Systems. PD&R is responsible for undertaking programs of research, testing, and demonstrations related to housing and community development.

The HUD User data base contains bibliographic information, including abstracts, on PD&R reports and on studies conducted by PD&R contractors. Among the subject areas covered by the file are building technology; community development; economic development and public finance; and energy and utilities. Some of the material is on barrier-free access and the housing needs of elderly and handicapped persons.

Information Services: Personalized searches of the HUD User data base are available; printouts contain information on how to obtain copies of documents.



While most of the publications announced in the above periodicals and contained in the HUD User data base are geared to professionals, titles on energy conservation, housing needs, and other high interest areas are designed for lay persons. Copies of many documents may be obtained from HUD User. Others must be purchased from the U.S. Government Printing Office, Washington, DC 20402, or the National Technical Information Service (see separate entry). There are document handling charges and charges for computerized literature searches. Prepayment is required.

Independent Living Research Utilization Project (ILRU)
The Institute for Rehabilitation and Research
P.O. Box 20095
Houston, TX 77225
(713) 797-0200

Handicapping Conditions Served: All disabilities.

Users Served: Disabled people with independent living goals, staff of rehabilitation agencies, medical facilities, staff of independent living programs, organizations of disabled people, disability-related service agencies.

The Organization: The Independent Living Research Utilization Project (ILRU), which receives funding from the National Institute of Handicapped Research, the Rehabilitation Services Administration, and private foundations, is a national resource center for independent living. Its goal is to make available results of research programs and demonstration projects in the field of independent living. ILRU was recently funded to serve as a research and training center on independent living, which will allow it to expand its efforts in conducting research and developing training programs on independent living issues and providing technical assistance to individuals and organizations in the independent living field.

Information Services: Project staff respond to requests for information on independent living, preferably by mail. ILRU has developed a variety of resource materials, including handbooks, monographs, pamphlets, a bimonthly newsletter, posters, and videotapes. Brochures are available on attendant care, facilitating independent living in rural areas and independent living topics in general. Other materials include a videotape on wheelchair maintenance, a manual on establishing and operating an independent living program, and a slide-sound package on independent living in a rural community. Listings of independent living centers may also be purchased (the Project does not make referrals to individual centers). A publication catalog is available upon request. There is a nominal charge for publications. Materials are available in braille or audiotape to people with visual impairments, upon request.

Information Development Corporation (IDC) 360 St. Alban Court Winston-Salem, NC 27104 (919) 760-3997 (Voice and TDD)

Handicapping Conditions Served: All handicaps.



Users Served: Disabled persons, architects, designers, engineers, physical and occupational therapists, municipal officials, and anyone concerned with making buildings and structures accessible.

The Organization: Information Development Corporation (IDC) is a company which publishes and disseminates information on products and designs for accessibility. IDC is affiliated with Barrier Free Environments, Inc. (see separate entry) which provides all technical services for it. In addition to marketing its products, IDC also provides full spectrum consulting and training services in access design and technical compliance with Section 504.

Information Services: IDC publishes various brochures and pamphlets on specific areas of accessibility in conjunction with professional organizations and disability groups. Major publications include THE GUIDE and THE SYSTEM. THE GUIDE is a three-piece package of training materials which includes a synchronized audio-visual presentation and step-by-step survey to help lay persons and professionals determine if buildings and facilities are accessible. THE SYSTEM is a comprehensive compendium of hard-to-find products and designs for making buildings and facilities accessible. In a pair of large ring binders, THE SYSTEM illustrates design solutions, compares the merits of alternative designs, describes products and tells how to install them, provides manufacturers' literature and ordering information, and tells how to preserve historical buildings. In conjunction with THE SYSTEM, IDC provides a telephone inquiry service on design and products for accessibility on a subscription basis. Both THE GUIDE and THE SYSTEM can be ordered from IDC.

Institute for Child Behavior Research (ICBR) 4182 Adams Avenue San Diego, CA 92116 (619) 281-7165

Handicapping Conditions Served: Childhood behavior disorders, particularly autism.

Users Served: Parents, teachers, physicians, researchers.

The Organizaton: Founded in 1967, the Institute for Child Behavior Research conducts research on autism. Ongoing projects include: investigation of adequate diagnostic methods; the study of biochemical defects in autistic children; vitamin B-6 as a treatment for autism; and operant conditioning (behavior modification) as a method of teaching autistic and schizophrenic children.

Information Services: The Institute maintains a library of detailed case studies of over 8,500 children from 37 countries. Information from these computerized files is available to researchers; a fee is charged for extensive searches. The Institute has compiled a comprehensive "Diagnostic Check List for Behavior-Disturbed Children." Copies of these forms are disseminated free to institutions and private practitioners, upon request.

A summary of the reports of 3,000 parents regarding the comparative effectiveness of drugs, psychotherapy, megavitamins, operant conditioning, and other forms of treatment has been published by the Institute. A periodic newsletter informs researchers, physicians, educators and parents of the latest research findings. Reprints of professional articles on autism and related disorders may be ordered from the Institute's publications list of 58 items.



### Institute for Scientific Information (ISI) 3501 Market Street Philadelphia, PA 19104 (215) 386-0100

Handicapping Conditions Served: All handicaps.

Users Served: Professors, researchers, students, clinicians.

The Organization: ISI produces a full line of information services in the sciences, social sciences, and arts and humanities. A major portion of the world's journal literature in the physical and social sciences is indexed according to: (1) citations, based on the concept that an author's references to previously published materials indicate a subject relationship between the author's paper and earlier citations in the bibliography; (2) subject, by means of title words (with each significant word in the title serving as an index term); (3) source, allowing access to articles according to author; and, (4) the organizational affiliation of the author.

The <u>Index to Social Sciences & Human Proceedings</u> (ISSHP), published quarterly and cumulated annually, is an index to individual papers presented at conferences. It provides full bibliographic information on approximately 20,000 papers each year in sociology, psychology, education, and other disciplines.

Current Contents/Social & Behavioral Sciences is a weekly alerting service that reproduces the contents pages of over 1,300 journals and nearly 800 new, multi-authored books in virtually every social sciences discipline. It can be used to locate recently published articles on disabilities, rehabilitation, and special education.

### International Institute for Visually Impaired, 0-7, Inc. 1975 Rutgers Circle East Lansing, MI 48823

Handicapping Conditions Served: Visual handicaps of preschool children.

Users Served: Disabled children and their families, teachers, students.

The Organization: The International Institute for Visually Impaired, 0-7, Inc., which was established in 1978, is a clearinghouse and information center for teachers, parents, and others concerned with the early development and education of visually handicapped preschool children and with the education of their families. As part of its efforts to increase worldwide awareness of the need for early services for preschool visually impaired children, the Institute sponsored, with the Israeli Institute for Rehabilitation of the Disabled, the International Symposium on Visually Handicapped Infants and Young Children: Birth to 7, in Tel Aviv in June 1981. The II International Symposium was held May 1983 in Aruba (South America). The III International Symposium is scheduled for July 1987, in Scotland.



Information Services: The Institute makes available a variety of materials for parents and teachers. The parent packet includes bibliographies of books for children and parents, and ideas for early home education. Teachers may obtain references to books on curriculum development and sources of information on visual impairments. The Institute also provides referrals to teachers and parents on services, when available, and on professionals able to give assistance. In addition, students interested in the field of early intervention with visually handicapped children receive information on appropriate training centers. A newsletter is available for a charge.

## The International Society for Research in Parenting (I.S.R.P.) P.O. Box 1344 Cook Brook, IL 60522 (312) 969-0318

Handicapping Conditions Served: All disabilities with reference to parent-child relationships.

Users Served: Medical and education professionals, psychologists, family counselors, social workers, early childhood development specialists.

The Organization: The International Society for Research in Parenting (I.S.R.P.) is a non-profit organization founded to facilitate research designed to improve the understanding of parenting. Parenting is defined as that which proceeds from the parent (natural, adoptive, foster, surrogate, institutional) to child, and contributes to the growth and development, health, education and well-being of the child. One of many sections and committees of the I.S.R.P. is the committee for Exceptional Parents and Children, designated as the primary facilitating group for research into the understanding of parenting by handicapped parents and the parenting of handicapped children. Major committee functions include facilitation of collaborative studies, publication of announcements for demographic studies requiring collaboration, facilitation of surveys to assist in research of psychosocial problems relative to parenting and handicaps and encouragement of university personnel to promote further study of parenting by and of handicapped persons. I.S.R.P. is an affiliate of the Eterna International Foundation (see separate entry) which provides support services.

Information Services: Parenting Research International is the official monthly newsletter of I.S.R.P. and contains organizational news, announcements of research projects and items of interest to the general membership. The Society also publishes an official journal, Parenting Studies, which appears quarterly. It includes original research, program descriptions, review articles and editorial material. I.S.R.P. membership is open to anyone engaged in research in parenting or otherwise interested in networking to facilitate research, and anyone with a sincere interest in the study of parenting. There is a subscription fee for publications.

#### Job Accommodation Network (JAN) P.O. Box 468 Morgantown, WV 26505 (800) JAN-PCEH (Voice and TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Business persons seeking accommodation information for employees or prospective employees.



The Organization: The Job Accommodation Network (JAN) brings together information from many sources about practical steps employers have been taking to make accommodations for functional limitations of employees and applicants with disabilities. Created by the President's Committee on Employment of the Handicapped and based at the West Virginia Rehabilitation Research and Training Center, JAN has a data base containing specific information about how individual tasks can be performed by persons with limitations. Via its toll-free number, JAN provides an information and consulting service to employers about accommodation devices or procedures that have been tried and proven successful by other employers.

Information Services: An employer calling the Network about an accommodation problem first discusses the situation with a human factors consultant who will clarify the problem. The computer is asked to supply information based on: the functional requirements of the specific job; the functional limitations of the worker; environmental factors and other pertinent business operations information. The computer will then print out a brief abstract for each accommodation it finds in its data base of "close-to-matching" situations, including the name, address and telephone number of the company representative for personal contact, if desired. JAN consultants provide technical details and assistance with accommodations and implementation of products and procedures in the workplace. Whenever necessary, JAN's consultants may provide referrals to placement services, government agencies, and private facilities or rehabilitation engineers. There is no charge to employers for JAN services; users are asked to provide information about accommodations made so they can be included in the data base and shared with other employers. Information can be provided in a special format as necessary, TDD and braille.

In addition to pamphlets about accommodations, functional limitation and disability cost containment, JAN publishes the <u>JAN Reports</u>, which contains employer testimonials and facts and statistics about JAN. Instructional materials on the subject of functional limitation and accommodation are also available.

LINC Resources, Inc.
Market Linkage Project for Special Education
3857 North High Street
Columbus, OH 43214
(614) 263-5462

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, parents, teachers, administrators, librarians, teachers, educators.

The Organization: Under a contract with Special Education Programs, U.S. Department of Education, LINC arranges commercial publication and distribution of special education products in order to make the products available to large numbers of users. LINC also provides free technical assistance and marketing services to developers of new special education products. LINC participates as a subcontractor for two other ED-funded projects: the Special Education Software Center (operated by SRI International) and the Center for Special Education Technology (see separate entry, operated by the Council for Exceptional Children). Through these contracts LINC collects, organizes, and disseminates information about special education resources available from private sector companies and organizations.

Information Services: Requestors may obtain a free catalog of special education products, which include instructional materials for use with children, assessment instruments, equipment, and training media for use with parents, regular and special educators, and



other practitioners working with handicapped children. Information is provided to enable users to contact publishers directly. (LINC does not distribute the materials.)

As part of the Special Education Software Center, LINC provides free searches of its data base on commercially available software. Parents, teachers, and others may call toll-free (800) 327-5892 to communicate their information needs and obtain a custom printout from the data base.

Finally, requestors may contact LINC to learn about the availability of related information products. For example, LINC publishes print directories that are distributed through Oryx Press of Phoenix, Arizona, and electronic editions of LINC products will be distributed (Fall 1985) through the Compuserve Information Service, a national on-line computer network based in Columbus, Ohio.

Materials Development Center (MDC)
Stout Vocational Rehabilitation Institute
School of Education and Human Services
University of Wisconsin-Stout
Menomonie, WI 54751
(715) 232-1342 (Voice and TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Vocational evaluators, adjustment specialists, rehabilitation facility managers and administrators.

The Organization: The Materials Development Center (MDC) is the national central source for the collection, development, and dissemination of information and materials in the area of vocational (work) evaluation, work adjustment, and facility management. MDC houses a comprehensive collection of publications and audio-visuals on such topics as work adjustment training, behavior modification, comparison of existing vocational evaluation systems, and rehabilitation workshop management. The Center monitors needs of professionals in these areas and conducts searches for materials which meet those needs. When suitable materials cannot be found, MDC develops, field tests, and disseminates products in the form of publications, slide/tape series, videotapes, and motion pictures.

Information Services: MDC publications and audio-visual materials are listed in the MDC catalog, available at no charge from the Center. Brochures describe slide/tape presentations, filmstrips and cassettes. A nominal fee is charged for materials and publications. Information searches are performed upon request at a reasonable fee. Literature in the information retrieval system is primarily on the topics of vocational evaluation, adjustment services and rehabilitation facility management and operations.

The Work Sample Manual Clearinghouse Catalog, available upon request, describes MDC's work sample manuals, designed to assess the ability to perform various types of mechanical and clerical tasks. The approximate cost of assessment tools is given.

A free quarterly newsletter describes MDC materials and services, as well as publications and products on evaluation, adjustment, and facility management available from other sources.



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### Mental Health Materials Center (MHMC) 30 East 29th Street New York, NY 10016 (212) 689-1386

Handicapping Conditions Served: Mental illness, emotional disorders, developmental disabilities, mental retardation, and deaf-blindness.

Users Served: Professionals and paraprofessionals in mental health.

The Organization: Since its establishment in 1953, one of the primary objectives of the Mental Health Materials Center (MHMC) has been to facilitate the effective dissemination and utilization of educational aids in support of programs to promote mental health and family life education.

In carrying out the above purpose, the organization has functioned in two primary ways. First, it has served as a clearinghouse to identify those publications and audio-visuals which have met criteria of excellence. Those meeting such standards have been recommended to a wide range of professionals in the health and behavioral sciences field through a series of Selective Reference Guides. Prominent among materials reviewed have been educational aids relevant to an understanding of mental and emotional disabilities.

A second major activity of the Mental Health Materials Center has been assisting other nonprofit agencies in developing effective techniques to produce and market educational materials. This service has been provided to such agencies on a cost sharing basis. The Center has also provided its expertise in this area to both Federal and state governmental agencies. Currently, the Mental Health Materials Center is engaged in services designed to help other nonprofit agencies to realize maximum potential from their educational materials with respect to both distribution and revenue.

The Center has recently established a division called the Resource Center for Developmental Disabilities. This division's areas of activity include, in addition to resource center services, providing training services to community groups serving the developmentally disabled in matters related to residential programs, public education, community acceptance, fund raising and advocacy.

Information Services: Professionals and paraprofessionals in mental health are the primary target group of MHMC. It will answer some questions for the general public; however, handicapped individuals are not directly served. Fees are charged for publications and for most research and consultative services. Organizational brochures are provided free to professionals.

MHMC's publications include a triannually updated reference work: The Selective Guide to Audio-visuals and Publications for Mental Health and Family Life Education. To augment and update the information provided in the Guide, two quarterly newsletters are available on a subscription basis under the umbrella title Current Information Service. The newsletters are: Sneak Previews, brief evaluative reviews of all audio-visuals seen by MHMC staff and advisors; and Best in Print, containing reviews of publications of interest to mental health educators. A publications catalog is also available.



National Agricultural Library (NAL) Science and Education U.S. Department of Agriculture Beltsville, MD 20705 (301) 344-3755

Handicapping Conditions Served: All handicapping conditions.

Users Served: All interested persons.

The Organization: The National Agricultural Library (NAL) was established in 1862 to provide effective dissemination of research, teaching, and information in the food and agricultural sciences.

AGRICOLA (Agricultural Cn. te Access), a family of data bases developed by NAL and its cooperators, indexes books, reports, and approximately 6,000 journals in agriculture-related fields, including food and nutrition, in the collections of the National Agricultural Library AGRICOLA contains more than two million citations, several hundred of which refer to documents on various aspects of handicapping conditions, for example, nutrition for disabled persons, independent living, and work experience programs for handicapped individuals.

Information Services: On-line access to AGRICOLA is available through DIALOG and BRS Information Technologies (see separate entries). Copies of most documents in AGRICOLA searches may be obtained from NAL for a nominal fee. Libraries may borrow books which are not classified as reference materials or rare books. The resources and services of the National Agricultural Library may be used on-site by any person with an interest in its collections.

National Autism Hotline

Mailing Address:

101 Richmond Street Huntington, WV 25702

Office Address:

Douglass High School Building Huntington, WV 25702 (304) 525-8014

Handicapping Conditions Served: Autism.

Users Served: Parents, teachers, speech therapists, doctors, directors of special education, advocacy agencies, students.

The Organization: The National Autism Hotline, which was established in 1979, is a project of the Autism Services Center, a nonprofit organization which provides consultation, training, and advocacy services to parents and professionals in the field of autism. There is a charge for the Center's direct service contincts; however, the telephone services are free.



Information Services: The Hotline offers comprehensive information services on autism to parents and professionals. In response to both telephone and letter inquiries, the project gives out information on autism; makes referrals for medical, residential, and educational services; assists parents and professionals in their advocacy activities; and gives technical assistance on autism to protection and advocacy systems and other agencies. Copies of articles are sent to requestors in areas such as education, rights, the language of autistic children, and research. There is a nominal charge for these services.

National Center for Education in Maternal and Child Health (NCEMCH)
38th and R Streets, NW
Washington, DC 20057
(202) 625-8400

Handicapping Conditions Served: Maternal and child health, including genetic disorders.

Users Served: Health professionals, educators, general public.

The Organization: The National Center for Education in Maternal and Child Health (NCEMCH) was established in 1982. The Center is a major link between sources of information/services and professionals in areas of maternal and child health, including genetics. The NCL ACH network includes: nurses, social workers, pediatricians, obstetricians, geneticists, genetic counselors, health administrators, educators, volunteer organizations, Federal, state and local agencies, professional societies, and public and private foundations.

Information Services: In addition to its resource network, NCEMCH provides a variety of services aimed toward facilitating the development and exchange of maternal and child health information. The Center provides assistance in the development and evaluation of new materials and educational programs and collects and disseminates information about available materials, programs, and research. The Center also offers conference assistance, including planning, support services and editing of conference materials for publication.

NCEMCH maintains a resource center of books, journals, articles, teaching manuals, brochures, fact sheets and educational materials. Organized by subject area, the resource center contains publications, audio-visual descriptions and information geared to the consumer/patient, professionals and associations/organizations.

Examples of NCEMCH publications include: bibliographies on sickle ceil and the social and psychological aspects of genetic disorders; newsletters targeted to specific professional groups; and directories of resources and services covering Federal resources in maternal and child health, voluntary organizations, clinical genetics service centers and others.



National Center for Health Statistics (NCHS)
Public Health Service
U.S. Department of Health and Human Services
3700 East-West Highway
Room 1-57
Hyattsville, MD 20782
(301) 436-8500

Handicapping Conditions Served: All handicapping conditions.

Users Served: All interested persons.

The Organization: The National Center for Health Statistics (NCHS) is the only Federal agency established specifically to collect and disseminate data on health in the United States. The Center designs and maintains national data collection systems, conducts research in statistical and survey methodology, and cooperates with other agencies in the United States and in foreign countries to increase the availability and usefulness of health data.

Through its survey and inventories, the Center produces and disseminates data on illness and disability, including prevalence and impact. Data has been collected on a number of handicapping conditions; data on the prevalence of most conditions includes some indicators of severity and impact. Also collected is data on the supply and use of health services.

Information Services: The primary information service of NCHS is distribution of its statistical data through published reports, which include the following:

The Vital and Health Statistics Series contains data on program and collection procedures, evaluation and methods research, and analytical studies. This series includes publications on: (1) the Health Interview Survey, which gives statistics on illness, disability, accidental injuries, and the use of hospital, medical, dental, and other services; and (2) the Health and Nutrition Examination Survey, which provides data from direct examination, testing, and measurement of national samples which is used to calculate distributions of the population with respect to physical, physiological, and psychological characteristics.

Two reports in the above series contain data on disability: <u>Prevalence of Selected Impairments</u>, <u>United States</u>, which gives statistics on impairments involving vision, hearing, speech, paralysis, absence of extremities, and orthopedic conditions, and <u>Uses of Special Aids</u>, <u>United States</u>, <u>1977</u>, which has figures on the distribution and use of artificial limbs, wheelchairs, walkers, and other devices and aids.

Advance Data from Vital and Health Statistics is a publication series begun in 1976 as the means for early release of selected findings from the health and demographic surveys of NCHS. Most of these releases are followed by detailed reports in the Vital and Health Statistics Series.

The Catalog of Publications of the National Center for Health Statistics is an index to the Vital and Health Statistics Series and Advance Data from Vital and Health Statistics according to demographic and socioeconomic variables. Section I includes topics and variables related to the health status of people; Section II covers the characteristics of health facilities and manpower. In addition, titles of published reports are given for each series.

Single copies of Advance Data releases and the Catalog of Publications are available free of charge from the Center. Information on the availability of reports from The Vital and Health Statistics Series may be obtained by telephoning NCHS at (301) 436-8500.



National Center for Research in Vocational Education The Ohio State University 1960 Kenny Road Columbus OH 43210-1090 (800) 848-4815 (Outside Ohio) (614) 486-3655 (In Ohio)

Handicapping Conditions Served: All handicaps.

Users Served: Vocational, technical and adult educators and administrators, education agencies.

The Organization: The National Center for Research in Vocational Education, established in 1965, is an independent research and development unit operating as part of The Ohio State University. The mission of the National Center is to increase the ability of diverse agencies and organizations to solve educational problems related to career planning, preparation, and progression through: (1) generating knowledge through research; (2) developing educational programs and products; (3) evaluating individual program needs and outcomes; (4) operating information systems and services; and (5) conducting leadership development and training programs; (6) providing information for national planning and policy; and (7) installing educational programs and products.

Information Services: The Center publishes a number of vocational education products for national dissemination, some of which focus on the needs of disabled persons (mainstreaming, characteristics of handicapped students, evaluation and placement, architectural considerations, guidance and counseling services, and collaborative planning for individual placement by parents, businesses, and the school). Vocational Education Special Needs Information Exchange, currently being developed, will provide: (1) coordination to many existing information services related to special needs groups, (2) single access point to inquiries related to special needs, and (3) various training experiences on high interest topics related to special needs. Materials on various aspects of vocational and career education, including programs for special needs populations, are announced in "Memo Newswire", an electronic newsletter available to members of ADVOCNET. ADVOCNET is an electronic mail network of adult and vocational educators made available through ITT Dialcom. Vocational educators may request the Vocational Educator, a quarterly newsletter that describes National Center products workshops, and services.

The National Center is involved in the production of several data bases:

- RIVE ongoing vocational education program improvement projects
- VECM vocational education curriculum materials

These data bases are publicly available through BRS Information Technologies (see separate entry).

Technical assistance to agencies and organizations is available in many different areas, including needs assessment, research and program planning, and curriculum design. The fee for this service varies according to the type of assistance required.

Persons interested in obtaining bibliographies on specific topics may request custom computer searches at the ERIC Clearinghouse on Adult, Career, and Vocational Education, which is housed at the Center (see separate entry).



Requestors may ask for a free catalog of the Center's publications. Inquiries on the Center's programs and activities should be directed to the Program Information Office. This office can be contacted at the above address and telephone numbers.

#### National Clearinghouse for Alcohol Information P.O. Box 2345 Rockville, MD 20852 (301) 468-2600

Handicapping Conditions Served: Alcoholism.

Users Served: All interested persons.

The Organization: The Clearinghouse was established in 1972 to make current knowledge on alcohol-related subjects widely available. Part of the National Institute on Alcohol Abuse and Alcoholism, it is operated for the Federal government by a private contract. The Clearinghouse has an information program for lay and professional users that includes the dissemination of materials on the prevention, training, treatment and research aspects of alcohol abuse and alcoholism.

Information Services: Reference and referral services and printed materials are available free of charge to any interested individuals. Custom computer searches of the Clearinghouse's data base may be requested at no charge to the user. Information for practitioners on the administration and operation of an alcoholism program or treatment center is particularly strong. Statistical information is available.

Medical research is also covered. Public education tools, including pamphlets and posters, are developed and distributed by the Clearinghouse. Information on alcoholism in persons with mental retardation, epilepsy, hearing impairments, visual impairments, and other handicapping conditions is available.

Publications produced by the Clearinghouse include the following: (1) a listing of publications available from the Clearinghouse; (2) a catalog providing citations to films and other audio-visuals; (3) Alcohol Health and Research World, a quarterly bulletin for researchers and treatment specialists, available from the Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402; and (4) Alcohol Awareness Service, a current awareness service of abstracts from the NCALI data base (six times a year, for a fee).

National Clearinghouse for Drug Abuse
Information (NCDAI)
National Institute of Drug Abuse
Alcohol, Drug Abuse, and Mental Health Administration
U.S. Department of Health and Human Services
P.O. Box 416
Kensington, MD 20795
(301) 443-6500

Handicapping Conditions Served: Drug abuse.



Users Served: Disabled persons, parents, teachers, researchers.

The Organization: Established in 1970 by Executive Order, the National Clearinghouse for Drug Abuse Information is the central source in the Federal government for collection and dissemination of information on drug abuse. Part of the National Institute of Drug Abuse (NIDA), it is responsible for providing information on the treatment and prevention of drug abuse, the renabilitation and maintenance of persons who abuse drugs, psychosocial services available, and research into the drug abuse problem.

In formation Services: The Clearinghouse responds to inquiries from researchers, administrators, and other professionals, students, and the general public by disseminating information packets on drugs and their effects, including fact sheets, short reference lists, research monographs and issue papers, and other public education and research literature. Treatment manuals for medical personnel, guides for training drug abuse workers, parent education materials, booklets on minority drug abuse, and information on drug abuse written in Spanish are available. Professionals seeking research information not available at the Clearinghouse are, when appropriate, referred to NIDA researchers.

The Clearinghouse also operates the Drug Abuse Communications Network (DRACON), which provides publications and technical assistance to local drug information centers.

There is no charge for Clearinghouse services or publications.

National Clearing House of Rehabilitation Training
Materials (NCHRTM)
Oklahoma State University
115 Old USDA Building
Stillwater, OK 74078
(405) 624-7650

Handicapping Conditions Served: All handicaps.

Users Served: Rehabilitation personnel, educators of rehabilitation counselors and professionals in related fields.

The Organization: The National Clearing House of Rehabilitation Training Materials (NCHRTM), located at Oklahoma State University, is funded by the Rehabilitation Services Administration, U.S. Department of Education, to disseminate information on rehabilitation with primary concentration on training materials for use by educators of rehabilitation counselors. Personnel working in the areas of staff development, in-service training, and continuing education are also served by the Clearing House.

NCHRTM houses a collection of "fugitive" materials and information not generally found in traditional libraries. The Clearing House reference collection contains about 3,000 titles in hard copy or microfiche format, back issues of major journals in the rehabilitation field, and various types of audio-visuals.

Information Services: NCHRTM usually has between 250 and 300 titles to distribute to requestors in the rehabilitation field. Microfiche or xerox copies of other publications in the Clearing House collection can be made for a cost recovery fee. An annotated bibliographic newsletter, NCHRTM Memorandum, on publications available from the Clearing House and other sources is published quarterly.



NCHRTM helps inquirers identify publications relevant to their information needs. Services are available primarily to professionals who have training interests in rehabilitation and related fields.

National Council on Family Relations (NCFR) 1910 West County Road B Suite 147 St. Paul, MN 55113 (612) 633-6933

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, parents, teachers, and professionals.

The Organization: The NCFR is an international nonprofit educational and resource organization dedicated to the strengthening of the family. The goal of the Council is to assist professionals in developing professional standards in the field. The membership of the Council is comprised of researchers, clinical practitioners in family therapy, and professionals in related disciplines.

Information Services: The main information component of the Council is the Family Resources Database (FRD) which is available for on-line searching through BRS Information Technologies and DIALOG, two national data-base vendors (see separate entries). The data base contains approximately 72,000 citations of books, journal articles, government documents, resource organizations, instructional materials, audio-visual materials, and a listing of community services which are concerned with the functioning of the family.

The data base comprises numerous citations of materials concerned with various disabling conditions as they relate to family interaction. A search of the data base yielded the following: families with handicapped persons (physical handicaps), 1369 citations; families with mental retardation, 844 citations; families with learning disabled members, 421 citations; families with emotionally disturbed members, 779; and families with schizophrenics, 60 citations.

Besides the bibliographic files, the data base contains a Human Resource Bank, which contains the vitae of hundreds of specialists working in the field who have expressed a willingness to provide consultation to lay and professional individuals when appropriate. In addition, a Work in Progress File lists ongoing research and Demonstration projects. Both government and private-sector-funded projects are included.

Nonsubscribers to BRS and DIALOG who wish to search the data base should contact local and university libraries, many of which provide searching assistance, or if local search facilities cannot be found, FRD staff will conduct custom searches on a cost-reimbursement basis.



National Data Bank for Disabled Student Services
Room 0126
Shoemaker Building
University of Maryland
College Park, MD 20742
(301) 454-5028 (Voice)
(301) 454-5029 (TDD)

Handicapping Conditions Served: Primarily physical disabilities.

Users Served: Directors and coordinators of disabled student services programs, disabled persons.

The Organization: The National Data Bank for Disabled Student Services, located at the University of Maryland, provides the means for accessing statistics related to services, staff, budget and other components of disabled student services programs across the country. The data bank cycle begins each summer when survey participants are recruited. The previous year's survey is updated and items are added so that roughly half of the questions are new each year, reflecting current concerns of participants. Examples of data included are: size and type of institution, date program was started, funding, staff (including education, experience, salary), number of disabled students, services provided, fees and new ideas. The surveys are mailed in October or November and returned for processing by January. In early spring, the data is returned to participants in coded form to preserve the confidentiality of institutions.

Information Services: As in financial banking, data may be withdrawn from the Data Bank only by those who have an "account" with a reserve of data of their own. Each participant is charged a modest fee. Directors and coordinators of campus programs can use the data to support program ideas, justify staff positions or compare service provision. Comparisons can be made based on such factors as size of institutions, sizes of disabled student population, size of staff, amount of budget, etc. In times of budget or personnel crises or in long-range planning, such supportive data can be invaluable.

National Diabetes Information Clearinghouse (NDIC) Box NDIC Bethesda, MD 20892 (301) 468-2162 (301) 496-7433

Handicapping Conditions Served: Diabetes.

Users Served: Dicabled persons, parents, teachers, patient-educators, physicians, nurses, dieticians.

The Organization: The NDIC, a service of the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases (NIADDK, see separate entry), NIH, collects, organizes, and disseminates information about diabetes programs and materials to health care providers, patients and the public. NDIC also provides technical assistance for the preparation of new materials and coordinates the evaluation of patient education materials.

Information Services: Reference/referral services are provided in response to requests for information. NDIC compiles and publishes annotated topical bibliographies which include source and pricing information for each item. The bibliographies are comprised of



professional and lay materials spanning the many aspects of and subjects related to diabetes: foot e; diet and nutrition; cookbooks; educational materials for young people; aging; mater is and aids for the visually impaired; Spanish language materials; and other topical areas. Other products available from the Clearinghouse are: Diabetes Dateline, a bimonthly newsletter; materials evaluation guidelines and worksheet; and The Diabetes Dictionary, a glossary of over 300 diabetes-related terms. Nominal fees are charged for NDIC-produced publications. While NDIC does not produce foreign language materials, it does collect and index such materials about diabetes.

NDIC maintains an automated file of brochures, audio-visual materials, books, articles, teaching manuals, fact sheets, and other educational materials. The file is part of the Combined Health Information Database (CHID), available through BRS Information Technologies (see separate entry).

National Diffusion Network (NDN) U.S. Department of Education OERI/NDN Washington, DC 20208 (202) 653-7000

Handicapping Condition Served: All handicaps.

Users Served: Classroom teachers, principals, and other educational personnel.

The Organization: The National Diffusion Network (NDN) is a nationwide system established in 1974 to improve educational programs in public and private schools through the adoption or adaptation of effective, validated programs. NDN links local educators to programs which have been rigorously evaluated and found to be effective.

The more than 40 special education projects that participate in NDN cover the majority of developmental and disorder areas. Some programs receive dissemination funds through the Department of Education's National Diffusion Network. Others receive dissemination funding from the Handicapped Children Early Education Outreach Program of Special Education Programs; these models focus on the identification of preschool handicapped children and teaching techniques to aid in their development.

Information Services: NDN State facilitators help schools identify and adopt the program most suitable for them. Adopting schools are then given implementation help, including training. A list of facilitators may be obtained from the above address. The catalog Educational Programs That Work provides an overview of all NDN programs and lists a contact person for each program. This publication may be purchased from Sopris West, Inc., 1120 Delaware Avenue, Longmont, CO 80501, (303) 651-2829.



National Eye Institute (NEI)
National Institutes of Health
U.S. Department of Health and Human Services
Building 31
Room 6A32
Bethesda, MD 20892
(301) 496-5248

Handicapping Conditions Served: Blindness and visual impairments.

Users Served: Disabled persons, parents, and professionals.

The Organization: The National Eye Institute (NEI) has primary responsibility within the National Institutes of Health and the Federal government for supporting and conducting research aimed at improving prevention, diagnosis, and treatment of visual disorders. In addition, NEI encourages the application of research findings to clinical practice, heightens public awareness of vision problems, and cooperates with voluntary organizations which engage in related activities.

Information Services: Printed material on the following eye conditions is available upon request: cataract, retinal detachment, glaucoma, refractive errors, corneal diseases, macular degeneration, diabetic retinopathy, and retinitis pigmentosa. Also available are statistics on eye disease and visual impairment, and information on NEI-supported research.

#### National Handicap Housing Institute (NHHI) 619 Lafayette Road St. Paul, MN 55101 (612) 772-3560

Handicapping Conditions Served: All disabilities.

Users Served: Disabled persons, designers, architects, developers, attorneys.

The Organization: The National Handicap Housing Institute (NHHI), a nonprofit organization formed in 1975, works to stimulate the development of barrier-free housing for disabled people. NHHI has conducted research resulting in the creation of design standards for accessible buildings. The Institute offers on-site consulting services in design, marketing, and management. The Institute also offers expert consultation and testimony to attorneys in cases involving personal injury, workers compensation, or other areas where a disability has affected functioning in the home or work environment. There is a charge for the Institute's services.

Information Services: NHHI disseminates information on design standards and when possible refers inquirers to local agencies and individuals who can provide technical assistance or information on accessible housing.

The <u>Product Inventory of Hardware.</u> Equipment and Appliances for Barrier-Free Housing <u>Design</u>, which describes and evaluates products enhancing accessibility, contains sections on kitchens, bathrooms, and recreational equipment. The <u>Survey of Handicapped Individual's Housing Preferences</u> may also be ordered.



National Health Information Clearinghouse (NHIC) and National Information Center for Orphan Drugs and Rare Diseases (NICODARD)
P.O. Box 1133
Washington, DC 20013-1133
(703) 522-2590 (Virginia)
(800) 336-4797 (All Others)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, parents.

The Organization: The National Health Information Clearinghouse (NHIC) and the National Information Center for Orphan Drugs and Rare Diseases (NICODARD) are projects of the Office of Disease Prevention and Health Promotion (ODPHP) of the U.S. Department of Health and Human Services. In addition to its clearinghouse function, NHIC has initiated liaison activities in order to encourage the exchange of ideas on common concerns and goals among health information providers.

Information Services: NHIC and NICODARD operate an information and referral center. Its data base of resource organizations helps consumers find the health information they need by locating the appropriate sources of the information. Resource organizations include disease prevention and health promotion programs, clearinghouses, professional associations, voluntary organizations and government agencies at the national and international levels. Organizations which provide information on the following topics are included: nutrition, cancer, immunization, accident control, infectious diseases, acupuncture, fluoridation, teenage pregnancy, hypertension, smoking, biofeedback, self-care, risk assessment, physical fitness, genetic diseases, and many others. The NHIC data base of referral organizations is accessible to the public through the National Library of Medicine data base DIRLINE.

NHIC publishes a series of directories and bibliographies on health topics of current interest. NICODARD produces fact sheets on rare diseases, a listing of drugs approved for orphan drug status by the Food and Drug Administration, and a directory of educational materials on rare diseases. NHIC and NICODARD information and referral services are available free of charge to lay persons and professionals.

National Heart, Lung, and Blood Institute (NHLBI)
National Institutes of Health
U.S. Department of Health and Human Services
Building 31
Room 4A21
Bethesda, MD 20892
(301) 496-4236

Handicapping Conditions Served: Cardiovascular disorders, respiratory conditions, stroke, and blood disorders (including hemophilia, Cooley's anemia, and sickle cell disease).

Users Served: Disabled persons, physicians.

The Organization: NHLBI funds a multimillion dollar research program at its own headquarters and around the country at universities and medical schools. Research and professional training are done on diseases of the heart, blood vessels, blood and lung, and in the use of blood and the management of blood resources.



Information Services: The focus of the Institute's information services is the Public Inquiries and Reports Branch. All information activities are aimed at reducing illness and death from heart, lung, and blood diseases. Advances in research are translated through press conferences, pamphlets, fact sheets, exhibits for use by professionals and lay audiences, audio-visuals, and special projects. Conference proceedings for scientists are prepared regularly, and professional and public education materials are made widely available.

Anyone may request information and most is provided free. Fees are levied for bibliographies, indexes or abstracts that must be specially prepared. On-site use of NHLBI holdings of books, indexes, and journals is permitted. Numerous professional and general publications are available. A list of current publications and materials produced by NHLBI shows dozens of resources which can be ordered. Some information is available in Spanish.

Specialized information on blood cholesterol is available at the Institute. A dietary series for patients with lipid disorders has been distributed throughout the world, accompanied by a companion handbook for physicians.

NHLBI also supports National Research and Demonstration Centers and clinical studies throughout the country, which generate their own materials and are a community source of information. For example, a center at the University of Vermont expedites translation of research findings on lung diseases into practical patient care in local communities; the center also coordinates the activities of several state and local groups concerned with respiratory diseases.

Several educational programs are being planned on various lung diseases, as a result of the work of a task force on respiratory diseases.

### National Information Center for Handicapped Children and Youth (NICHCY) Box 1492 Washington, DC 20013

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, parents, teachers, physicians, nurses, therapists, legislators, policy makers, members of Congress, members of the press.

The Organization: The National Information Center for Handicapped Children and Youth (NICHCY) is a free information service that helps parents, educators, caregivers, advocates and others to improve the lives of children and youth with handicaps. NICHCY is funded through a cooperative agreement between the U.S. Department of Education and Interstate Research Associates, Inc. of Rosslyn, Virginia. Its purpose is to ensure that accurate, timely information is available free to anyone who requests it.

NICHCY answers questions, develops and shares new information through fact sheets, directories and newsletters, provides advice to people working in groups, and connects people all across the country who share similar goals and concerns. When a program or project proves especially effective, the Center collects information on it to share with others. Resource files are maintained for each of the states and territories, by organization and by subject.



Information Services: NICHCY provides brochures describing the project, with a form to indicate the desire to be added to the mailing list for free subscriptions to materials. NICHCY publishes two newsletters. News Digest is circulated quarterly and focuses on single important issues affecting families of children and youth with handicaps and other special education concerns. Transition Summary is a compilation of articles on transition issues that is distributed semiannually. Also available are fact sheets on all major disabilities and parent groups; general information about handicaps; listings of major public agencies in each state and territory and state level chapters of other organizations; directories of organizations; and information about careers in special education. Some materials are available in Spanish.

NICHCY staff members provide consultative and technical assistance on topics of collaboration, respite, group organization and maintenance, evaluation, media presentation, conference and workshop presentations, group facilitation, and location of information and resources.

National Information Center on Deafness (NICD)
Gallaudet College
800 Florida Avenue, NE
Washington, DC 20002
(202) 651-5109 (Voice)
(202) 651-5976 (TDD)

Handicapping Conditions Served: Hearing impairments.

Users Served: Disabled persons, parents, teachers, professionals, general public.

The Organization: The National Information Center on Deafness (NICD), a unit of the Division of College Relations, was established in 1980 to meet the need for accurate, current information on topics dealing with deafness. NICD has access to experts in the field of deafness at Gallaudet as well as names of national, state and local programs and services from its in-house resource collection.

Information Services: NICD provides either direct information, printed materials, and/or when appropriate, referrals to other helpful resources. NICD has developed numerous fact sheets and resource listings on such areas as deafness, TDD's, alerting and communication devices, hearing ear dogs, financial aid for hearing-impaired students, travel resources for hearing-impaired people, and short reading lists on topics in education of deaf children. NICD information services and single copies of publications are provided free.

National Institute for Burn Medicine HBM)
909 E. Ann Street
Ann Arbor, MI 48104
(313) 769-9000

Handicapping Conditions Served: Burn injury.

Users Served: Health care professionals, attorneys, manufacturers, teachers, students, general public.



The Organization: The National Institute for Burn Medicine works to improve care available for burn victims through its research, professional training, technical assistance, and information dissemination programs.

The Institute supports research designed to improve infection control and to develop better burn care equipment and surgical techniques and to improve rehabilitation services. Specialized training for burn patient care is available for physicians, nurses and technicians. Communities and hospitals may receive help in planning and establishing burn facilities.

Information Services: The National Burn Information Exchange provides a way for hospitals to share information about patients, including the way they were burned and the type of treatment received. Doctors at non-participating hospitals and other interested persons may also access data collected by the Exchange, although there is a charge for requests requiring research. Statistics on the incidence of burns, mortality rates, and body area covered are available, as well as figures for specific age groups. The Exchange publishes a newsletter, N.B.I.E., for which there is no charge.

Reprints of articles on burn treatment may be obtained from the Institute's International Library, which also researches requests for references on specific topics. There is a charge for searches of library holdings and a nominal photocopying fee for reprints.

The Institute distributes a variety of professional and public education materials in print and audio-visual formats, including free brochures on burn prevention and first aid.

The Institute responds to a wide range of requests from medical professionals, lawyers, manufacturers, teachers, students, and the public. When staff research time is required, there is a fee for services, which is lower for community service organizations and other nonprofit groups. Inquirers are asked to send written requests, outlining how the information they need will be used.

National Institute of Allergy and Infectious Diseases (NIAID)
National Institutes of Health
U.S. Department of Health and Human Services
Building 31
Room 7A32
Bethesda, MD 20892
(301) 496-5717

Handicapping Conditions Served: Allergies and infectious diseases of all kinds; also transplantation and immune deficiency disease.

Users Served: Disabled persons, health care professionals, medical researchers, general public.

The Organization: NIAID supports a multimillion dollar research effort across the country at research institutions, aimed at a better understandin; of the causes of allergic, immunologic, and infectious diseases and to the development of better means of preventing, diagnosing, and healing these illnesses. Some of the studies are of infectious agents found in other countries, which cause death or severe handicaps for people living in the tropics and other areas outside of the U.S. (e.g., malaria and other parasitic diseases, leprosy, cholera, and viral diarrheas).



NIAID supports Asthma and Allergic Disease Centers in 15 institutions which translate basic concepts in immunology, genetics, biochemistry and pharmacology into clinical research. Six Comprehensive Immunologic Research and Disease Centers study immunologic diseases.

Information Services: NIAID provides general information about disorders currently being studied at the Asthma and Allergic Disease Centers and the Immunologic Centers. Two tenminute slide shows are available: "What You Should Know about Asthma" and "How to Cope with Your Environment If You Have Allergies." The Institute has numerous publications for the lay person which cover the range of infectious diseases and allergies (e.g., asthma, genital herpes, sinusitis, the common cold, influenza, and viral hepatitis). Booklets are also available on viruses and bacteria and on bacterial meningitis, rabies and sexually transmitted diseases. A 28-minute color film called "Jennifer" describes genital herpes, including diagnosis, treatment, and research efforts underway to control this recurrent disease.

NIAID does not make referrals to sources of financial assistance for medical care, transportation, etc.

National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases (NIADDK)
National Institutes of Health
U.S. Department of Health and Human Services
Building 31
Room 9A04
9000 Rockville Pike
Bethesda, MD 20892
(301) 496-3583

Handicapping Conditions Served: Arthritis, diabetes, digestive diseases, endocrine and metabolic disorders, kidney and urinary tract infections. Specific disorders include such diseases as: ulcer, colitis, ileitis, systemic lupus erythematosus, gout, scoliosis, cystic fibrosis, osteogenesis imperfecta, and others.

Users Served: General public.

The Organization: NIADDK supports millions of dollars of research each year on the causes of and improved treatment for more than 100 different forms of tissue diseases; diabetes and other metabolic disorders; digestive diseases and nutrition; diseases of the kidney and urinary tract; and certain diseases of the bones and skin. NIADDK also supports Multipurpose Arthritis Centers that emphasize research and pilot programs in health education. Most centers have clinics.

Information Services: NIADDK's Arthritis Information Clearinghouse and its National Diabetes Information Clearinghouse (see separate entries) work with health educators and health professionals and handle requests for professional literature. At the central information office of NIADDK (address above), basic brochures are available on How to Cope with Arthritis, and on several other subjects (cystic fibrosis, urinary tract infections, kidney dialysis, systemic lupus erythematosus, peptic ulcer, and gout). Lists of the NIADDK Multipurpose Arthritis Centers and Diabetes Research and Training Centers are also available.

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National Institute of Dental Research (NIDR)
National Institutes of Health
U.S. Department of Health and Human Services
Building 31
Room 2C35
Bethesda, MD 20892
(301) 496-4261

Handicapping Conditions Served: Dental diseases and disorders of the craniofacial area, including cleft lip and cleft palate.

Users Served: Dental professionals, other medical professionals, disabled persons, general public.

The Organization: The National Institute of Dental Research (NIDR) is the chief sponsor of dental research and related postdoctoral training in the United States. NIDR studies relate to the cause, prevention and methods of diagnosis and treatment of dental disease and conditions.

Information Services: The NIDR information program provides members of the dental profession and the lay public with reports of dental research progress.

For the professional, periodic iscuances of NIDR Research News provide reports of current research activities. The Institute also funds state-of-the-art conferences and workshops and makes the published proceedings of these meetings available. Exhibits depicting research findings and known methods of dental disease prevention are developed and shown at medical/dental, scientific, and health educator meetings. Films on topical fluorides and dental scalants, both useful methods in the prevention of dental caries in the general public and in the handicapped patient, are available as teaching tools for dental clinicians.

For the lay person, pamphlets on general dental health and on specific problems of relevance to the Institute (e.g., Cleft Lip and Cleft Palate) are distributed to the general public. Inquiries from the public are answered with information from the latest research reports and citations to the general dental literature. When appropriate, information is supplied regarding grantee institutions where possible service can be offered to the handicapped patient.

National Institute of Neurological and Communicative Disorders and Stroke (NINCDS)
National Institutes of Health
U.S. Department of Health and Human Services
Building 31
Room 8A-16
Bethesda, MD 20892
(301) 496-5751

Handicapping Conditions Served: Neurological disorders in general, communicative disorders in general, cerebrovascular disease, metabolic disorders affecting the nervous system, head and spinal cord injury.



Users Served: Disabled persons, parents, teachers, health professionals, voluntary health organizations.

The Organization: NINCDS is one of 11 research institutes making up the National Institutes of Health. The Institute's mission is to conduct, support, and coordinate research in the causes, prevention, diagnosis, and treatment of neurological and communicative disorders and stroke, and in basic sciences relevant to these problems. Support of postdoctoral training for research careers is also a basic component of the Institute's mission

The Institute supports clinical research centers at university medical complexes, where patient research is conducted on epilepsy, stroke, spinal cord injury, multiple sclerosis, neural prostheses, and other neurological conditions. The Institute also collects and disseminates information on research in its field.

Information Services: NINCDS maintains an Office of Scientific and Health Reports (GSHR) whose services are available free to both lay and professional users. Inquiries about the Institute program, neurological and communicative disorders, and research progress in these fields are answered by phone and mail. Approximately 60 publications are kept in stock and sent out in response to inquiries. Publications include a "Hope through Research" series of 17 pamphlets (many covering disabling conditions), a fact sheet series consisting of 11 titles, and 10 miscellaneous pamphlets, reprints, and other publications. Annual special reports on research progress in the major neurological and communicative areas are available, as well as scientific and technical documents, such as a monograph series containing reviews, reports of advisory committees, and proceedings of scientific meetings. A publications list and single copies of NINCDS publications are available free to individuals; organizations may order small quantities for their own distribution. A monthly news service, "NINCDS Notes," is available to journals and newspapers.

NINCDS supports scientific reference services in the fields of epilepsy and stroke. The epilepsy service is a periodical, Epilepsy Abstracts, published by Elsevier Scientific Publishing Group, with headquarters in Amsterdam, The Netherlands. The stroke service consists of abstracts appearing in the journal, Stroke, A Journal of Cerebral Circulation, published by the American Heart Association, (see separate entry).

For further information, call or write the Office of Scientific and Health Reports at the above address.

National Library of Medicine (NLM)
National Institutes of Health
U.S. Department of Health and Human Services
8600 Rockville Pike
Bethesda, MD 20894
(301) 496-6095

Handicapping Conditions Served: All handicaps.

Users Served: Physicians, research scientists, clinicians, other health professionals.

The Organization: The National Library of Medicine is a part of the National Institutes of Health (NIH), one of the five health agencies of the Public Health Service. The Library was established in 1836 as the Library of the Army Surgeon General's Office and remained



under the armed forces until 1956, when it was designated as the National Library of Medicine and placed within the Public Health Service by an Act of Congress.

The world's largest research library in a single scientific and professional field, the Library serves as the nation's chief medical information source. The Library, which collects materials exhaustively in approximately 40 biomedical areas, has holdings of about three and a half million books, journals, technical reports, theses, microfilms, and other materials.

Information Services: The Library's computer-based Medical Literature Analysis and Retrieval System (MEDLARS) was established to achieve rapid bibliographic access to NLM's store of biomedical information. It became operational in 1964 with the publication of the first computer-produced issue of Index Medicus, a comprehensive, monthly subject-author index to articles from approximately 2600 of the world's biomedical journals. The principal objective of MEDLARS is to provide references to the biomedical literature for research scientists, clinicians, and other health professionals. MEDLARS contains over four million references dating from 1964 and covering virtually all handicapping conditions, rehabilitation medicine, and rehabilitation engineering. MEDLINE (MEDLARS On-Line), which became operational in late 1971, provides the capability in medical libraries around the country to query the NLM computer's store of journal article references for quick retrieval. MEDLINE contains over 500,000 recent references.

Other computerized data bases developed by NLM include the following (numbers of records contained in these files are from May 1985):

- TOXLINE (Toxicology Information On-Line) is a collection of 1.6 million references from the last five years on published human and animal toxicity studies, effects of environmental chemicals, and adverse drug reactions.
- CANCERLIT (Cancer Literature) is sponsored by NIH's National Cancer Institute and contains more than 450,000 references on various aspects of cancer.
- AVLINE (Audiovisuals On-Line) is a file of about 14,000 audio-visual teaching packages used in health sciences education at the college level and for the continuing education of practitioners.
- HEALTH PLANNING & ADMIN (Health Planning and Administration) contains about 310,000 references to literature on health planning, organization, financing, management manpower, and related subjects. (This file may be accessed through BRS Information Technologies and DIALOG, see separate entries).
- BIOETHICSLINE, developed at the Center for Bioethics, Kennedy Institute of Ethics, Georgetown University, gives bibliographic information on questions of ethics and public policy arising in health care or biomedical research. It contains about 18,000 records.

Seven Regional Medical Libraries, each responsible for a geographic area, coordinate NLM's on-line search services in the United States. In addition to conducting searches themselves, they can provide the user with the location of the nearest on-line center with access to NLM data bases. (There are over 3,300 of these centers located in hospitals, universities, state libraries, organizations, and companies throughout the country). The charge for NLM searches varies with each Regional Medical Library and local center; in some cases there is no cost to certain classes of users. The Regional Medical Libraries also handle requests for health literature not available locally, referring to NLM requests they cannot fill. Inquirers may contact NLM for the location of the Regional Medical Library serving their area.



NLM publications include <u>Index Medicus</u>, described above, <u>Abridged Index Medicus</u>, <u>NLM Current Catalog</u>, <u>NLM Audiovisuals Catalog</u>, and published literature searches on a variety of topics. A list of publications with ordering information is available upon request.

Direct access to MEDLARS and MEDLINE is also available through BRS Information Technologies and DIALOG (see separate entries).

National Library Service for the Blind and Physically Handicapped (NLS)
Library of Congress
1291 Taylor Street, NW
Washington, DC 20542
(202) 287-5100

Handicapping Conditions Served: Blindness, visual impairment: deaf-blindness, reading disabilities resulting from organic dysfunction, and other physic: I limitation that prevents the normal use of standard printed material.

Users Served: Disabled persons, parents, teachers.

The Organization. The National Library Service for the Blind and Physically Handicapped (NLS) collection of full-length braille and talking books and magazines produced for blind and physically handicapped readers is loaned free to individuals who cannot hold, handle, or read conventional printed matter. Books, magazines, and playback equipment provided by NLS are distributed through a national network of 160 locally funded cooperating libraries and agencies where they are circulated to eligible residents of the United States and its territories. NLS has developed a national automated bibliographic service that enables cooperating network libraries to identify and locate books produced in special formats for handicapped readers.

NLS trains and certifies volunteers in braille transcribing and in braille proofreading. Eligible readers can request that a local volunteer group braille or record materials they cannot locate elsewhere. Volunteers Who Produce Books: Braille, Tape, Large Type is a directory that lists by state the names of volunteer groups and individuals who transcribe and record books and other reading materials for blind and physically handicapped persons. Voice auditions and informal training are given to organized groups of volunteer tape narrators. The Telephone Pioneers of America, senior or retired telephone industry workers, maintain and repair playback equipment.

Information Services: Questions on various aspects of blindness and physical handicaps may be sent to NLS or to any network library. Reference circulars, bibliographies, directories and other compilations of information are free on request. The national book collection includes more than 35,000 titles of bestsellers, classics, gothic and romantic novels, mysteries, science fiction, history, biography, religion, poetry, essays, how-to-do-it books, foreign language materials, and children's books. The children's collection includes a number of special books that combine print with braille, enabling blind and sighted children and adults to read together. Some of these print/braille books are illustrated with fragrance strips that emit scents when scratched. Currently recorded and brailled books are announced in the bimonthly magazines, Talking Book Topics and Braille Book Review. Eligible readers receive these publications in large type, recorded, and/or braille versions.



Seventy magazines on disk and in braille are offered through the program. Readers majequest free subscriptions to Harper's, U.S. News and World Report, National Geographic, Sports Illustrated, and many other popular magazines. Current issues are mailed to readers at about the same time the printed issues appear.

Playback equipment is loaned free to readers for as long as library materials are being borrowed. Talking-book machines are designed to play disk recorded books and magazines at 8 rpm and 16 rpm, cassette book machines are designed for cassettes recorded at 15/16 ips and the standard spped of 1.7/8 ips as well as on 2 tracks and 4 tracks. Available accessories for playback equipment include earphones and pillowphones. An auxiliary amplifier for hearing-impaired persons is available from NLS on special request.

National Parkinson Foundation 1501 N.W. Ninth Avenue Miami, FL 33136 (305) 547-6666

Handicapping Conditions Served: Parkinson's disease, multiple sclerosis, and many related neurological disorders.

Users Served: Disabled persons, health care professionals, researchers.

The Organization: The National Parkinson Foundation supports the National Parkinson Institute, which provides outpatient diagnostic, treatment, and rehabilitation services to patients with Parkinson's disease and related neurological diseases, such as multiple sclerosis. The Foundation also funds the Bob Hope Parkinson Research Center, which investigates the causes and treatment of Parkinson's disease. The Center is affiliated with the University of Miami Department of Neurology, which conducts research into other neurological disorders as well. The Foundation offers research grants to other medical centers for Parkinson's disease.

Information Services: The Foundation publishes a periodic research newsletter, of interest to both lay and professional readers. Additional publications include What the Patient Should Know About Parkinson's Disease and Psychological Factors in the Management of Parkinson's Disease. All Foundation publications are free in limited quantities.

National Rehabilitation Information Center (NARIC) 4407 Eighth Street, NE
The Catholic University of America
Washington, DC 20017-2299
(202) 635-5826 (Voice and TDD)
(800) 34-NARIC

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, parents, teachers, administrators, direct service providers, researchers, educators, students.

The Organization: The National Rehabilitation Information Center (NARIC) is a rehabilitation information center and research library funded by the National Institute of Handicapped Research, U.S. Department of Education, to make NIHR and Rehabilitation



Services Administration research available and to develop supplementary materials and strategies to foster research utilization. NARIC offers information on disability products, research and resources. NARIC's collection includes documents and audio-visual materials produced by NIHR-funded projects and a core library of rehabilitation materials.

Information Services: The NARIC computerized data base, REHABDATA, covers all aspects of the rehabilitation field, and contains bibliographic data and abstracts on reports, journals, and audio-visuals in the Center's collection. The data base contains over 12,000 citations. NARIC performs customized searches of this file and of other relevant commercially available computerized data bases. There is a nominal charge for these services. The NARIC data base is also available publicly through BRS information Technologies (see separate entry). Copies of documents cited in the data base may be obtained for a photocopying fee.

NARIC also produces ABLEDATA, a computerized source of information on commercially available products for rehabilitation and independent living. ABLEDATA contains over 12,000 listings. Products are included for activities of daily living and recreation, home management, communication, transportation, mobility, ambulation, and other areas. Requests may be made for ABLEDATA searches by contacting NARIC or publicly through BRS. NARIC'S library contains catalogs and other literature on all the products included in ABLEDATA, as well as manufacturers' names and addresses.

NARIC offers general brochures and publications, and flyers describing its services and materials. Via D:ATA Institute, NARIC distributes <u>Current D:ATA</u>, a quarterly newsletter focusing on rehabilitation and special education technology. NARIC also produces the Rehabilitation Research Review series, state-of-the-art publications providing a topical summary of the research literature on key rehabilitation topics. Other publications available include <u>The Author's Handbook: A Guide to Professional Journals in Rehabilitation</u>; The Periodical List: A Guide to Disability-Related Journals and Newsletters; The Resource Directory: A State Guide to Disability-Related Information; REHABDATA Thesaurus, and ABLEDATA Thesaurus. NARIC also offers resource guides on a variety of topics, including appropriate references:

NARIC's information specialists provide reference services, helping inquirers locate names, addresses, statistics and other factual information. Users may consult NARIC's collection of books and audio-visuals at the Center.

National Resource Center for Paraprofessionals in Special Education (NRC)
New Careers Training Laboratory
City University of New York
33 West 42nd Street
New York, NY 10036
(212) 840-1278
(212) 840-7619

Handicapping Conditions Served: All handicaps.

Users Served: Public school administrators, directors of community-based programs for disabled people, teacher educators, staff developers.

The Organization: The National Resource Center for Paraprofessionals in Special Education and Related Services (NRC) was established in 1979 by the New Careers Training



Laboratory Center of the City University of New York. Its mission is to promote an increase in the use of trained paraprofessionals in special education.

Information Services: NRC disseminates information for the use of employers, program managers and trainers on such issues as skills and competencies needed by paraprofessionals, credentialing, new roles for paraprofessionals in education and related services, career mobility, and funding sources. The Center also has information on pre and in-service training models and training materials in use by state and local education agencies and by institutions of higher education.

Besides a quarterly newsletter, New Directions, NRC publications include the Paraprocessional Bibliography: Training Materials, Resources and Programs for Paraprofessionals Working in Educational Programs for Persons with Handicapping Conditions (1981); Special Needs, Special People, which examines the state of training programs for special education paraprofessionals throughout the nation (1980); Paraprofessionals in Special Education: The State of the Art, which gives results of a survey of state departments of special education covering the use and training of paraprofessionals over the last decade; and The Employment of Paraprofessionals in Special Education. There is a charge for postage and handling of the publications and a subscription fee for New Directions.

In addition, technical assistance is available to state and local education agencies and institutions of higher education through the NRC.

The Center's services are available to all agencies concerned with the delivery of educational services to children with handicapping conditions.

National Spinal Cord Injury Hotline (SCIH) 22 S. Greene Street Baltimore, MD 21201 (800) 526-3456 (Nationally) (800) 638-1733 (In Maryland)

Handicapping Conditions Served: Spinal cord injuries.

Users Served: Disabled persons and their families and friends, health care professionals.

The Organization: The focus of the Spinal Cord Injury Hotline (SCIH) is to provide consumers, spinal cord injury patients, families and friends with up-to-date information and referral resources. Additionally, the caller is given peer support and encouragement. Through a toll-free 24-hour hot line, spinal cord victims (both new and existing injuries) are linked with a local contact person with a similar level of injury and age who lives near the caller's community. The contact person provides peer support and assistance in locating physicians, services, equipment, etc. The hot line is located at the National Study Center for Emergency Medical Systems (NSC/EMS), established by the Maryland Institute for Emergency Medical Services Systems (MIEMSS) which provides staff and other support.

Information Services: The Hotline provides specific information and referral on a variety of topics including: acute injury care, rehabilitation, activities of daily living, research, local contacts and spinal cord injury organizations. Callers are referred to local contacts for specific questions about their community and accessing services in a particular area. Some local contacts offer 24-hour information and referral; all are operational at least five days a week during business hours. The Hotline is planning to publish pamphlets and a newsletter.



National Technical Information Service U.S. Department of Commerce 5285 Port Royal Road Springfield, VA 22161 (703) 487-4600 (For General Information) (703) 487-4642 (To Order Search) (703) 487-4650 (To Order Documents)

Handicapping Conditions Served: All handicaps.

Users Served: Business, educators, government, and the public.

The Organization: The National Technical Information Service (NTIS) is an agency created by Congress in 1950 to provide technical reports and other information products of specialized interest to business, educators, government, and the public. NTIS is the central source for the public sale of U.S. and foreign government-sponsored research, development and engineering reports, and other analyses prepared by national and local government agencies, their contractors or grantees, and other technical groups. The NTIS information collection exceeds 1.3 million titles, all for purchase. About 200,000 of these are of foreign origin. As directed under legislative mandate, NTIS functions on a cost recovery basis; all the costs of its products and services are paid from sales income.

Information Services: Customers may use NTIS's on-line computer service to identify abstracts of interest from the Bibliographic Database, which contains over one million federally sponsored research reports completed and published from 1964 to date. Most of the documents cited are available only through NTIS. This data base contains documents on handicapping conditions and programs for disabled persons, including rehabilitation, rehabilitation engineering, transportation, and health care. Before initiating a search, users may consult with NTIS information specialists, who will determine the likelihood of retrieval of relevant documents. Published searches on over 3,000 topics of wide interest may be ordered from NTIS. These are listed in the Master Catalog of Published Searches, available without charge (ask for PR-186). Direct U.S. on-line access to the Bibliographic Database may be arranged through BRS Information Technologies, DIALOG, the System Development Corporation (see separate entries), or Mead Data Central:

The Government Reports Announcements and Index Journal lists summaries of U.S. government research on a biweekly basis. It is indexed by key word, personal and corporate author, government/contract grant number, and report number. In addition, 27 Abstract Newsletters provide readers with research summaries within three weeks of their receipt by NTIS from the originating agencies. Abstract Newsletters of interest to professionals in the handicapped field include the following: Behavior and Society, Biomedical Technology and Human Factor Engineering, Health Planning, and Medicine and Biology.

Selected Research in Microfiche (SRIM), a subscription service available in 500 subject categories, provides on a biweekly basis full text microfiche copies of reports in only the subject areas selected by the requestor.

The Federal Software Exchange Center, operated by NTIS, serves as a clearinghouse of federally created computer programs. An annual catalog lists products and the agencies from which they are available.



NTIS publishes many other periodicals and catalogs containing technical information on safety statistics, human services, municipal information systems, and other specialized subjects. In addition, a number of periodicals and reports make available information on research performed outside of the U.S., political and economic analyses of foreign countries, and foreign news releases and articles from periodicals. The free catalog NTIS Information Services describes all products and services of the agency.

NTIS also prepares a data base called Federal Research in Progress (FEDRIP) which carries summaries of research in progress from the Veterans Administration, the National Institutes of Health, the Department of Energy, the National Science Foundation and other Federal agencies. The file is updated twice a year and on-line access is available through DIALOG (see separate entry) and Mead Data Central. Output received by the user contains essential information about each project, including the supporting agency, the performing organization, the principal investigator, the time covered by the project, and, in most cases, a 200-word description of the research. No further information product is available from NTIS from this file. For further information on any project included in the file, contact the project's principal investigator at the address listed in the summary.

Office of Cancer Communications
National Cancer Institute (NCI)
National Institutes of Health
U.S. Department of Health and Human Services
Bethesda, MD 20892
800-4-CANCER
In Maryland: (800) 492-6600

Handicapping Conditions Served: All cancers.

Users Served: Health professionals, cancer patients, and the general public.

The Organization: NCI conducts and funds the Nation's major cancer research program. NCI grants and contracts support cancer research in most of the Nation's university medical centers and many other non-Federal institutions. NCI also coordinates the cancer research programs of Federal and private institutions in accordance with a constantly updated National Cancer Program, which encompasses the lines of research effort considered to be most important in solving the major problems of cancer.

A network of 20 Comprehensive Cancer Centers around the country engage in the wide range of cancer-related research and demonstration, encompassing basic research, diagnosis, treatment, rehabilitation, public and patient education. The Centers also educate and train professionals in the various clinical and research specialties.

At the community level, patients may be admitted to clinical studies conducted by NCI Clinical Cooperative Groups. These groups exist at hospitals throughout the United States and involve thousands of physicians. Investigational drugs are provided free by the NCI.

NCI also supports 22 Clinical Cancer Centers, centers specializing in cancer treatment, and 17 Non-Clinical Cancer Centers. Information about Cancer Center and Cooperative Group programs is available from the Office of \_\_\_\_\_er Communications.



Information Services: To speed the translation of research resu'ts into Widespread application, the National Cancer Act of 1981 authorized a Cancer Control Program to demonstrate and communicate to both the medical community and general public the latest advances in cancer prevention and management. The program identifies cancer knowledge and technology and makes it available to health practitioners and the public through cooperative efforts with private and community organizations. Prevention, detection, and treatment information is prepared by NCI and distributed through community-based organizations and Comprehensive Cancer Center's communications offices to high-risk groups.

The Cancer Information Service (CIS) is a toll-free telephone hot line, which supplies information about cancer and resources available to cancer patients. Regional CIS offices serve about 70 percent of the U.S. population; the remainder is served by the CIS at the National Cancer Institute in Bethesda, MD. CIS offices can provide specific information on particular cancer sites, detection programs, local resources for cancer patients (e.g., treatment and rehabilitation facilities, home care assistance, availability of transportation) and facts about the process of patient referral to physicians and consultation among health professionals. Information about possible causes of cancer, how to help prevent cancer, and how different forms of cancer are detected also is available. For the nearest CIS office, consult the white pages of your telephone directory or call the appropriate telephone number listed above.

NCI's Office of Cancer Communications distributes printed materials free of charge to the general public, patients, and health professionals. These include general pamphlets about cancer, its causes, preventions, and treatment, as well as publications on specific types of cancer, guidelines for patients undergoing therapy, and resource booklets for professionals. A list of publications distributed by the NCI is available from the Office of Cancer Communications, listed above.

NCI's Organized Dissemination Projects, multimedia information activities, center on specific topics. Health planners and communicators review the state of knowledge in particular subject areas and produce educational materials covering such topics as treatment options, diagnosis, and prevention. Dissemination projects have included smoking, breast cancer, coping with cancer, and asbestos. Hundreds of thousands of patient information and physician kits are distributed, along with posters, slide-tape presentations, and booklets on each topic. Materials are tested by NCI for effectiveness before being used in the projects.

NCI also supports the Cancer Information Clearinghouse (see separate entry) which documents the availability of cancer education materials around the country.

The monthly <u>Journal of the National Cancer Institute</u> presents original reports of cancer research by scientists around the world. Other NCI publications include the <u>Monograph Series</u> for proceedings of scientific meetings and other lengthy reports, and <u>Cancer Treatment Reports</u>.

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Office on Smoking and Health
Technical Information Center (TIC)
U.S. Department of Health and Human Services
Parklawn Building
Room 1-16
5600 Fishers Lane
Rockville, MD 20857
(301) 443-1690

Handicapping Conditions Served: Smoking-related health problems.

Users Served: Researchers and health professionals.

The Organization: Established in 1978, the Office on Smoking and Health (formerly the National Clearinghouse for Smoking and Health) is the U.S. Public Health Service program most concerned about the health hazards of smoking. Its Technical Information Center (TIC) collects, organizes, and disseminates the world's literature on smoking and its effects on health. TIC's scientific and technical collection comprises over 55,000 hard copy reports on all aspects of smoking and health. In addition, a bibliographic data base has more than 50,000 records in machine-readable form. It is expected that this file will be greatly expanded over the next three years. During 1980, TIC's numerical data base became operational. Survey research information from several smoking and health sources is available through this service.

Information Services: Computer searches of TIC's bibliographic data base are performed upon request; users are asked to submit completed Search Request Forms, available from TIC. Both technical and public education publications may be obtained from the Center, and include the Bibliography on Smoking and Health, the Directory of On-Going Research in Smoking and Health, and the Smoking and Health Bulletin, a current awareness periodical listing references on all aspects of smoking and health. Current research from the Directory is available in machine-readable form. Reprints of articles included in the Bulletin are available on a limited basis. There is no charge for TIC services and publications.

Parkinson's Disease Foundation (PDF) William Black Medical Research Building Columbia University Medical Center 640 W. 168th Street
New York, NY 10032 (212) 923-4700

Handicapping Conditions Served: Parkinson's disease and related disorders.

Users Served: Disabled persons, parents, teachers, therapists, other health care professionals.

The Organization: The Parkinson's Disease Foundation is primarily a research organization. It supports the Parkinson Research Laboratories at Columbia University Medical Center, where research is conducted in neuropharmacology, neurophysiology, neuropathology, and neurovirology. Patient care and services are provided through Presbyterian Hospital's Vanderbilt Clinic and Neurological Institute. In 1960, the Foundation established a Brain Bank at Columbia University Medical School to give scientists the opportunity to study the brains of deceased Parkinson patients. The Foundation awards research grants and fellowships to investigators at Columbia and other medical schools. It sponsors symposia



where scientists from the United States, Europe, and the Orient present findings of their long-term studies of Parkinson's disease. The Foundation also sponsors patient conferences.

Information Services: Proceedings from the symposia and other reports are published and distributed to all medical practitioners and institutions requesting them. For the lay and professional inquirer, the Foundation provides general information about Parkinson's disease. Some information is available in Spanish. These booklets are published by the Foundation specifically for the patient and his family: The Parkinson Patient at Home, Exercises for the Parkinson Patient, and Parkinson's Disease: Progress, Promise and Hope. A film is available on loan to health care groups and groups of patients, "Management of Parkinson's Disease and Syndrome with Levadopa." The Foundation also publishes the PDF Newsletter three times annually to report on research developments and other items of interest; it is also available on cassette. An Annual Research Report covers projects undertaken by the PDF research group. The Foundation will refer patients and family members to specialists and to self-help groups.

Polic Information Center (PIC) 510 Main Street Suite A446 Roosevelt Island, NY 10044 (212) 223-0353

Handicapping Conditions Served: Poliomyelitis and post polio.

Users Served: Disabled persons, physicians, health professionals.

The Organization: The Polio Information Center (PIC) attempts to locate and list on computer post-polio individuals throughout the country in order to gather information about present health status, disseminate information on post-polio research and locate health care professionals who are knowledgeable about post-polio care. PIC offers referral services for people who had polio to physicians and other health care professionals. The Center has begun networking across the country. As they are organized, regional groups are listed with the Center and become part of the national network.

Information Services: The Polio Information Center News is an annual newsletter sent to all members which includes survey results, news updates and conference reports. The Center provides referrals to local physicians around the country who are familiar with post-polio care. Referrals are also made for shoes, clothing, orthotists and to support groups across the country. Information is also provided on conferences and publications. The PIC maintains a computer listing of over 2,000 individuals who had polio and knowledgeable physicians. Statistical data on types of polio, medical problems and years of onset is available. Membership dues are charged.

Project SHARE
National Clearinghouse for Improving the Management
of Human Services
1530 East Jefferson Street
Rockville, MD 20852
(301) 231-9539

Handicapping Conditions Served: All handicaps.



Users Served: Human services managers.

The Organization: Established in 1975, Project Share (National Clearinghouse for Improving the Management of Human Services) compiles and disseminates information on human services planning, administration, and evaluation to human services managers. The Project is operated by Berul Associates, Ltd. for the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.

Information Services: Users may request searches of Project Share's bibliographic data base, which includes records of documents on services integration, model programs, cost analysis, and records management. Copies of most documents cited, which include working papers, project descriptions, manuals, feasibility studies, conference proceedings, and reports prepared by Federal, state, and local government agencies, government contractors, and national associations, are available from the Project or the National Technical Information Service (see separate entry). Sources for other documents are clearly indicated in the printout which also gives descriptive abstracts of each publication. Among topics of interest to professionals in the handicapped field are the following: deinstitutionalization, normalization of the lives of chronically ill and disabled persons, alternative care, advocacy, and transportation services for handicapped persons.

The <u>Journal of Human Services Abstracts</u>, published quarterly by the Project, provides in each issue approximately 300 bibliographic citations and abstracts of all documents recently added to the data base. It is restricted to items acquired by the Clearinghouse and is not meant to provide comprehensive coverage of the field.

Project Share also publishes the following: (1) monographs which survey the literature and state of the art in various areas of human services and management; (2) annotated bibliographies of Project Share materials on selected topics of major interest to human services planners and managers; (3) comprehensive summaries of major documents in the Project collection; and (4) a newsletter which highlights social services and information programs, new publications, and current research problems, and announces selected national meetings of interest to readers.

The Project's reference service provides individuals and organizations with information on any topic within the scope of the Project. In addition to customized bibliographies generated from the Project's data base, inquirers may receive manually prepared citations and referrals to other organizations. There is a charge for searches and most publications. Project Share publishes a Highlight Catalogue which lists some of the publications available and which also contains membership information.

Psychological Abstracts Information Services American Psychological Association 1200 17th Street, NW — Washington, DC 20036 (800) 336-4980 (Except Virginia) (703) 247-7829 (Virginia)

Handicapping Conditions Served: All handicaps.

Users Served: Psychologists, educators, health care professionals.



The Organization: Part of the American Psychological Association, a professional society of psychologists and educators, Psychological Abstracts Information Services (PsycINFO) is a family of interrelated information services providing a variety of ways to access the world's published literature in psychology and related behavioral and social sciences.

Information Services: PsycINFO publishes the Psychological Abstracts (PA) journal, a comprehensive monthly compilation of non-evaluative summaries of the world's literature in psychology and related disciplines. Each year PsycINFO scans materials from over 1300 periodicals and conference reports, technical reports, and monographs for inclusion in PA and the PsycINFO data base. Among the 16 major classification categories according to which abstracts are grouped are the following: "Physical and Psychological Disorders," "Psychometrics," "Treatment and Prevention," and "Educational Psychology," which includes special education. Documents on the characteristics of physically and psychologically disabled populations and their treatment may be found under these categories. PA's Volume Index, a subject and author index, is published yearly; cumulative indexes from 1969-71, 1972-74, 1975-77, 1978-80, and 1981-83 are available.

Three PsycScan publications, quarterly current awareness journals, are available in the areas of clinical, developmental and applied psychology. A fourth quarterly journal, <u>PsycScan</u>: <u>LD/MR</u>, covers learning disabilities, communication disorders, and mental retardation. To complement <u>PsycScan</u>: <u>LD/MR</u>, PsycINFO has published two comprehensive bibliographies, <u>PsycINFO Retrospective</u>: <u>Mental Retardation</u> and <u>PsycINFO Retrospective</u>: <u>Learning and Communication Disorders</u>.

Computer searches of the PsycINFO data base from 1967, a file containing nearly 480,000 items, may be ordered from PsycINFO. Approximately 28% of the documents included in this on-line data base concern characteristics of physically and psychologically impaired persons and their treatment. In addition, about 14% of the documents in the data base are on educational research; items on handicapped students form a subset of these records. Many of the terms used by PsycINFO's information specialists to search this file are related to specific handicapping conditions and treatment, including physical and mental disorders; attitudes towards mental illness, mental retardation, physical handicaps, and sensory handicaps; rehabilitation; and special education and mainstreaming. These keywords are listed in the Thesaurus of Psychological Index Terms which may be purchased from PsycINFO. Descriptions of Psychological Index Terms which may be purchased from request. Direct on-line access to the PsycINFO data base may be arranged through BRS Information Technologies, the System Development Corporation, or DIALOG Information Services, Inc. (see separate entries).

Research to Prevent Blindness 598 Madison Avenue New York, NY 10022 (212) 752-4333

Handicapping Conditions Served: Blindness and visual impairments.

Users Served: Opthalmologists, other vision researchers, general public.

The Organization: Research to Prevent Blindness provides financial support to ophthalmology departments of more than 50 U.S. medical schools for the purpose of scientific research on the causes, prevention, diagnosis and treatment of visual disorders. It has supported the development of techniques such as laser treatment, vitrectomy, microsurgery and therapeutic use of contact lenses as well as extensive basic studies of the



eye and its diseases. Incentives are provided to attract outstanding scientists to eye research through annual awards.

Information Services: RPB provides information concerning vision research to news media, legislators, practicing ophthalmologists and the public. The RPB National Science Writers Seminar in Eye Research, conducted every several years, brings together outstanding vision scientists, news editors and writers for reports and discussions of progress in the management and prevention of blinding eye diseases. RPB publishes the formal scientific reports for dissemination to the nation's practicing eye physicians. RPB answers general inquiries about eye research on a limited basis. It does not offer specific advice or recommendations on individual eye problems. All applications for support of vision research must be made through chairmen of departments of ophthalmology.

Rural Rehabilitation Technologies Database (RRTD) Medical Center Rehabilitation Hospital (MCRH) Box 8202 University Station Grand Forks, ND 58202 (701) 780-2489

Handicapping Conditions Served: All disabilities.

Users Served: Disabled persons, parents, teachers, physical and occupational therapists, rehabilitation engineers, vocational rehabilitation counselors.

The Organization: The Rural Rehabilitation Technologies Database (RRTD) is an effort to identify and catalog those innovations, inventions and ideas which have benefit for persons with disabilities living in rural settings. The RRTD is a joint project of the Engineering Experiment Station (EES) of the University of North Dakota and the Medical Center Rehabilitation Hospital (MCRH). Many of these devices, ideas and products, designed or developed by or for use by people in rural areas, have never been published or shared with others. The RRTD provides a means by which ideas and information can be stored in a data base and extracted as needed to help those interested in rural rehabilitation technolog. The information will be published in catalog form and will also be available on diskette for use with personal computers.

Information Services: A descriptive brochure of the RRTD project is available. It is anticipated that the RRTD catalog of ideas and products stored in the databank will be published early in 1986. Also included in the catalog will be bibliographies of rural rehabilitation services and technology publications, resources and related subjects. Individuals are encouraged to share their ideas, devices or products by submitting them for entry into the database. The registration form available from RRTD allows for pr tection if the idea is not yet patented.

The RRTD provides technical assistance with invention registration and disclosure for those devices not currently patented or commercially available. The project will also refer direct inquiries concerning rural rehabilitation technology to appropriate organizations.

EES and MCRH are the originating and co-host organizations for the Internation (I Conference on Rural Rehabilitation Technology (ICRRT).



Sociological Abstracts, Inc. (SA) P.O. Box 22206 San Diego, CA 92122 (619) 565-6603

Handicapping Conditions Served: All handicaps.

Users Served: Researchers, administrators, professionals.

The Organization: Founded in 1953 by a group of sociologists, Sociological Abstracts (SA) has continued to provide non-evaluative abstracts from core and relevant journal literature in sociology and related disciplines. SA's collection contains material on the sociological aspects of handicapping conditions, including major diseases, mental illness, and physical disabilities, provided the authors are sociologists and/or the articles are written from the conceptual view of sociology.

Information Services: Researchers, administrators, and other users may obtain custom searches of SA, including searches of pre-1963 records, and of related data bases. Cost estimates for these searches may be prepared in advance without obligation.

In addition to Sociological Abstracts, SA Inc.'s major subscription journal, Linguistics and Language Behavior Abstracts (LLBA) is also available on a subscription basis. This journal is devoted to linguistics and related disciplines, and its contents may be searched by SA. LLBA contains abstracts on learning disabilities from a large serial base.

The following publications are also available from SA Inc. <u>International Review of Publications in Sociology</u> (IRPS), which lists sociology books and book reviews published in sociology journals; <u>Supplements</u>, containing abstracts of papers presented at regional, national, and international meetings of sociologists; and <u>Social Welfare</u>, <u>Social Policy</u>, and <u>Social Development</u> (SOPODA), SA Inc.'s new publication of non-evaluative abstracts in the three title areas.

Searches of the <u>SA</u>, <u>LLBA</u>, <u>SOPODA</u>, and <u>IRPS</u> files are available on-line through DIALOG and BRS Information Technologies (see separate entries). In Europe <u>SA</u> and <u>LLBA</u> are available on Data Star.

Tel-Med, Inc. National Headquarters 952 South Mt. Vernon Avenue P.O. Box 1768 Colton, CA 92324 (714) 825-6034

Handicapping Conditions Served: All handicars.

Users Served: Disabled persons and their families, general public.

The Organization: Tel-Med is a library of tape-recorded health or re messages, which are disseminated nationwide to over 370 hospitals, medical societies, iniversities, and other agencies that are licensed to sponsor Tel-Med programs. Licensees it is dephone line to communicate taped messages to the public. An individual calls, selected appropriate message. The three to five-minute is an arrewritten ty physicians and other health care specialists, and are reviewed periodically insure that



they contain the most current information on the subject. Tapes are also reviewed by local community medical boards of the sponsoring agents.

Information Services: Tel-Med's library consists of more than 467 tapes on health care subjects. Of specific interest to handicapped persons are Tel-Med's series of tapes on diabetes, eye care and hearing, and cancer. Tel-Med also produces tapes on arthritis-rheumatism, cleft lip and palate, cystic fibrosis, muscular dystrophy, sickle cell anemia, multiple sclerosis, brain damage recovery, social security, and SSI and state disability insurance. The selection of tapes available varies among licensees.

Tel-Med sends organizational brochures, including information on licensing procedures, and a list of Tel-Med licensees, upon request. Tel-Med publishes a newsletter for licensees and will provide them with copies of resources used to document the tapes.

Trace Research and Development Center on Communication, Control and Computer Access for Handicapped Individuals 154 Waisman Center 1500 Highland Avenue Madison, WI 53706 (603) 262-6966 (Voice) (608) 263-5408 (TDD)

Handicapping Conditions Served: Physical disabilities, speech and language disorders (all disabilities served in the area of computer access).

Users Served: Disabled persons, parents, teachers, physicians, physical therapists, occupational therapists, speech pathologists, rehabilitation engineers, researchers.

The Organization: The Trace Center was formed in 1971 to address the communication problems faced by non-vocal severely disabled children and adults. The Center is primarily concerned with research and development in the areas of augmentative communication (conversation and writing) and computer access for individuals with physical disabilities. In 1983, it received a grant from the National Institute of Handicapped Research to conduct research as a Rehabilitation Engineering Center. The Center does not manufacture or distribute equipment, but will make referrals to specific sources of information regarding equipment, software, service centers, related professionals and other information networks. Current projects involve efforts to make standard computer hardware and software accessible to disabled individuals, to standardize electronic communication aids which will provide compatibility between devices from different manufacturers and to develop keyboard emulating interfaces which allow disabled individuals to use non-standard input devices to access standard computers.

Information Services: The Trace Center publishes brochures and pamphlets on a variety of topics in the areas of funding resources, augmentative communicative principles and systems, and information on microcomputers and computer access for disabled persons. The Center further aims to meet its objectives of commercial facilitation and information dissemination through a series of workshops, articles available through the Reprint Service, and the development and updating of publications. Resource books include The International Software/Hardware Registry, a listing of software and hardware for disabled computer users, and the Non-Vocal Communication Resource Book, a listing of aids and devices for non-vocal disabled persons. Information on specific aids available, software and hardware, manufacturers, and other resources is provided to individuals, parents, educators, researchers and clinicians. A resource list of referral sources is printed in braille. Audio-



visuals covering equipment development in the areas of augmentative communication and computer access, training materials and perspectives on the disabled population are available. The Center is in the process of preparing a list of service centers for augmentative communication nationwide. There is a nominal charge for most materials from the Center and from the Reprint Service, which operates on a cost recovery basis.

Travel Information Service
Moss Rehabilitation Hospital
12th Street and Tabor Road
Philadelphia, PA 19141
(215) 329-5715 Extension 2233 (Voice)
(215) 329-4342 (TDD)

Handicapping Conditions Served: Physical disabilities.

Users Served: Disabled persons, travel organizations and agencies.

The Organization: Moss Rehabilitation Hospital's Travel Information Service collects and disseminates worldwide travel accessibility information to requestors in the United States and abroad.

information Services: The Travel Information Service prepares information packages on cessible travel from material in its files and mails them to requestors. Referrals are made by relephone, mail or in person to appropriate travel information resources that can assist disabled people in planning a trip. There is a nominal charge for materials to cover postage and and ling.

University Microfilms International (UMI) 300 N. Zeeb Road Ann Arbor, MI 48106 (313) 761-4700 (800) 521-0600 (For Information) (800) 521-3042 (For Ordering)

Handicapping Conditions Served: All handicaps.

Users Served: Researchers, health care professionals, teachers.

The Organization: University Microfilms International (UMI) was founded in 1938 to provide researchers with difficult-to-obtain books and articles. Its publications include dissertations, masters theses, books, periodicals, and monographs, which are printed, photocopied, or microfilmed. UMI also operates information retrieval systems to access the more than 800,000 published dissertations accepted at North American colleges and universities. Recently this program has been broadened to include some foreign universities.

Information Services: Custo, ers may order searches of UMI's Comprehensive Dissertation Data base. Computer printouts delivered to the user include the dissertation title, author, publication date, degree, subject field, school, and for dissertations published by UMI, the page and volume reference to Dissertation Abstracts International (DAI), a UMI monthly publication giving concise author-prepared summaries of dissertations.



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Users may also consult the Comprehensive Dissertation Index (CDI), which gives bibliographic information on almost every doctoral dissertation accepted in North America since 1861. CDI contains more than 5,000 titles on deafness, blindness, mental retardation, birth defects, special education, rehabilitation and other disabling conditions and related subjects. Users with computer terminals may access CDI directly through arrangement with BRS Information Technologies or DIALOG (see separate entries).

World Institute on Disability (WID) 1720 Oregon Street Suite 4 Berkeley, CA 94703 (415) 486-8314

Handicapping Conditions Served: All disabilities.

Users Served: Disabled persons, government agencies, legislative bodies, disability organizations, centers for independent living.

The Organization: The World Institute or. Disability (WID) is a public policy institute seeking solutions to major problems faced by people of all ages with disabilities. It was founded in 1983 by persons who have extensive personal and professional knowledge of disability-related issues. The Institute functions as a research center and as a resource for information, training, public education and technical assistance. WID has focused on five program areas which have significant impact on the basic human rights and needs of disabled individuals. These areas are: attendant care, public education, polio, service systems consultation and international development of independent living. Examples of current projects in these areas include: a survey of attendant care services in 50 states, gathering information on the scope of the polio problem in the world today and educating the public to the facts about polio; creating and producing media materials which enable people to learn about disability-related issues, including a weekly PBS radio talk show; and promoting international relations between the disabled communities of different countries through exchange programs, training programs and participation in international conferences.

Information Services: Publications include Report on the California In-Home Supportive Services System, and The Independent Living Workbook, a peer counseling training manual. The Institute offers consultation in the areas of employment, transportation, architectural barriers, attendant care and independent living. Statistical data is available on attendant care policy, related legislation and financing in all 50 states, with a detailed survey in progress. Fees for services and materials vary and are negotiable.

The Institute offers information and referral on independent living programs, rehabilitation centers and disability-related organizations within the United States and throughout the world. Consultation is available to government agencies, organizations and individuals in the U.S. and abroad, with conferences, workshops and training sessions tailored to specific information needs about disability policy issues and services. Additionally, the World Institute provides an international base for the storing and exchange of knowledge about disability issues between people of different countries.



## Data Base Vendors

Three major commercial organizations that offer access to on-line data bases are described below. These on-line data bases contain machine-readable records which give bibliographic information on documents in defined subject areas. A user's computer terminal is linked to the vendor's computer system via telephone allowing a user to search selected data bases in an interactive mode. A search strategy, formed by combining key words (or subject descriptors), is used to sean the data base. Documents of interest may be displayed for review or printed off-line (saving expensive connect-time) and mailed.

The organizations listed offer training courses in using the data bases.

Note: In addition to the accompanying list of data bases available from the major data base vendors, a table of data bases by subject area is included in the Appendix.

BRS provides access to about 90 data bases for on-line searching; for some of these, BRS is the only commercial vendor. Data bases of particular interest to professionals in the handicapped field are listed in the table at the end of this section. Several larger data bases permit on-line searches of documents from recent years and off-line processing of earlier materials.

Charges for BRS searches include subscription fees (which give lower per hour rates to large volume users), royalties for some data bases, telecommunication fees, and off-line print and search charges. The BRS System Reference Manual, containing information on all BRS data bases, and individual data base guides and aid pages may be purchased from BRS. Also available are the Database Catalog, the BRS/SEARCH system User's Manual, manuals for user-friendly services and training publications. BRS offers several user-friendly (i.e., menudriven) search services which offer reduced rates for non-prime-time searching. Customer service is available 8 a.m. to 1 a.m. weekdays, 8 a.m. to 5 p.m. Saturday, and 8 a.m. to 2 p.m. Sunday (Eastern Time).

DIALOG Information Services, Inc. (DIALOG) 3460 Hillview Avenue Palo Alto, CA 94304 (800) 3-DIALOG

DIALOG Information Services allows access to over 200 data bases, some of which are available only through DIALOG. The files containing information on various aspects of disabling conditions and services to handicapped individuals are listed in a table at the end of this section.

Prices for data base searches vary and are based on computer connect time, use of data communications networks, and off-line printing of records. During the first month of service, new users receive a credit of up to \$100 for computer connect time. The DIALOG



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pricing schedule also offers discounts based upon the quantity of work to be performed and contractual arrangements.

The <u>Database Catalog</u>, which describes available files, and the <u>Pocket Guide to DIALOG</u> are available free of charge in limited quantities. The <u>Guide to DIALOG Databases</u> and guides to specific files may be purchased.

SDC Information Services
System Development Corporation (SDC)
2500 Colorado Avenue
Santa Monica, CA 90406
(800) 352-6689 (California)
(800) 421-7229 (Outside California)

Through ORBIT (On-Line Retrieval of Bibliographic Text), SDC's retrieval system, the user may access more than 70 data bases, many of which are available exclusively through SDC. The SDC files which reference documents on handicapping conditions and programs for disabled persons are listed in a table at the end of this section.

The fee structure for SDC's Information Services has three elements: computer time, usage of a telecommunications network, and off-line printing of citations. Discounts are applied automatically to accounts which use the system for at least five hours in any given month.

Copies of original documents from selected SDC data bases, including ERIC and NTIS, may be ordered on-line; document suppliers then forward copies of requested reports and articles to the user. Charges for documents vary according to the suppliers and the length of the article.

Consultation with information professionals is available free of charge via the toll-free numbers listed above. SDC staff responds to systems questions and advises on search strategies and which data bases to use.

Literature describing the SDC Information Services, including descriptions of ORBIT's data bases, is available free of charge. A complimentary copy of the <u>Quick Reference Guide</u>, a desk-top reference tool giving concise information on the system and data bases, is supplied to users; additional copies may be purchased. The <u>Basic ORBIT User Manual</u> is also for sale.



## DATA BASES AVAILABLE FROM MAJOR DATA BASE VENDORS

	BRS	DIALOG	SDC
ABLECATA (see National Rehabilitation Information Center)	Х		
AGRICOLA (see National Agricultural Library)	X	x	
Combined Health Information Data Base (CHID)	X		
Dissertation Abstracts Online (see University Microfilms International)	$\ddot{\mathbf{X}}$	X	
Educational Resources Information Clearinghouse (ERIC)	X	X	$\overline{\mathbf{X}}$
Exceptional Child Education Resources (ECER) (see Council for	1.	.:	
Exceptional Children)	X	X	
EMBASE (formerly Excerpta Medica)	X	X	
Family Resources (National Council on Family Relations)	X	$\hat{\mathbf{X}}$	
Federal Research in Progress (see National Technical Information Service)		x	
Heal: Planning and Administration (see National Library of Medicine)	X	Ŕ	
Language and Language Behavior Abstracts (see Sociological Abstracts)	X	X	
Legal Resource Index TM (Information Access Company)		Ÿ	
MEDLINE (see National Library of Medicine)	X	x	
National Technical Information Service (NTIS)	$\ddot{\mathbf{X}}$	X	x
PsychINFO (American Psychological Association)	X		x.
REHABDATA (see National Rehabilitation Information Center)	X		



	BRS	DIALOG	SDC
Resource Organizations and Meetings for Educators (see National Center for Research in Vocational Education)	X		
Resources in Vocational Education (sectional Center for Research in Vocational Education)	X		
School Practices Information File (SPIF)	X		
SOCIAL SCISEARCH (see Institute for Scientific Information)	X	X	
Sociological Abstracts (see Sociological Abstracts)	X	x	
TRIS (see Highway Research Information Service) TRIS includes the HRIS data base and additional material on transportation.		$\tilde{\mathbf{x}}$	
Vocational Education Curriculum Materials (see National Center for Research in Vocational Education)	X		

## FEDERAL GOVERNMENT OTHER THAN INFORMATION UNITS

These government agencies educate the general public about the specific mandate of each and the methods chosen to carry out that mandate. Such agencies implement legislation and develop policy, programs and projects relative to a particular subject area. They may provide grants and contracts to fund research, der onstration and training programs; some sponsor direct care facilities. Agencies responsible or upholding nondiscrimination laws provide information and technical assistance regarding compliance. Often, Federal agencies provide information of a general nature, making referrals to regional, state or local offices for response to specific information requests or individual problems. These agencies sometimes function in an advisory role, linking public concerns to government, in an attempt to influence government to be more responsive to the needs of disabled persons.



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Architectural and Transportation Barriers Compliance
Board (ATBCB)
330 C Street, SW
Room 1010
Washington, DC 20202
(202) 245-1591 (Voice and TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, Federal and state governments, building, construction, and design industries, and the general public.

The Organization: The Architectural and Transportation Barriers Compliance Board (ATBCR) was created by Section 502 of the Rehabilitation Act of 1973 to enforce the Architectural Barriers Act of 1968 (P.L.90-480) which requires that most buildings and facilities designed, constructed or altered by the Federal government since 1969 be accessible to handicapped persons. As the Federal agency established to monitor P.L.90-480, the Board is responsible for ensuring that all waivers and modifications are consistent with the Act, and for ensuring that standards issued by other Federal agencies comply with the Board's minimum guidelines and requirements. The Board handles complaints about inaccessible facilities through its Executive Director. Only written complaints are accepted. The complainant's name is not disclosed without written consent. The Board may conduct investigations, hold public hearings, and issue orders to comply with the Act. Among the Board's responsibilities is the planning for accessible transportation and housing for handles also working toward such goals. The Board is also responsible for exploring communication barriers and for making administrative and legislative recommendations:

Information Services: Publications, available free of charge, include: About Barriers and Access America: The Architectural Barriers Act and You. The Board answers technical information questions through its technical services number (202) 472-2700 (Voice and TDD).

National Institute of Handicapped Research (NIHR)
Office of Special Education and Rehabilitative Services
Mail Stop 2305
U.S. Department of Education
400 Maryland Avenue, SW
Washington, DC 20202
(202) 732-1134

Handicapping Conditions Served: All handicaps.

Users Served: Researchers, rehabilitation professionals, physicians, professionals, disabled persons, and parents.

The Organization: Established in November 1978 by Public Law 95-602, the National Institute of Handicapped Research (NIHR) provides leadership and support for a national and international program of comprehensive and coordinated research regarding the rehabilitation of disabled individuals. The Institute's mission also encompasses the dissemination of information concerning developments in rehabilitation procedures, methods and devices which can improve the lives of people of all ages with physical and mental handicaps, especially those who are severely disabled. One of the most important aspects of



research supported by the Institute is that it helps to assure the integration of disabled persons into independent and semi-independent community life.

In Fiscal Year 1985, the Institute funded 37 Rehabilitation Research and Training Centers and 15 Rehabilitation Engineering Centers, as well as research and demonstration projects, field-initiated research projects, innovation grants, and fellowships.

Information Services: Requestors may obtain a listing of current NIHR projects. Information on research reports generated by NIHR projects, and on other rehabilitation research, may be obtained from the National Rehabilitation Information Center (NARIC, see separate entry). In addition, NIHR publishes the Rehab Briefs, four-page digests of current research information presented in a format readily usable by rehabilitation practitioners. Twelve Briefs are published each year

Office for Civil Rights (OCR) U.S. Department of Education 400 Maryland Avenue, SW Washington, DC 20202 (202) 732-1496 (202) 732-1467 (TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, parents, advocates, general public. Also provides technical assistance to recipients that receive Federal financial assistance from the Department.

The Organization: The Office for Civil Rights (OCR) is responsible for investigating discrimination on the basis of race, color, national origin, sex, mental and physical handicaps, and age in programs and activities that receive Federal financial assistance from the Department of Education. Recipients of Federal funds include elementary and secondary schools; colleges and universities; health, welfare and social service programs; and state agencies. OCR has the responsibility, as mandated by Congress, to implement and enforce Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of handicap. Section 504 is the Federal civil rights law protecting the rights of handicapped persons.

Information rvices: OCR maintains a headquarters office in Washington, DC, and ten regional office. In addition to investigative activities, the regional offices are available to enswer questions and provide technical assistance about civil rights compliance. They are a source for printed material on Section 504. For example, a brief description of the requirements of the Department's regulations under Section 504 can be obtained from the regional offices in the pamphlet: Section 504 of the Rehabilitation Act of 1973; Handicapped Rights Under Federal Law. This publication also lists the addresses and phone numbers of the regional offices, and directs further inquiries and complaints to them.

Procedures for Filing Complaints: Section 504 complaints may be filed in one of the 10 regional offices located in Boston, MA; New York, NY; Philadelphia, PA; Atlanta, GA; Chicago, IL; Dallas, TX; Kansas City, MO; Denver, CO; San Francisco, CA; and Seattle, WA.



Office of Vocational and Adult Education (OVAE) U.S. Department of Education 400 Maryland Avenue, SW Washington, DC 20202 (202) 732-2436

Handicapping Conditions Served: All handicaps.

Users Served: Vocational and special education specialists.

The Organization: The function of the Office of Vocational and Adult Education (OVAE), U.S. Department of Education, is to assist the states to expand, improve modernize and develop quality vocational education programs to meet the needs of the nation's existing and future work force for marketable skills. The agency is also concerned with improving productivity and promoting economic growth. OVAE works to ensure that individuals who are handicapped are assured access to at ity vocational education programs.

Information Services: Vocational education programs are offered to the consumer by local education agencies according to the needs of the existing and future work force for marketable skills in the geographical area served. OVAE provides technical assistance to the states related to the provision of occupational preparation and the necessary services to persons with handicapping conditions: The state offices of vocational education, in turn, pass on the information to the local education agencies for application to local vocational education programs.

Rehabilitation Services Administration (RSA)
Office of Special Education and Rehabilitative Services
U.S. Department of Education
Switzer Building
330 C Street, SW \_\_\_\_\_\_
Washington, DC 20202
(202) 732-1294

Handicapping Conditions Served: All handicaps.

Users Served: Professionals in rehabilitation and related fields and disabled persons.

The Organization: The Rehabilitation Services Administration (RSA) supports a variety of services to assist disabled individuals to maximize their potential for employment and independent living. Programs are designed to reduce dependency, increase self-reliance, and utilize the productive capabilities of disabled individuals. Priority is focused on severely disabled individuals.

RSA's major components, which work directly with the programs, are the Office of Program Operations and Office of Developmental Programs. The Office of Program Operations has the primary responsibility for administering the Basic State Grants, Client Assistance, and Independent Living - Part A programs, and programs authorized by the Randolph-Sheppard Act. The Basic State Grants program makes grants to states for the provision and administration of vocational rehabilitation services to assist physically and mentally handicapped individuals in becoming gainfully employed. Services provided include diagnosis, counseling, placement, training and physical and mental restoration. The Client Assistance program makes grants to states to provide assistance in informing and advising clients and applicants of available benefits under the Rehabilitation Act and, upon their



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request, to assist them in their relationships with project programs and facilities providing services. This includes assistance in pursuing legal, administrative, or other appropriate remedies to ensure the protection of the rights of such individuals under the Rehabilitation Act. The Independent Living - Part A program makes grants to states to assist in providing comprehensive services for independent living. These services are designed for individuals whose disabilities are so severe that they do not presently have the potential for employment but who nevertheless may benefit from vocational rehabilitation services which will enable them to live and function independently.

The Office of Program Operations also oversees the implementation of the Randolph-Sheppard Act and provides leadership and consultation for public and private agencies serving persons who are blind and visually handicapped. Some of the functions relating to the Randolph-Sheppard Act include: developing guidelines and regulations for Federal departments and blind licensees to conduct vending facilities programs; working with state agencies to increase the range and number of employment opportunities for blind persons; providing technical consultation; and interpreting provisions of the Act for the convening and operation of state and Federal arbitration panels.

The Office of Developmental Programs provides leadership in and manages RSA's discretionary program development activities including support for training, rehabilitation facilities, service projects and Independent Living - Part B initiatives. Discretionary grants are awarded for projects of national significance and for projects meeting the unique needs of special handicapped populations.

Service projects are funded to: demonstrate methods of expanding assistance to underserved disability groups; develop new and innovative approaches to meeting the needs of severely disabled clients; and provide special training and emissoyment opportunities to severely disabled individuals. Activities include: Projects with Industry; Special Projects for the Severely Disabled; Migratory Workers Projects; Service Grants to Indian Tribes; Helen Keller National Center for Deaf/Blind Youths and Adults; Supported Work; and Special Recreation.

The Independent Living Center program provides grants for the establishment and operation of independent living centers, which offer an array of services to assist clients to function independently. These grants are available to any designated state unit which administers the state plan under Section 705 of the Rehabilitation Act.

Training Projects increase the number and improve the skills of personnel qualified to provide vocational rehabilitation and independent living services to handicapped individuals.

Information Services: Individual inquiries to RSA are handled by the Correspondence Control Unit, (202) 732-1369.

Special Education Programs (SEP)
Office of Special Education and Rehabilitative Services (OSERS)
U.S. Department of Education
400 Maryland Avenue, SW
Switzer Building
Room 3511-2313
Washington, DC 20202
(202) 732-1007

Handicapping Conditions Served: All handicaps.



Users Served: Educators, state and local education agencies, parents, administrators, rolleges and universities:

The Organization: Special Education Programs (SEP) is the principal agency for develoring Federal policy, programs, and projects relating to the education and training of handicapped children (birth-21 years old). SEP provides funds to state education agencies to assist in the provision of a free appropriate public education for handicapped children. It also deals with state agencies of education, institutions of higher education, and other public and private agencies which receive grants and contracts for activities which support the provision of these services. Local education districts are the prime contact points for families of handicapped children. SEP has four divisions:

The Division of Innovation and Development (DID), (202) 732-1161, administers research and model demonstration programs which support the basic service (2) actives of SEP. Research activities deal with a broad array of instructional, administrative and policy topics focused on improving educational opportunities for handicapped individuals. Model demonstration projects focus on development of innovative and improved services delivery models in four areas: preschool education, education for school-age children, postsecondary education, and programs for severely handicapped individuals. Agencies which have developed successful projects are funded by DID to replicate their models. Model programs are disseminated through the National Diffusion Network (see separate entry) for projects approved by the Joint Dissemination Review Panel.

The Division of Personnel Preparation (DPP), (202) 732-1070, administers a grant program and provides technical assistance to colleges and universities, state education agencies, and other nonprofit agencies that train special education teachers, administrators, related service personnel, and parents and volunteers who have a special interest in educating handicapped children. The Division is responsible for preservice training for regular and special educators, and new school personnel who interact with handicapped students in the least restrictive environment appropriate for them.

The Division of Assistance to States (DAS), (202) 732-1014, administers grant programs under Part B of the Education of the indicapped Act (EHA-B), as amended by P.L. 94-142, and Title I of the Elementary and Secondary Education Act, as amended by P.L. 89-313. The Division is responsible for: (1) the supervision, review and negotiation of program plans and applications for EHA-B grants, incentive grants and P.L. 89-313 funds, as well as the processing and tracking of formal complaints from individuals and organizations; (2) the continuing development and clarification of policies and regulations governing the administration of these grant programs and the set-asides under the Vocational Education Act; and (3) the development, implementation and effectiveness of the SEP's monitoring of state educational agencies under EHA-B and P.L. 89-313.

The Division of Educational Services (DES), (202) 732-1064, administers grants and contracts which provide support for research, demonstration, development, evaluation, and educational technology activities aimed at improving educational programs and services for handicapped children. The Division is also responsible for the preparation of the Annual Report to Congress on the progress being made to provide all handicapped children a free appropriate public education; maintenance of a Federal/state partnership in obtaining an evaluation of the effectiveness of the Act; and the conduct of Congressionally mandated evaluation studies.

Information Services: SEP handles inquiries from state agencies and educators about its own activities and funding through its four Divisions. DID provides information regarding funds for research and development projects involving children ages 0-21; DPP provides



information regarding personnel preparation funding and higher education training programs; DAS responds to complaints from parents and educators on policy and problems with the system; and DES provides technical materials to local and state agencies for use in public and special schools.

SEP has funded a National Information Center for Handicapped Children and Youth (see separate entry) which handles parent inquiries. Such inquiries can be sent to: National information Center for Handicapped Children and Youth, Box 1492, Washington, DC 20013.

Administration on Aging (AOA) U.S. Department of Health and Human Services 330 Independence Avenue, SW Washington, DC 20201 (202) 245-2158

Handicapping Conditions Served: Aging, including aged disabled.

Users Served: Older persons, general public.

The Organization: The Administration on Aging (AOA) is the principal Federal agency concerned with identifying the needs, concerns, and interests of older persons and with the administration of the programs of the Older Americans Act. ACA is also the principal agency for promoting coordination of Federal resources available to meet the needs of older persons. AOA provides technical assistance to Federal, state and local agencies in a wide variety of program areas concerning the aging.

Information Services: AOA has information on its programs and connects inquirers with state and area agencies on aging for information on local services.

Administration on Developmental Disabilities (ADD) Office of Human Development Services U.S. Department of Health and Human Services Room 348F HHH Building 200 Independence Avenue, SW Washington, DC 20201 (202) 245-2890

Handicapping Conditions Served: Developmental disabilities including mental retardation. The handicap must originate before age 22, be expected to continue indefinitely, and expected a major handicap in three of seven specified life functioning areas.

Users Served: Officials of training and service agencies and facilities.

The ganization: The Administration on Developmental Disabilities (ADD) is responsible for administering the provisions of the Developmental Disabilities Act of 1984 (P.L. 98-527). The Act makes available a range of strategies to meet the problems of developmentally disabled persons in terms of strengthening services and safeguarding individual rights. The Administration on Developmental Disabilities administers: state protection and advocacy agencies to assure that developmentally disabled persons in each state cotain their rights and quality services; formula grants to states for planning and



administering programs, and delivering services to developmentally disabled persons; special project grants to improve the quality of services and programs, and for technical assistance and training of a ecialized personnel; and grants to university affiliated facilities which operate der. Date atton facilities for services to developmentally disabled persons and for atterdiscipated personnel.

Information Services: Information available from ADD relates to the programs it administers and is geared to officials of training and service agencies and facilities. Specific information regarding state services may be obtained from individual state agencies which operate developmental disabilities programs; for the names of state agencies, contact ADD.

Crippled Children's Service
Division of Maternal and Child Health
Bureau of Health Care Delivery Assistance
U.S. Department of Health and Human Services
5600 Fishers Lane
Room 7-22
Rockville, MD 20857
(301) 443-2350

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons and their families, health care professionals.

The Organization: The Office for Maternal and Ch. Health provides block grants to states for direct medical and related services to children with handicapping conditions. Other funding activities include: project grants for training; research grants for applied research programs; special project grants for projects of regional or national significance; hemophilia diagnostic and treatment centers; and the contest of diseases testing and counseling services.

Information Services: Since each state has its own plan for service tailored to constituents' needs, information about direct services can best be obtained from each state health agency.

Health Care Financing Administration (HCFA)
East Highrise Building
Room 793
6325 Security Boulevard
Baltimore, MD 21207
(301) 594-9732

Handicapping Conditions Served: All handicaps.

Users Served: General public.

The Organization: The Health Care Financing Administration (HCFA) was created in 1977 to oversee two major Federal medical assistance programs, Medicare and Medicaid, and related Federal medical quality control programs. HCFA administers funds for the Medicare program and the Federal portion of the Medicaid program. Medicare provides health insurance to persons over 65 and to disabled persons under 65 who meet the

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disability insurance (SSDI) requirements (see separate entry for the Social Security Administration) or who have permanent kidney failure.

Medicaid is a joint Federal/state program which provides health care services to persons with low incomes. Disabled persons may be eligible for Medicaid on the basis of their incomes. Because eligibility is determined by each state's program of public assistance (welfare) on the basis of broad Federal guidelines, there are geographic differences between eligibility requirements and types of service covered. Medicaid services are available in all states and in Guam, Puerto Rico, and the Virgin Islands.

Information Services: HCFA responds to inquiries from the general public. This includes inquiries about Medicare and Medicaid.

National Institute of Child Health and Human Development (NICHD) National Institutes of Health U.S. Department of Health and Human Services Building 31
Room 2A32
Bethesda, MD 20892
(301) 496-5133

Handicapping Conditions Served: Mental retardation (particularly Down syndrome) and learning disabilities (particularly dyslexia). A few genetic and metabolic disorders are studied.

Users Served: Parents, teachers, health care professionals.

The Organization: NICH unds a multimillion dollar research program at its headquarters and around the country, a universities and medical schools. Research and doctoral training are done in the areas of maternal and child health, human development, and reproduction/population, with the focus on the continuing growth and development process (biological and behavioral) from the prenatal period to maturity. The NICHO also supports 12 Mental Retardation Research Centers across the country, where research, professional education, patient care, and counseling are undertaken.

Information Services: Information is particularly strong on resea the related to Down syndrome, mental retardation, speech and language, and speech and reading. Most information describes various conditions and what is currently known about them. Patients may be referred by NICHD to the programs of the Mental Retardation Research Centers for diagnosis, treatment, and other services. Publications include Developmental Dyslexia and Related Reading Disorders, and other speech/reading and speech/language materials; and booklets on Down syndrome, smoking during pregnancy, childhood hyperactivity, anorexia nervosa, caesarean childbirth, oral contraceptives, precocious puberty, low birth weight babies, and sudden infant death. A Parent's Guide to Cystinosis provides an explanation of the disease and how it is diagnosed, and offers advice on day-to-day care of the child with the disorder, including a discussion of emotional and school-related problems that can arise. A new report, Prenatal and Perinatal Factors Associated with Brain Disorders, presents current knowledge about prenatal and perinatal causes of neurological dysfunction.



Office for Civil Rights (OCR)
U.S. Department of Health and Human Services
Room 5514
North Building
330 Independence Avenue, SW
Washington, DC 20201
(202) 245-6700
(202) 472-2916 (TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, health care providers such as hospitals and nursing homes, general public.

The Organization: The Office for Civil Rights (OCR) is responsible for investigating discrimination on the basis of race, color, age, national origin, religion mental and physical handicaps, and sex in programs receiving assistance from the Department of Health and Human Services. Recipients of Federal funds from the department include health and human services agencies such as family health centers and clinics senior citizen centers, hospitals, and nursing homes. OCR has the responsibility, as mandated by Congress, to implement and enforce Section 504 of the Rehabilitation Act of 1973, as amended, which prohibits discrimination on the basis of handicaps. Section 504 is the only major Federal civil rights legislation for handicapped persons which guarantees their access to program services and employment. OCR provides technical assistance to recipients of HHS funds to help them achieve voluntary compliance with governing regulations:

Information Services: OCR maintains a headquarters unit in Washington and ten regional offices. Requests for assistance and information should be made to the regional offices. Complaints should be filed with the regional offices. Fact sheets on definitions, regulations, policy statements and guidelines relating to Section 504 may be obtained from OCR; some are available in recorded form. Pamphlets relating to Section 504 include: Your Responsibilities to Disabled Persons as a Health Care or Social Service Administrator and Your Rights as a Disabled Person. Your Rights as a Disabled Person and Section 504 regulations are available in Spanish. Section 504 regulations and Title VI regulations can be obtained in braille. Publications are free but quantities are limited. A nominal fee may be required for Freedom of Information/Privacy Act requests. OCR has also a number of industrial-sized video cassettes dealing with disability-related topics such as attitudes, reasonable accommodation, deaf patients and handicapped parking areas.

President's Committee on Mental Retardation (PCMR) 330 Independence Avenue, SW Washington, DC 20201 (202) 245-7634

Handicapping Conditions Served: Mental retardation.

Users Served: Government officials, general public.

The Organization: The President's Committee on Mental Retardation (PCMR), established by Executive Order 11280 of May 11, 1966, is composed of twenty-one citizen members appointed by the President, and six points members (ex officio). The Secretary of Health and Human Services is chairperson. The primary objectives of the Committee are to: advise and assist the President and the Secretary of Health and Human Services on all matters



pertaining to mental retardation; evaluate national, state and local efforts; kelp coordinate Federal activities; facilitate communication between Federal, state and local agencies; inform the public about mental retardation; and mobilize support for related activities to promote self-sufficiency.

The Committee's principal activities are directed toward the prevention of mental retardation, enhancement of the quality of life of persons with mental retardation, promotion of the legal rights of retarded citizens and increased public sensitivity and awareness regarding people with mental retardation, both nationally and internationally.

Information Services: PCMR provides single copies of publications free of charge. Major publications available are: Reports to the President: The Mentally Retarded Worker: An Economic Discovery (1983) and Mental Retardation: Plans for the Future (1985); Parents Concerns and Advice: A Summary of Interview Findings (1985); Assessment of the National Effort to Combat Mental Retardation from Biomedical Causes (1983); National Open Forum can Prevention of Mental Retardation from Environmental and Psychosocial Causes (1984); and Community Forum on Employment of Handicapped People - "A Primer" (1985).

Project Head Start
Administration for Children, Youth and Families
Office of Human Development Services
U.S. Department of Health and Human Services
P.O. Box 1182
Washington, DC, 20013
(202) 755-7710

Handicapping Conditions Served: All handicaps.

Users Served: Disabled children, child care professionals.

The Organization: Project Head Start, administered by the Admin cration for Children, Youth and Families, was reauthorized by the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35). The law requires that no less than 10 percent of enrollment opportunities in Head Start programs in each state be available for handicapped children and that cervices be provided to meet their special needs. HHS regional offices award grants to local public and private agencies for the purpose of operating Head Start programs in their communities. Intended primarily for preschool children from low income families, the program was funded to serve over 400,000 children through almost 1,300 grantees located in rural and urban areas throughout the U.S. and territories. Of the enrollment for the 1983-84 Head Start program year, children professionally diagnosed as handicapped accounted for 12.5 percent of the total.

Information Services: Local Head Start programs are the main source of information about specific services and eligibility. General information about Head Start is a allable from the national office, and includes an annual report and a directory of local Head Start programs listed by state. Head Start produces a number of materials designed for professional workers in child care programs. These materials include program manuals on mainstreaming handicapped preschoolers who have visual, hearing, speech and language, health, orthopedic, learning, and emotional disorders, or are mentally retarded. Materials for the child care professional can be obtained only from the Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402.



Social Security Administration (SSA) 6401 Security Boulevard Baltimore, MD 21235 (301) 594-7700 (SOC) (800) 325-0778 (TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons.

The Organization: The Social Security Administration administers a national program of contributory social insurance which pays benefits when earnings stop or are reduced because a worker retires, dies, or becomes disabled. Disability insurance (SSDI) provides a partial replacement of monthly earnings to disabled persons who meet work requirements for eligibility. After 24 months of receiving benefits under SSDI, persons automatically qualify for hospital and medical insurance under Medicare. (Persons of any age who need kidney dialysis or kidney transplant for permanent kidney failure also may be eligible for Medicare. Medicare protection for these people starts with the third month after they begin maintenance dialysis. Under certain conditions, protection can begin earlier).

Supplemental Security recome (SSI), a noncontributory program financed out of general Federal funds, is also administered by SSA. SSI provides monthly payments to indigent aged, blind, and disabled persons, without regard to prior employment:

More than 1300 local Social Security offices are responsible for processing applications and claims for SSDI and SSI programs; they also determine eligibility for Medicare, although Medicare claims are processed by independent contractors or carriers.

Information Services: Local Social Security offices are often the best access points for information about possessions and eligibility. Some local offices operate Teleservice Centers (TSC) so that program formation and applications can be obtained by phone. TSC service representatives recommended to be obtained by phone. TSC service detailed information is required. SSA publishes mor some problem of the disabled. Those services when more than the disabled of the disabled. Those services are available in braille and in Span and the disable of the disable o

The Office of Public Inquirie phone number above) responds to questions about SS and SSI programs, proposed legislation, actuarial and statistical figures and general information.

The Office of Governmental Affairs, (301) 594-5295, responds to requests for inferration from advocacy groups and organizations about programs administered by the Social Security Administration.

The Office of Research, Statistics and International Policy (ORSIP) conducts research on the following programs: old age, survivors, disability, SSI, aid to families with dependent children, and child apport enforcement. Findings are published in a variety of technical publications including.

- (1) ORSIP Publications Catalog. Describes published reports and computerized data files available from SSA.
- (2) 1974 Followup Survey of Disabled and Nondisable: Adults. A series of reports based on information collected during interviews with 16,000 persons who had been interviewed in 1972. Changes over a two-year period in disability and economic



status of the working-age population and how those changes relate to entitlement to social security disability benefits are examined. Titles of reports published are General Characteristics. Nork Experience of the Disabled, 1972 and 1974; and Functional Capacity Limitations and Disability, 1572-74.

Two reports from the most recent survey of disabled persons, the 1978 Survey of Disability and Work, are also available. The Technical Introduction describes the survey methodology. The 1978 Survey of Disability and Work Data Book is a compilation of 175 tables showing the major findings of the survey.

(3) Work Disability in the United States: A Chartbook. Charts depicting prevalence of disability, demographic characteristics of disabled persons, and their health and economic status, summarizing highlights from the 1978 Survey of Disability and Work.

For information about ORSIP publications, contact the office at 1875 Connecticut Avenue, NW, Room 921, Washington, DC 20069, (202) 673-5579.

Office of the Special Advisor for Disability Issues to the Deputy Under Secretary for Intergovernmental Relations Department of Housing and Urban Development 451 7th Street, SW Room 10184 Washington, DC 20410 (202) 426-6030

Handicapping Conditions Served: Ail handicaps.

Users Served: Disabled persons, special interest groups and organizations.

The Organization: Out of the functions of the Office of the Special Advisor for Disability Issues is to ensure that disabled persons are appropriately represented and address it throughout the programs and activities of the Department of Housing and Urban Development (HUD).

The Special Advisor analyzes and evaluates Departmental policies and guidelines for HUD programs in order to respond to the nousing, community development, and related needs of people with physical and mental disabilities.

Information Services: The Special Advisor responds to inquiries on uses of HUD programs by and for disabled people, and makes available an information kit containing a variety of publications on HUD programs.

Employment Standards Administration (ESA)
and Employment and Training Administration (ETA)
Department of Labor (DOL)
200 Constitution Avenue, NW
Washington, DC 20210
(202) 523-6666

Handicapping Conditions Served: All handicaps.



Users Served: Disabled persons, general public.

The Organization: The Department of Labor (DOL) develops policy and implements legislation for all workers in the nation. It is responsible for the enforcement of laws that protect the safety, health, job, and pension rights of workers. Each of DOL's 10 regional offices deals with issues affecting American handicapped workers and, within the Department's units, specialized services are being implemented for disabled individuals

The Employment Standards Administration (ESA) of DOL administers programs through the Office of Federal Contract Compliance Programs, which processes conplaints of handicapped individuals in cases of employment discrimination by Federal contractors. Complaints can be filed personally or by an authorized representative of the complainant, at any of the 10 DOL regional offices. DOL intervenes only when the cases cannot be findled locally. The Wage and Hour Division authorizes subminimum wages under the Fair Labor Standards Act to prevent curtailment of opportunities for employment for handicapped individuals who would not be able to command the minimum wage. The Division of Special Minimum Wages administers the regulations governing the employment of handicapped clients in sheltered workshops, hardicapped workers in industry, and employment of patient workers based on their individual productivity.

The Office of Workers' Compensation Programs administers three basic Federal workers' compensation laws, whereby Federal employees (if injured on the job) can apply for a constitued salary and assistance with medical expenses. The Office also administers the Black Lung Act for coal mine workers.

The Employment and Training Administration (LTA) of DOL includes the U.S. Employment Service (LT

Information Services: Inquiries about programs of the Employment Standards Administration should be addressed to: Director, ESA Office of Information and Consumer Affairs, NDOL, Room C 4331, 200 Constitution Avenue, NW, Washington, 2 20010. Regulations relevant to safety, health, employment and pension rights of vorkers are available in Spanish, if required. The U.S. Employment Service has developed a series of interviewing guides (e.g. cerebral pulsy, mental retardation) which can be purchased from: Superintendent of Documents, U.S. Government Printing Office, Washington, L. 20402. Inquiries about programs of the U.S. Employment Service should be addressed to: Director, ETA Public Affairs Office, 601 D Street, NW, Room 10418, Washington, DC 20213. Inquiries about jobs on the local level should be addressed to the local Job Service office.

President's Committee on Employment of the Handicapped (PCEH) 1111 20th Street, NW 6th Floor Washington, DC 20036 (202) 653-5044

Handicupping Conditions Served: All handicaps.



Users Served: Disabled persons, employers, labor leaders, physicians, rehabilitation and placement specialists.

The Organization: The President's Committee on Employment of the Handicapped (PCEH) serves an advocacy and public awareness role in fostering job opportunities for handicapped people. As part of this effort, PCEH works with autonomous committees on employment of the handicapped at state and local levels, as well as producing its own publications and services. The Committee has a leading role in stablishing an acceptable climate in industry and labor towards hiring handicappe individuals.

PCEH has organized around the national committee a number of subcommittees which deal with special topics, and cooperating governors' and mayors' committees. Also, PCEH has been a strong advocate in the areas of architectural accessibility and in education and social activities for handicapped youth. The Committee has produced sensitizing campaigns to educate the general public on the employment and physical mobility needs of the handics appulation.

Information Services: PCEH provides information primarily in the area of employment, and has published pamphlets on architectural accessibility and education for handicapped youth. General information is provided on the Committee's activities and selected materials published by PCEH are sent on request. All services are free.

Publications developed by PCEH are representative of the Committee's advocacy efforts. Some sample titles are: Special Report, Disability and Employment and Look Who's Minding the Store: Supervising Disabled Employees, giving current information on employing handicapped people; ABC's of Hiring People with Disabilities, a brief fact sheet to persuade employers to hire disabled people; Mainstreet, Community Action Guide for Disabled Americans; and several brochures on hiring people with specific disabilities. PCEL also publishes a quarterly newsletter, Tips and Trends. Another periodical, Disabled USA, carries articles about disabled people, employment programs trends and related topics.

PCEH sponsors the Job Accommodation Network (see separate listing), a data base system for providing information on resolving accommodation problems in placing disabled work in private sector employment.

National Park Service
Department of the Interior
18th and C Street, NW
P.O. Box 37127
Washington, DC 20013-7127
(202) 343-4747

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons and their families.

The Organization: The National Park Service administers the nation's national park system, including parks and natural, historical, recreational, and cultural areas and facilities. In addition to its central office, the Park Service has 10 regional offices.

Information Services: The Park Service accepts inquiries on all of its national park activities and facilities. Information on access bility of park programs, facilities, and services should be acquired directly from the park or area you plan to visit. For general information on



park areas and activities and a listing of park phone numbers, call Public Information on (202) 343-4747. All information is free. The Special Programs and Populations Branch ((202) 343-3674; TTY 343-3679) handles lay and professional inquiries on national park facilities for the handicapped. Also, the office offers technical assistance to service providers, and deals with policies and procedures for all special groups.

To obtain the addresses of regional offices, contact the National Park Service.

Urban Mass Transportation Administration (UMTA)
Department of Transportation
Office of Public Affairs
Washington, DC 20590
(202) 426-4043

Handicapping Conditions Served: All disabilities because of which handicapped and elderly persons are unable, without special facilities or special planning or design, to utilize mas transportation facilities and services effectively.

Users Served: Transit operators and planners, general public.

The Organization: The Urban Mass Transportation Admin stration (UMTA) was established to assist the development of improved mass transportation facilities, equipment, techniques, and methods; to encourage the planning and establishment of urban mass transportation systems; and to provide assistance to state and local governments in financing such systems. Several types of grants are available to transportation agencies to improve services to the handicapped and elderly. For example, one UMTA program provides funds to nonprofit organizations to purchase vehicles to transport handicapped and elderly persons.

Information Services: Most information provided by UMTA is directed to transit operators are planners. The ten regional offices of UMTA are the best sources of information for local providers. The Public Affairs office (telephone number above) will direct inquiries to the appropriate national or regional office. Information about UMTA's program of assistance to nonprofit organizations is available from TA regional offices or designated that agencies, and frequently from the state dependence of transportation. Handicapped persons who need information about the services are advised to contact local transportation authorities:

An annual UMTA publication is <u>Innovation in Public Transportation</u>: <u>UMTA Technical Assistance Program Directory</u>, which contains descriptions of technical assistance projects in transit-related areas including analysis, planning, demonstrations, management, vehicles equipment and facilities. <u>UMTA-sponsored studies and surveys are published by the National Technical Information Service (NTIS, see separate entry) and are available from NTIS or from UMTA directly. The Transportation Research Board can do a crarch of publications on transportation studies dealing with elderly and handicapped persons (see Highway Research Information Service, separate entry).</u>



National AudioVisual Center
National Archives and Records Administration
8700 Edgeworth Drive
Capitol Heights, MD 20743-3701
(301) 763-1896
(301) 763-4385 (TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Teachers, general public.

The Organization: The National Audio Visual Center was created in 1969 to serve the public by making federally produced audio-visual materials available for use through distribution services and by serving as the central clearinghouse for all U.S. Government audio-visual materials. Through the Center's distribution programs, the public has access to audio-visual materials covering a variety of subjects, which include rehabilitation, special education, and health and medicine, including treatment of stroke, canero, spinal cord injuries, arthritis, alcoholism, drug abuse, and other disabling conditions.

Many of the Center's audio-visual materials are for general use, while others are designed for specific training or instructional programs. To complement and increase the effectiveness of these programs, many are accompanied by printed materials such as teacher manuals, student workbooks, or scripts.

Information Services: Federal audio-visual materials are available through the following programs: Sales: various audio-visual formats are available for purchase through the Center, including motion pictures, slide sets, audiotapes, and moltimedia kits. Media conversion to special formats is available on request. Preview prior to purchase is available for 16 mm motion pictures. Rental: Only 16 mm motion pictures, representing about 3,000 titles from the Center's collection, are available through the rental program. Loan Referrals: Loan distribution of 16 mm films is often available to the public from commercial distribated from regional Federal agency offices. The Center keeps informed of fessponsored loan programs and refers the user to the closest loan source.

The Center has some films available with closed captioning and with Spanish soundtracks.

The Center maintains a master data file on audio-visual materials produced by the U.S. Government. This resource is used by the reference staff to respond to inquiries.

Printed materials issued by the Center are the principal means of keeping the public informed of the availability of Federal audio-visual materials. The Center publishes subject specific catalogs of listings from over 8,000 titles available for sale and/or rental and also puts out brochures describing single or multiple titles. A 1981 catalog entitled Special Education lists a wide variety of materials on early, elementary, secondary, adult, and parent education geared to persons with specific disabilities. Publications of the Center are available free upon request.



Technology Utilization Program (TU)
National Aeronautics and Space Administration (NASA)
600 Independence Avenue, SW
Washington, DC 20546
(202) 755-2420

Handicapping Conditions Served: All handicaps.

Users Servea: Disabled persons, rehabilitation engineers, bester into professionals, researchers.

The Organization: The National Aeronautics and Space Administration (NASA) Technology Utilization Program (TU), as part of its mission, adapts aer server to technology to the development of equipment for the prevention of illness and the care of sick, handicapped, and elderly persons. NASA's TU Program operates in areas from bidengineering to human services delivery. Among the products that have been developed using aerospace technology as rechargeable pacemakers; portable cassette units for electrocardiograms; coin operated high blood pressure machines; a voice controlled wheelchair which responds to 35 one-word commands; "Meals for the Homebound," food which can be easily prepared and is designed for mailing and long storage without refrigeration; a foldable walker designed for use on stairs; and a cardiology mannequip that can simulate 40 heart disease conditions with a high degree of realism for the education of medical students in cardiology.

Information Services: Information on manufacturers of technological innovations such as the ones listed above can be obtained by writing to NASA's Scientific and Technical Information Facility, TU Office, P.O. Box 8756, Baltimore-Washington International Airport, Baltimore, MD 21240, (301) \$59-5300 ext. 210. Also available is a general brochure which describes many of the technical products from NASA's TU Program entitled, Technologies for the Handicapped and the Aged. NASA Tech Briefs, a free indexed quarterly journal utilized by the U.S. engineering community an other professionals, describes innovations. NASA SP's, a series on complex technological advances, are also available.

Other services sponsored by the NASA TU Program are available through the Industrial Application Centers, which provide access to the world's largest depository of technical data; the State Technology Application Centers (STAC), which apply technology to specific needs in states; and NASA's Computer Software and Management Information Center (COSMIC), which makes selected computer programs from NASA available to engineers and researchers.

Office of Personnel Management (OPM)
Office of Affirmative Employment Programs
Selective Placement Programs
1900 E Street, NW
Room 7317
Washington, DC 20415
(202) 632-6158

Handicapping Conditions Served andicaps.

Users Served: Disabled person all agency program officials and supervisors.

The Organization: The O onnel Management is the central personnel agency of the Federal government.



OPM's Selective Placement Programs provide personnel with information on flexibilities applicable to handicapped individuals and monitor and coordinate Federal personnel regulations and policies to ensure that handicapped individuals are not adversely affected by barriers in the personnel system. A major focus is on technical assistance to agency program officials in regard to the use of the personnel system, development of understanding about disabilities, job and work site modifications, and resources for obtaining rehabilitation assistance.

Information Services: OPM provides, through a nationwide system of job information offices, information on all aspects of employment of handicapped individuals in the Federal government. Selective Placement Coordinators in each agency provide counseling for job placement and work with supervisors to increase awareness of the capabilities of a handicapped person and techniques for accommodating such persons.

Small Business Administration (SBA)
Special Projects Section
Office of Business Loans
1441 L Street, NW
Washington, DC 20416
(202) 653-6570

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, nonprofit organizations established to employ handicapped persons.

The Organization: The Small Administration (SBA) was established to encourage, assist, and protect the interests of small businesses. Financial assistance is available through Handicapped Assistance Loans to small business concerns owned or to be owned by handicapped individuals and to nonprofit organizations established to employ handicapped persons.

special assistance will be provided if funds are otherwise available from the applicant's own resources, from a private institution or from other Federal, state or ideal programs, including SBA's Guaranty Loan Program.

SBA may guarantee up to 90 percent, not to exceed \$500,000, of a loan made by a private lending institution. Direct loans by SBA are limited to \$150,000. Interest rates on direct loans are 3 percent per year. Interest rates on guaranteed loans are set by the participating lending institution and must be legal and reasonable and within a maximum allowable amount which is set periodically by SBA. No direct loan can be approved if a guaranteed loan is available.

Information Services: SBA provides information about the Handicapped Assistance Loan Program to any interested individual. SBA has offices located in major cities where individuals can apply for information and other small tusiness training. For the actresses of these offices, write to the address above.



Veterans Administration (VA) 810 Vermont Avenue, NW Washington, DC 20420 (202) 389-2886 (Department of Veterans Benefits) (202) 389-5010 (Department of Medicine and Surgery)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled veterans and their families.

The Organization: The Veterans Administration (VA) provides a wide range of benefits to those who have served in the Armed Forces, their dependents, beneficiaries of deceased veterans, and dependent children of seriously disabled veterans. Two national offices administer programs of financial benefits and direct health care services for veterans:

Department of Veterans Benefits and the Department of Medicine and Surgery.

The Department of Veterans Benefits (DVB) conducts an ated program of veteran benefits through 58 regional offices. In addition to the benefits through 58 regional offices. In addition to the benefits provided by other Federal agencies, the service-disabled veteran is and benefits provided by other Federal agencies, the service-disabled veteran is and benefits and services. These include: disability compensation for injuries, make or disabilities incurred while on active duty in the Armed Forces; dependency allowances for wives and children of service-disabled veterans; medical care, including hospitalization, outpatient services, nursing services, and prosthetics and sensitive aid services; and vocational counseling, rehabilitation, and training. After completion training, the VA will assist the veteran to find and hold a suitable job. Severely disable veterans, including the blind, paraplegic, and amputees, may be entitled to specially adapted (wheelchair) homes, automobiles, or other means of conveyance, and assistance to live more independently in their community. The VA provides technical assistance in situations where a worksite or training site modification is needed to accommodate the veteran.

Viterans awarded pensions during the period February 1, 1985, through January 31, 1989, may be eligible for up to 24 months or more of vocational training to prepare for and enter employment. The veteran's VA health care eligibility (including any applicable priority) will be preserved for a three-year period following the date on which pension is terminated due to income from employment:

The Department of Medicine and Surgery (DM and S) provides health care to veterans in 172 medical centers, 225 outpatient clinics, 110 nursing homes, and 16 domiciliaries. The YA has also opened 189 veterans centers to assist Vietnam Era veterans with special problems related to that war. The department divisions offer medical, psychological, educational, social and vocational services to all qualified veterans. Rehabilitation services for handicapped persons include Rehabilitation Medicine, Blind Rehabilitation, Prosthetic and Sensory Aids Service, Spinal Cord Injury Service, and Audiology and Speech Pathology Service. There are programs especially designed for handicapped individuals such as driver training, independent living, case management, cardiopulmonary rehabilitation, and compensal 1 work therapy.

in the Department of Medicine and Surgery, the Office of Research and Development (R&D) administers intramural projects and programs in medical research. The Rehabilitation Research and Development Service conducts additional research on prosthetics, sensory aid devices, and other equipment for handicapped individuals. The Office of Academic Affairs, also in the Department of Medicine and Surgery, conducts an extensive health manpower education and training program.



Information Services: Information concerning benefits and services is and lable from VA field offices located in many cities throughout the 50 states. Each field offices located in many cities throughout the 50 states. with benefits counselors who advise applicants and process application for enefits. VA field offices provide assistance to veterans seeking to appeal claims decisions, this assistance is also provided by private veterans associations, some located in VA regional offices. Each state has a toll-free telephone service to VA regional offices. This service provides information about benefits as well as counseling assistance to nonambulatory persons who cannot apply for benefits in person. Information about specific rehabilitation programs may be cotained from a local medical center or by contacting the Rehabilitation Medicine Service at the is ional office. Libraries at VA medical centers can provide medical reference mater to medical personnel and other interested parties. Applications for medical service way be made to VA medical centers or any VA office with medical ation Federal Benefits for Veterans and Dependents, which describes ligibility requirements, and lists local offices and treatment facilities benefits, serv through the Superintendent of Documents, U.S. Government Princing Office, by state, is Washington DC 10402.

The Office Techn ogy Transfer (OTT), located at 252 Seventh Avenue, New York, NY 10001 (212) 6. 659, maintains a reference collection on rehabilitative engineering. Organized more than 30 years ago, the collection contains books, periodicals, technical reports, reprints, patents, and audio-visuals. Materials cover a wide range of subject areas: prosthetics, orthotics, communication aids, mobility aids, driving aids, artificial eye and other cosmetic restorations, wheelchairs, mobility and reading aids for the blind and partially sighted, hearing aids, and surgical implants. The collection is available for use by all individuals, but is primarily useful to the medical, allied health, and engineering professions.

OTT is a source of information on new devices and techniques developed in the VA's rehabilitation engineering programs. Its main vehicle for dissemination of new research information is the semiannual <u>Bulletin of Prosthetics Research</u>. The Bulletin includes scientific papers, progress reports on research projects, and abstracts of recent patents and publications. Bulletins may be purchased from the Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402. OTT provides copies of reference materials or individualized letters in response to clearly stated and specific inquiries for information.

Office of Into mation Management and Statistics is the principal data collection office of the 'A. Statistics are available on disability compensation and the type and extent of disability for veterans with both service and nonservice connected handicapping conditions. While most of the statistics compiled by this office have not been published, data is readily available to requestors. The following information sheets have been published: "Selected Compensation and Pension Data by State of Residence," "Disability Compensation Data," and "Disability and Death Pension Data." A special study on the disabled veterans of the Vietnam era is also available. All of the above are available from the Statistical Review and Analysis Division (202) 389-3930. The Annual Report of the Administrator, which may be obtained from the Reports Preparation Division (202) 389-3677, includes statistical tables on the 'revalence of disability among veterans.



#### PROFESSIONAL AND TRADE ORGANIZATIONS

The objective of these organizations is to promote quality professional services by providing accreditation of programs and facilities, certification of practitioners, professional development, public education and advocacy. The accreditation function involves the development of standards for facilities and services and assessment of compliance with these standards. Certification serves to improve standards of professional training and practice by testing the ability of the practitioner to meet and maintain certain levels of competence. Some organizations are also involved in approving academic programs. These organizations encourage professional development through a variety of continuing education courses and workshops, research fellowships, and the publication of journals, periodicals and newsletters. For public education, many groups publish directories of professional members and facilities or programs which meet accreditation standards. Organizations may provide career information, lists of approved schools in specialty areas and job exchange programs or other employment services. Several groups focus on professionals with disabilities, particularly in the science and health fields, serving as support groups and vehicles for career development.



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# Academy of Dentistry for the Handicapped (ADH) 211 E. Chicago Avenue 21st Floor Chicago, IL 60611 (312) 440-2660

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, parents, dentists, dental hygienists, and allied professionals.

The Organization: The Academy of Dentistry for the Handicapped (ADH) is an organization of dentists, dental hygienists, and allied professionals. ADH provides educational services to professionals and information and referrals to handicapped persons seeking dental treatment. The organization also acts as an advocate for improved dental treatment, research, and legislation for handicapped persons.

Information Services: Information on preventive dentistry for handicapped persons is available to lay inquirers for a nominal donation. A resource list on dental care for handicapped persons includes written and audio-visual materials (including materials for the blind) for lay and professional people. For the professional, ADH publishes a bimonthly journal, and it sponsors an annual continuing education course on improved dental methods and treatment for special patients. ADH maintains a referral directory of dentists who treat handicapped persons.

Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (AC MRDD) 4435 Wisconsin Avenue, NW, Suite 202 Washington, DC 20016 (202) 363-2811

Handicapping Conditions Served: Mental retardation, cerebral palsy, autism, epilepsy, and other developmental disabilities.

Users Served: Disabled persons, parents, professionals, agency personnel.

The Organization: As the national, independent, voluntary accrediting body for agencies serving persons with developmental disabilities, AC MRDD develops standards for services; assesses, on request, the compliance of agencies with the standards; and awards accreditation to agencies found to be in substantial compliance with the standards. It also offers workshops and consultation to help agencies implement accreditation standards and prepare for accreditation survey, and to assist both service consumers and service providers in using the accreditation process to help to improve services. Established in 1969 as a component of the Joint Commission on Accreditation of Hospitals, the Council was reorganized as an independent, not-for-profit corporation in 1979. Its ten sponsoring organizations include the major developmental disability advocacy groups.

Information Services: The Council responds to questions about its accreditation process, interprets its standards, and provides information concerning requirements for quality services for developmentally disabled persons. The Standards for Services for Developmentally Disabled Individuals, 1984 edition, and the Survey Questionnaire for use with the Standards, which are used by agencies in evaluating their own services and used by the Council in conducting accreditation surveys, may be purchased from the Council.



#### Alternative Living Managers Association (ALMA) 1642 North Winchester Avenue Suite 100 Chicago, IL 60622 (312) 276-3176

Handicapping Conditions Served: Developmental disabilities.

Users Served: Managers of community-based residences, for persons who have developmental disabilities.

The Organization: The Alternative Living Managers Association (ALMA) is a professional organization formed to provide a communication and support network for managers of community-based residences for persons who are developmentally disabled.

Information Services: ALMA publishes a quarterly newsletter, ALMA MATTERS, for residence managers which includes legislative updates, profiles of successful community-based programs, management principles, and reviews of books and program materials. Also included is a two to four page feature supplement directed to high-functioning residents, persons living independently and parents or guardians of persons living at home. ALMA is currently compiling a membership directory listing group homes throughout the country which it plans to publish by early spring, 1986 Directories may be purchased from ALMA.

American Academy of Physical Medicine and Rehabilitation (AAPM&R) 30 North Michigan Avenue Chicago, IL 60602 (312) 236-9512

Handicapping Conditions Served: Physical disabilities treatable through physical medicine and rehabilitation.

Users Served: Physicians in physical medicine and rehabilitation.

The Organization: The American Academy of Physical Medicine and Rehabilitation (AAPM&R) was founded to promote the art and science of medicine and the improvement of health through an understanding and utilization of physical medicine and rehabilitation. Practitioners of this medical specialty, termed physiatrists, are concerned with the optimal functional restoration of patients with disabilities, the physical treatment of neuromuscular impairments, and the use of electrodiagnostic studies. Physical medicine and rehabilitation (PM&R) focuses on diagnostic, therapeutic and management procedures through which the patient can attain maximal physical functional capacity and psychosocial adjustment.

Through publications, courses, workshops and other means, the AAPM&R promotes research and education in physical medicine and rehabilitation, including continuing medical education. The organization also provides legislative guidance on rehabilitation issues.

The Academy shares joint responsibility for administrative expenses, an annual meeting and publication of a monthly scientific journal with the American Congress of Rehabilitation Medicine (see separate entry).



Information Services: The Academy offers brochures on careers in the field of physical medicine and rehabilitation. Other publications include a quarterly newsletter, The Physiatrist; a monthly scientific journal, Archives of Physical Medicine and Rehabilitation; and a PM&R syllabus. Information services are intended primarily for members and there is a nominal charge for materials to cover costs.

American Alliance for Health, Physical Education, Recreation and Dance (AAHPERD) 1900 Association Drive Reston, VA 22091 (703) 476-3400

Handicapping Conditions Served: All handicaps.

Users Served: Teachers and professionals in physical education, health education, sports, recreation and dance.

The Organization: The American Alliance for Health, Physical Education, Recreation and Dance (AAHPERD) is a nonprofit association of professionals concerned with improving programs in schools and communities in the areas of physical education, sports, health and safety education, recreation and dance. The American Alliance provides members with opportunities and materials for professional growth through information on the latest issues, trends, technologies and legislative developments.

Information Services: The American Alliance issues numerous publications dealing with planning, organizing, conducting, and evaluating general and specific physical education, recreation, sports and related programs for disabled persons. The newsletter, Able Bodies, reports on programs, activities, methods, research, and legislation for special educators in health, physical education, recreation and dance. It is published three times a year and is available to Alliance members indicating an interest in receiving it; nonmembers must pay an annual fee. Periodicals of general interest include The Journal of Physical Education, Recreation and Dance (published 9 times per year), Health Education (published bimonthly) and Research Quarterly for Exercise and Sport. The annual national AAHPERD convention includes numerous sessions and in-depth conferences on topics dealing with research methods and new developments in the fields of adapted physical education, therapeutic recreation and related specialties.

American Art Therapy Association (AATA) 1980 Isaac Newton Square South Reston, VA 22090 (703) 437-6012

Handicapping Conditions Served: All handicaps.

Users Served: Art therapists.

The Organization: The American Art Therapy Association (AATA) was established to improve the standards of art therapy training and practice, and to widen employment opportunities for art therapists. Art therapy provides the opportunity for nonverbal



expression and communication. AATA approves graduate level training programs in art therapy and registers professional art therapists.

Information Services: Literature on standards of registration, a list of university training programs, and bibliographies of professional literature are free from the Association, AATA publishes a professional journal, a newsletter, and the proceedings of its annual meetings, which may be purchased by nonmembers. Audio-visual materials depict art therapists working with different populations, such as mentally retarded, emotionally disturbed, and elderly individuals. Professionals and students are referred to local art therapy associations and professional contacts working in specific areas of the field.

### American Association for Music Therapy (AAMT) 66 Morris Avenue Springfield, NJ 07081 (201) 379–1100

Handicapping Conditions Served: All handicaps.

Users Served: All interested persons.

The Organization: The American Association for Music Therapy approves academic programs in music the apy and certifies professional music therapists.

Information Services: Free information is available on music therapy as a career, academic program approval, and professional registration requirements. AAMT has a suggested reading list for music therapists. For university program administrators, the Association publishes standards for evaluating students within those programs. AAMT holds one or two seminars per year, where professional papers are delivered on various aspects of music therapy. A research journal and newsletter containing information about workshops, new publications in the field, job openings, and activities of AAMT are available.

### American Association for Rehabilitation Therapy, Inc. (AART) P.O. Box 93 North Little Rock, AR 72116

Handicapping Conditions Served: All disabilities.

Users Served: Rehabilitation therapists and allied health professionals.

The Organization: The philosophy of the American Association for Rehabilitation Therapy, Inc. is that rehabilitation should begin as soon as a patient enters the hospital. Members-industrial rehabilitation therapists, educational therapists, recreation therapists, and rehabilitation therapists—work mostly in hospital settings under medical supervision. AART offers national and regional education seminars devoted to these specialty areas. The Association sponsors the American Certification Council for Medical Rehabilitation Therapists and Specialists which certifies professionals working in these areas who meet specific educational and experience requirements and pass a national certification examination.

Information Services: AART publishes brochures on careers and training in each of the specialty areas. It publishes the Directory of American Certification Council of Medical



Rehabilitation Therapists and Specialists, a quarterly newsletter, The Rehab Bulletin, and a journal, The American Archives of Rehabilitation Therapy.

### American Association for Respiratory Therapy (AART) 1720 Regal Row Dallas, TX 75235 (214)630-3540

Handicapping Conditions Served: Respiratory conditions.

Users Served: Respiratory therapists and therapy technicians, pulmonary laboratory technicians, critical care nurses, physicians, students.

The Organization: Members of the American Association for Respiratory Therapy (AART) include professionals who provide health care to persons with lung disease, such as respiratory therapists, respiratory therapy technicians, pulmonary laboratory technicians, and critical care nurses. The Association divides into several specialty sections (e.g., adult acute respiratory care, cardiopulmonary, education, management, perinatal-pediatrics, and continuing care and rehabilitation); and seminars and workshops are sponsored in these areas by the national and state affiliates. AART offers nontraditional degree programs in conjunction with major universities. CRTE, AART's Continuing Respiratory Therapy Education Program, assists educators and managers in the development of continuing education activities, accredits continuing education programs and recognizes and documents membership participation in continuing education.

Information Services: AART provides information on professional training and career opportunities for respiratory therapists, and publishes a list of approved schools of respiratory therapy. Information is provided to professionals on diagnostic evaluation and treatment of respiratory conditions and on equipment and special devices used in respiratory therapy. The Association publishes continuing education materials for each specialty area. Monthly publications include a professional journal, Respiratory Care, and a feature magazine, AARTimes, about people working in the profession. Brochures and pamphlets are low cost. Prices and descriptions of professional books and manuals can be requested.

American Association of Diabetes Educators (AADE) 500 N. Michigan Avenue Suite 1400 Chicago, IL 60611 (312) 661-1700

Handicapping Conditions Served: Diabetes.

Users Served: Diabetes educators.

The Organization: The AADE is a nonprofit organization founded in 1974 to promote the growth of quality diabetes education for the diabetic consumer in the United States.

Information Services: Publications include a quarterly journal, <u>The Diabetes Educator</u>, a bimonthly newsletter which discusses organizational activities and special events, and other materials such as <u>National Community Resource Guidelines for Diabetes Educators</u> and



Guidelines for Evaluation: A Diabetes Education Program. Price lists and description of various memberships offered by the AADE are available upon request.

American Association of Disability Communicators (AADC) 2100 Pennsylvania Avenue, NW Suite 232 Washington, DC 20037 (202) 653-5010 (Voice) (202) 653-5044 (TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, editors, writers and public relations people concerned with disability.

The Organization: AADC was founded in 1983 with the support of the President's Committee on Employment of the Handicapp'd and the National Organization on Disability (see separate entries). Its purpose is to identify disability as a major, ongoing priority in American society by improving media relations and media access for all disability communicators in nonprofit agencies, advocacy groups, independent living centers and government. AADC is also actively involved in encouraging job opportunities for disabled people in the media and in professional disability communications.

The Association serves as a national resource for disability communicators, providing materials, unique information and opportunities for the exchange of ideas. AADC offers special mailings and technical expertise to member organizations and organizes media and disability workshops. Referrals are made to a network of disabled people working in the media, including writers, broadcasters, editors and reporters.

In conjunction with the President's Committee on Employment of the Handicapped, AADC holds an annual MEDIA AWARD program honoring the finest materials concerning disability produced by both media and disability organizations.

Information Services: AADC publishes a quarterly newsletter which covers developments and information about new ideas and programs concerning disability communications and spotlights disabled people working in the media. A membership brochure outlining services and fees is also available.

American Association of Psychiatric Services for Children (AAPSC)
1133 Fifteenth Street, NW
Suite 1000
Washington, DC 20005
(202) 429-9713

Handicapping Conditions Served: Mental and emotional disorders.

Users Served: Child mental health professionals.

The Organization: The American Association of Psychiatric Services for Children (AAPSC) is a membership organization of psychiatric clinics and services and professionals



specializing in the field of mental health. The Association stresses high quality standards for clinical practice, training, and services among its goals. Towards those aims, AAPSC offers consultation to service providers on planning, development, evaluation, standards, accreditation, and financing of child mental health facilities. AAPSC supports and conducts research, represents the concerns of its membership before Congress and Federal agencies, and cooperates with other professional organizations in developing strategies to increase the impact of mental health considerations on the health planning process. A roster of available staff positions in the child mental health care field is maintained at the national office.

Information Services: AAPSC's legislative activities are reported in a quarterly newsletter. The Association publishes the results of its own studies and papers from its annual conference. At the conference, short courses on aspects of child mental health care are offered for continuing education credits. AAPSC also provides referral services for emotionally disturbed children

American Association of University Affiliated Programs for Persons With Developmental Disabilities (AAUAP) 8605 Cameron Street Suite 406 Silver Spring, MD 20910 (301) 588-8252

Handicapping Conditions Served: Developmental disabilities, chronic handicapping illness.

Users Served: Health, education and social service professionals; developmentally disabled and chronically ill individuals.

The Organization: The purpose of the Association is to provide a central office and focal point to the 54 University Affiliated Facilities (UAF) located across the nation. UAF's meet the needs of developmentally disabled persons through the following services: (a) comprehensive and interdisciplinary training of a broad range of professionals and paraprofessional persons; (b) comprehensive and interdisciplinary screening, evaluation, treatment, planning and educational programming; (c) technical assistance to generic and specialized agencies; and (d) dissemination of research findings.

The Association also works with Department of Health and Human Services (HHS) agencies dealing with developmental disabilities and with congressional committees and their staffs.

Information Services: Lay and professional inquirers can request information on education and employment in professions serving developmentally disabled individuals. Also, the Association provides technical assistance for personnel dealing with developmentally disabled persons.

Publications include the quarterly <u>AAUAP Network News</u> which contains reports on Association activities and news relevant to the UAF network, to the Developmental Disabilities program and to the Title V (Maternal and Child Health) program. Other publications include the <u>Resource Guide to Organizations Concerned with Developmental Handicaps</u>, published annually, and <u>Applied Research in Mental Retardation</u>, published quarterly. <u>Developmental Handicaps</u>: <u>Prevention and Treatment</u>, published annually, contains state of the art papers on developmental and prevention issues and reports on linkages between UAF's and state Maternal and Child Health/Crippled Children programs.



Brochures are available which describe the UAF Network and the SCAN program (Shared Communication and Assistance Network). SCAN is a national electronic link for immediate, accurate communication in resources and services for disabled persons, with state, local and regional options. Services available include electronic mail, file transfer, bulletin boards, information and referral and resource data bases. There is no subscription fee for SCAN, but users pay the connection cost. An on-line version of the Resource Guide is being developed.

### American Association on Mental Deficiency (AAMD) 1719 Kalorama Road, NW Washington, DC 20009 (202) 387-1968

Handicapping Conditions Served: Mental retardation.

Users Served: Mental retardation professionals.

The Organization: The American Association on Mental Deficiency (AAMD) is an organization of professionals working in the field of mental retardation. It was established in 1876 to improve services to people who are mentally retarded. The Association has 35 state chapters, organized into 9 geographic areas, and 17 divisions and subdivisions for specific professional disciplines. AAMD and each regional association hold annual conferences where workshops and seminars (some for continuing education credits) are offered on a variety of topics related to serving mentally retarded persons.

Information Services: AAMD publishes two professional journals, The American Journal on Mental Deficiency, devoted to research in the field, and Mental Retardation, devoted to program activities for mentally retarded persons. The Association's testing materials include the Adaptive Behavior Scale, a test to measure the abilities of the retarded.

Other publications include <u>Classification in Mental Retardation</u>, monographs, and occasional publications on social and legislative issues, and AAMD official policy statements. Each region publishes its own newsletter

#### American Bar Association (ABA) 1800 M Street, NW Washington, DC 20036 (202) 331-2200

Handicapping Conditions Served: Developmental disabilities, mental illness, and physical disabilities.

Users Served: Disability professionals and advocates.

The Organization: The American Bar Association (ABA), a professional membership organization for lawyers, through its Commission on the Mentally Disabled, formulates policy on mental disability issues and monitors legal developments affecting mentally disabled, developmentally disabled, and physically disabled persons.

Information Services: The ABA publishes the Mental and Physical Disability Law Reporter, which contains articles on important cases, decisions, laws, codes, and regulations affecting



mentally disabled, developmentally disabled, and physically disabled individuals. Since 1980 the publication's base of interest has been broadened to include education and accessibility issues, Sections 503 and 504 of the Rehabilitation Act, and other matters of interest to all disabled people. Since 1976 the Reporter has covered over 6000 cases and each ar it covers 1000 new cases. The cases are summarized and indexed by over 200 subject matter topics. The Reporter is published six times per year and is available by subscription. Legal Resources for the Mentally Disabled: A Directory of Lawyers and Other Specialists may also be ordered from the ABA. Other major publications include Mental Disability Law: A Primer and A Model Act Regulating Board and Care Houses: Guidelines for States.

The ABA is developing a data base which will be operational in 1986. It will include citations and summaries (from the <u>Reporter</u>) of mental and physical disability law decisions since 1976. As in the <u>Reporter</u>, the cases will be indexed by over 200 subject matter topics.

American Cleft Palate Association (ACPA) 331 Salk Hall University of Pittsburgh Pittsburgh, PA 15261 (412) 681-9620

Handicapping Conditions Served: Cleft lip and palate.

Users Served: Speech pathologists, dentists, plastic surgeons, and other allied health professionals.

The Organization: The American Cleft Palate Association (ACPA) is a professional organization of people involved in the rehabilitation of persons with cleft lip or palate. ACPA advocates a team approach in the treatment of patients in which speech pathologists, dentists, plastic surgeons and other professionals work together to develop individual rehabilitation programs. The Association works with the American Cleft Palate Educational Foundation (see separate entry) in sponsoring an annual convention. Both organizations conduct continuing education programs for professionals.

Information Services: ACPA publishes a directory of members and multidisciplinary teams; the Cleft Palate Journal, a quarterly; and a newsletter which reports on ACPA activities.

American Congress of Rehabilitation Medicine (ACRM) 30 North Michigan Avenue Suite 922 Chicago, IL 60602 (312) 236-9512

Handicapping Conditions Served: All disabilities.

Users Served: Physicians, rehabilitation nurses and counselors, speech pathologists, physical and occupational therapists, psychologists, social workers, prosthetists and orthotists, administrators, scientists, engineers.

The Organization: The purpose of the American Congress of Rehabilitation Medicine (ACRM) is to promote and advance the art and science of rehabilitation medicine. As used here, rehabilitation medicine means the diagnosis of, prescription for, and treatment of



disease, defect or injury by physical or other means, and restoration to the highest quality of physical, mental, social, vocational and economic life possible. Objectives of the Congress include: provision of a scientific forum for communication among the rehabilitation disciplines; provision of national leadership in the development of an improved and expanded delivery system for rehabilitation services; encouragement of individual professional development through continuing education in scientific assemblies, seminars and postgraduate courses; recognition of contributions to scientific research, education and practice in rehabilitation medicine; and assistance in recruitment of personnel for careers in rehabilitation medicine fields.

An annual meeting is held for educational, social and networking purposes. The ACRM is affiliated with the American Academy of Physical Medicine and Rehabilitation (see separate entry), and shares joint responsibility for publication of a scientific journal, sponsorship of the annual meeting and administrative expenses.

Information Services: The Congress and the AAPM&R (see above) publish the Archives of Physical Medicine and Rehabilitation, a monthly scientific journal which includes articles of interdisciplinary interest written by professionals in the related fields of rehabilitation. A subscription is included in the membership dues. Information services are provided primarily for members only, with nominal fees for most products. The Congress also sponsors an annual essay contest for medical students, graduate students in rehabilitation medicine professions, interns and residents.

# American Corrective Therapy Association (ACTA) c/o David Ser, Executive Director 259-08 148 Road Rosedale, NY 11422

Handicapping Conditions Served: All handicaps.

Users Served: Corrective therapists.

The Organization: The American Corrective Therapy Association (ACTA) recommends standards for certification of professionals and for training facilities. It offers a limited number of scholarships to students and funds professional research. Corrective Therapy is the applied science of medically prescribed therapeutic exercise, education, and adapted physical activities to improve the quality of life and health of adults and children, by developing physical fitness, increasing functional mobility and independence, and improving psychosocial behavior. The Corrective Therapist evaluates, develops, implements, and modifies adapted exercise programs for disease, injury, congenital defects, and other functional disabilities.

Information Services: The Association is a source of information about education and training of corrective therapists. A publication list, available on request, includes titles of reprints, handbooks, and manuals on standards and practice in the field. These publications are available at a minimal charge. ACTA publishes a professional journal which is clinical and research oriented.



American Council on Rural Special Education (ACRES)
Attention: Dr. Doris Helge
National Rural Development Institute
Western Washington University
Bellingham, WA 98225
(206) 676-3576

Handicapping Conditions Served: All handicaps.

Users Served: Teachers, administrators, support personnel, parents.

The Organization: The American Council on Rural Special Education (ACRES), founded in May 1981, is a membership organization for persons interested in improving services for disabled students living in rural areas. ACRES has initiated a number of national projects to increase educational opportunities and to improve direct services for the handicapped and rural population. ACRES sponsors an annual national conference, and members participate in action task forces.

Information Services: A brochure on ACRES is available upon request. Members receive a newsletter published several times a year and discounts on other ACRES publications. The organization also offers rural jobs services by which persons seeking positions are linked with jobs available. In addition, ACRES has developed a data bank on the members of the organization which serves as a means for linking professionals or other members with specific interests and abilities. Members living in a particular geographic area can also be identified via this system. (Each member receives a membership resource book upon joining).

American Dance Therapy Association (ADTA) 2000 Century Plaza Suite 108 Columbia, MD 21044 (301) 997-4040

Handicapping Conditions Served: All handicaps.

Users Served: Dance therapists.

The Organization: The American Dance Therapy Association (ADTA) approves educational programs in dance therapy and registers professional dance therapists.

Information Services: ADTA has free information on educational programs, guidelines for dance therapy training and internship, professional registration requirements, and regional professional contacts. The Association publishes The American Journal of Dance Therapy (available at reduced rates to members), a newsletter, monographs, bibliographies and reports of conference proceedings which are free to members and are available for a charge to nonmembers. ADTA sponsors annual educational workshops, and its regional chapters hold similar workshops throughout the year. Nonmembers are welcome to attend.



# American Deafness and Rehabilitation Association (ADARA) 814 Thayer Avenue Silver Spring, MD 20910 (301) 589-0880 (Voice and TDD)

Handicapping Conditions Served: Deafness, hearing impairments, and deaf-blindness.

Users Served: Health care professionals, students.

The Organization: The American Deafness and Retardation Association (ADARA) is a network of professionals and community persons who are active in the field of deafness. These areas include rehabilitation, mental health, education, social work, speech therapy, medicine, psychiatry, psychology, and many other areas; students are included. ADARA offers opportunities for professional enhancement available to deaf persons, and serves as a vehicle of communication through its forums, conferences, workshops, and publications. This network of professionals consists of local chapters and special interest sections: Counseling, Deaf-Blindness, and the State Coordinators of Services to Deaf Persons. It has two affiliate organizations, the National Association of State Agencies for the Deaf (NASAD) and the American Society of Deaf Social Workers (ASDSW). ADARA was formerly known as the Professional Rehabilitation Workers with the Adult Deaf (PRWAD).

Information Services: ADARA gives referral service on information regarding careers, university programs, job opportunities, and the general topics of deafness and deaf-blindness. The national office provides this service free of charge to inquirers. Information regarding certain legislation, conferences, and workshops can also be obtained through the national office. The ADARA publishes the quarterly Journal of Rehabilitation of the Deaf, the bimonthly ADARA newsletter, and occasional special publications and monographs. The most recent monograph is Deafness and Mental Health: Emerging Responses. A publication list with a complete listing of all ADARA publications is available upon request from the national office.

# American Disability Evaluation Research Institute (ADERI) P.O. Box 7735 Ann Arbor, MI 48107 (313) 971-1177

Handicapping Conditions Served: Persons with physical disabilities.

Users Served: Professionals involved with the disability claims process.

The Organization: ADERI was chartered in 1981 to assist in meeting the research and information needs of persons involved in processing disability claims. Under grants and contracts, ADERI sponsors research to determine the most effective techniques and equipment for use by practicing physicians for evaluating the scope and effect of disabling conditions as they relate to job requirements. It also conducts studies of disability epidemiology covering such areas as historical reviews of state and Federal programs, job risk assessment, rehabilitation program assessment, the medical/legal interface, and guidelines for determining work capacity and disability status.

ADERI's affiliate, the National Association of Disability Evaluating Professionals (NADEP), located at the same address, was organized to serve the specific needs of physicians who are



requested to perform medical examinations of persons filing various types of work disability claims. Its objectives, which are similar to those of ADERI, are to establish recognition of and support for this medical responsibility. Membership in NADEP is open to all professionals for an annual fee.

Information Services: ADERI/NADEP sponsors conferences, workshops, and seminars nationwide on such topics as the medical and legal aspects of disability, quantification of work capacity, guidelines for determining disability or work ability for specific conditions, and how to serve as an expert witness.

Seminars are also held for other professionals involved with the disability claims process: lawyers, employers, unions, insurance investigators, and vocational rehabilitation specialists.

American Federation of Teachers (AFT)
AFT Teachers' Network for Education of the Handicapped
555 New Jersey Avenue, NW
Washington, DC 20001
(202) 879-4460

Handicapping Conditions Served: All handicapping conditions for which mainstreaming is possible.

Users Served: Teachers.

The Organization: The AFT Teachers' Network for Education of the Handicapped, a program of the American Federation of Teachers (AFT, AFL-CIO), has as its goal to facilitate the ability of regular education teachers to work effectively with handicapped children. The Network assists AFT locals in providing in-service training to regular education teachers with a focus on practical instructional techniques to use with the mainstreamed child. The program also assists other educational and community organizations by giving workshops and technical assistance.

in formation Services: The Network responds to requests for information on mainstreaming handicapped children, and has developed a series of pamphlets on mainstreaming children with particular disabilities. The pamphlets have information on the disabling condition, instructional techniques, and resource materials and organizations. There is a nominal charge for these publications.

A film and video tape, "The ACB's of Teaching the Learning Disabled Student," is available for renta, or purchase. The film and its training manual have been developed as an inservice training module to enhance regular educators' efforts to teach learning disabled students more effectively.

American Health Care Association (AHCA) 1200 15th Street, NW Washington, DC 20005 (202) 833-2050

Handicapping Conditions Served: All disabilities (including aging) requiring long-term health care.



User: Served: Personnel of long term health care facilities.

The Organization: The American Health Care Association (AHCA), founded in 1949, is a federation of licensed nursing homes and allied long term health care facilities, including adult day care, mental health, and child care service. AHCA and its 50 affiliated state associations work to promote professional standards in long term health care delivery. All AHCA members must be licensed by their state governments, as must be the administrators who manage them.

AHCA represents its members on issues before Congress and Federal regulatory and executive agencies, and offers a variety of professional and educational programs.

Information Services: Upon receipt of a business-sized self-addressed, stamped envelope, AHCA sends free copies of their brochure Thinking about a Nursing Home? A catalog of the Association's publications and materials on nursing home management training and community involvement may be purchased.

American Library Association (ALA)
Association of Specialized and Cooperative
Library Agencies (ASCLA)
50 East Huron Street
Chicago, IL 60611
(312) 944-6780

Handicapping Conditions Served: All handicaps.

Users Served: Librarians.

The Organization: The Association of Specialized and Cooperative Library Agencies, a division of the American Library Association, is a professional organization for librarians serving communities and special populations such as blind, physically handicapped, deaf, and impaired elderly persons. ASCLA serves in an advisory capacity, helping its members to develop and evaluate policies and activities. ASCLA also sponsors programs at the ALA Annual Conference.

Information Services: Standards and guidelines for libraries developing services for the blind and mentally retarded are available in print form. Special issues of the ASCLA journal which relate to library services to the handicapped are: Bibliotherapy, Information Needs of Hearing Impaired People, and Library Services for the Blind and Physically Handicapped. Other publications available from ALA or ASCLA include The Librarian and the Patient, Equal Access: A Manual of Procedures for Initiating a Public Library Home Service Program, and The World of Work: A Handicapped Person's Cuide to Finding a Job-A Bibliography. The ASCLA publications list gives sources on library service to disabled persons and design of a barrier-free environment. Cassettes of some of ASCLA's conference programs are available. There is a charge for publications and cassettes. ASCLA publishes a quarterly newsletter, Interface, which includes articles, book reviews, news items, product evaluations, and news of conferences.



# The American Occupational Therapy Association (AOTA) 1383 Piccard Drive Rockville, MD 20850 (301) 948-9626

Handicapping Conditions Served: All disabilities, and problems associated with aging.

Users Served: Occupational therapists.

The Organization: The American Occupational Therapy Association, Inc. (AOTA) promotes quality occupational therapy (OT) services by providing accreditation of educational programs, certification of practitioners, professional development, public education, and advocacy on programs related to national health care issues.

Information Services: Information is available to the general public about OT as a career and schools that offer professional programs in OT. A variety of print and audio-visual materials for the OT practitioner are published and sold by the organization. AOTA has professional information packets on 38 subject areas including adapted clothing and equipment, alcoholism, arthritis, cancer, cerebral palsy, drug abuse, geriatrics, handicapped homemakers, home health, mental health, prevocational/vocational, and spinal cord injuries. These packets contain the names of OT resource persons who specialize in the particular field, special facilities, bibliographies of printed materials, and selected reprints. The Association sponsors regional workshops on topics such as the elderly, vocational readiness, quality assurance, prosthetics, orthotics, OT and pediatrics, neurophysiological approaches to treatment, and reality orientation for the elderly. AOTA publishes a monthly professional journal, the American Journal of Occupational Therapy, a monthly newspaper, and a Federal Report, available by subscription. Also available by subscription are quarterly newsletters published by AOTA's six Special Interest Sections: Administration and Management, Developmental Disabilities, Gerontology, Mental Health, Physical Disabilities, and Sensory Integration. The organization's state associations provide inquirers with referrals to local OT practitioners and facilities.

# American Orthotic and Prosthetic Association (AOPA) 717 Pendleton Street Alexandria, VA 22314 (703) 836-7116

Handicapping Conditions Served: Musculoskeletal and orthopedic conditions.

Users Served: Manufacturers of orthotic and prosthetic devices and facilities which render orthotic and prosthetic patient care services.

The Organization: The American Orthotic and Prosthetic Association (AOPA) represents the interests of manufacturers of orthotic and prosthetic devices and facilities which render orthotic and prosthetic patient care services by interacting with government agencies and assisting in the preparation of Federal and state legislation. National and regional meetings are held to keep members of the profession abreast of technological advances and to discuss facility management.

Information Services: A list of educational institutions which offer a curriculum in orthotics and/or prosthetics for students interested in entering the profession is available from the Association. AOPA publishes a quarterly journal and a monthly news magazine



which emphasize professional, technical and business topics. A listing of members is compiled annually. AOPA has published a <u>Medicare Manual</u> and a <u>Durable Medical Equipment Manual</u>. Publications are free to members and available to nonmembers for purchase.

#### American Physical Therapy Association (APTA) 1111 North Fairfax Street Alexandria, VA 22314 (703) 684-2782

Handicapping Conditions Served: Physical disabilities and developmental disabilities.

Users Served: Physical therapists, disabled persons, parents, and teachers.

The Organization: The American Physical Therapy Association (APTA) fosters the development and improvement of physical therapy services and education by: (1) accrediting academic programs in physical therapy; (2) assisting in composing state certification examinations; and (3) offering continuing education courses and workshops in specialty areas (e.g. arthritis, central nervous system disorders, burn treatment, sports medicine, etc.) at the national and local levels. For its members, APTA provides research fellowships and legal assistance for alleged malpractice. APTA has 52 state chapters.

Information Services: Free information is available about physical therapy as a career, accredited professional training programs, sources of financial assistance for students, and employment statistics.

Pamphlets are available on subjects such as improving movement, comfortable pregnancy, and managing stress. APTA publishes a newsletter, a monthly research periodical, a bimonthly magazine on patient care, and books related to practice in the field. A publications list is available. APTA provides free bibliographies on such topics as geriatric exercises, handicapped children, holistic health, and stroke. Educational Resource guides on such subjects as back care, burn care, stroke, diabetes, decubitus ulcer, Parkinson's Disease, and cancer are available at a small charge. APTA also refers handicapped individuals to facilities which offer physical therapy services. Further information may be obtained by contacting Information Central.

# American Rehabilitation Counseling Association (ARCA) 5999 Stevenson Avenue Alexandria, VA 22304 (703) 823-9800

landicapping Conditions Served: All disabilities.

Isers Served: Rehabilitation counselors, administrators and educators.

he Organization: The objective of the American Rehabilitation Counseling Association ARCA) is to continually improve the profession of rehabilitation counseling in its service persons with disabilities. Toward this end, ARCA: (1) exercises leadership in developing the profession and science of rehabilitation counseling; (2) advocates for the maintenance standards in rehabilitation counseling practice and education; (3) promotes relevant search and research dissemination; (4) encourages dialogue and coordination among



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rehabilitation professionals, within and among various specialty areas; and (5) engages in active collaboration with other national professional organizations and with consumer groups. Much of ARCA's work is performed through nationwide committees. During 1985-86, eleven task groups are examining ways in which the rehabilitation counseling profession can better serve persons with disabilities in specific topical areas. ARCA has four state chapters:

The American Association for Counseling and Development (AACD) is ARCA's parent organization. ARCA conducts workshops related to rehabilitation counseling at AACD's annual conference. ARCA supports and participates in AACD certification, licensure and accreditation activities and is a member organization of other national groups with accreditation responsibilities in the rehabilitation field.

Information Services: A brochure describing ARCA membership benefits is available upon request. By spring, 1986, a brochure describing rehabilitation counseling will also be available. A newsletter, the ARCA News, is published 4-5 times per year. It contains timely information on legislation, organization activities, professional developments, and items relevant to the rehabilitation of persons with disabilities. ARCA's journal The Rehabilitation Counseling Bulletin, is also published 4-5 times per year and contains major professional articles relevant to the rehabilitation of persons with disabilities. Special issues devoted to single topics are sometimes published. Recent topics include "Implementing Computers in the Rehabilitation Process" and "Career and Life Transition." Both the journal and newsletter are received by members as a membership benefit. In 1986, a special monograph will be published through the AACD press, containing the findings of ARCA's task groups on such current areas as independent living, consumer involvement, supported employment, transition, sensory impairments and others. A bibliography of doctoral dissertations in rehabilitation is also available.

ARCA provides technical assistance to any organization concerned with the rehabilitation of persons with disabilities. The extent of such assistance depends on the specific request and ARCA's abilities in that area.

### American Society of Handicapped Physicians (ASHP) 137 Main Street \_\_\_\_\_ Grambling, LA: 71245 (318) 247-3000

Handicapping Conditions Served: All handicaps.

Users Served: Physicians and allied health professionals.

The Organization: This organization was established by Spencer B. Lewis, MD, a blind physician, to assist the estimated 18,000 disabled physicians in the United States. Its goals include: promoting unity, understanding and camaraderie among handicapped physicians and their families; advocating for political and legislative action in medicine, government, and education; providing education and supportive services during the rehabilitation process of the disabled physician, and educating society through media exposure regarding the capabilities of handicapped persons in the medical field.

Membership in this organization has grown rapidly since it came into being in 1982 and includes physicians in 46 states and a number of foreign countries. All age groups, medical specialties, and disabilities are represented.



Information Services: The Society publishes a quarterly newsletter, Synapse, and holds annual national conferences. Eventually this organization hopes to serve as a national clearinghouse for information on the varied needs and concerns of handicapped medical professionals. ASHP makes referrals in the areas of employment, medical education, residency programs and hospital staff positions. Some information offered by the Society is available on tape.

American Speech-Language-Hearing Association (ASHA) 10801 Rockville Pike Rockville, MD 20852 (301) 897-5700 (Voice/TDD)

Handicapping Conditions Served: Speech, language, and hearing disorders.

Users Served: Physicians, speech-language pathologists, audiologists.

The Organization: The American Speech-Language-Hearing Association (ASHA) is a certifying body for professionals providing speech, language, and hearing therapy to the public, and is an accrediting agency for college and university graduate school programs in speech-language pathology and audiology, and for clinic and hospital programs which offer such services. The Association conducts research in communication disorders and studies of community needs for direct services.

Informations Services: Public information brochures about communication disorders and roles of speech-language pathologists and audiologists are available from ASHA. ASHA has extensive career information in the areas of possible employment, university training programs, and certification requirements. Its publications include the Journal of Speech and Hearing Research; Journal of Speech and Hearing Disorders; Language, Speech and Hearing Services in the Schools; Guide to Professional Services in Speech-Language Pathology and Audiology; and an ASHA Directory of membership. A monthly magazine, ASHA, features organizational news, announcements of meetings, job openings, and research reports. Some publications are free to members, but all may be subscribed to or purchased by interested persons. Fifty state affiliates provide information about clinical services at the local level, and some publish their own newsletters. ASHA sponsors conferences, short courses, institutes, and workshops as part of its professional education program.

American Spinal Injury Association (ASIA) 250 East Superior Street Room 619 Chicago, IL 60611 (312) 908-3425

Handicapping Conditions Served: Spinal cord injury.

Users Served: Physicians, paraprofessionals.

The Organization: The American Spinal Injury Association (ASIA) is a corporation organized for the following purposes: to augment and encourage knowledge and investigation of the causes, cure and prevention of spinal injury and related trauma; to promote and exchange ideas between professionals in the field of spinal injury management; to support, coordinate and encourage basic research in the field of management of spinal



injury and related trauma; to develop teaching and educational material and provide specialized training for physicians and allied health personnel in the management of spinal injury; and to support and develop education of the medical profession and the laity in the prevention and proper management of spinal injury.

The Association sponsors an annual scientific/clinical meeting for physicians and other health care professionals involved in spinal cord injury and its management. ASIA is affiliated with the American Spinal Injury Foundation.

Information Services: The Association publishes the ASIA BULLETIN, three times annually. ASIA members automatically receive a subscription with dues. Other publications include: Standards for Neurological Classification of SCI; Task Force Report on Spinal Cord Administration; Task Force Report on Training Guidelines for SCI Physicians; Guidelines for Facility Categorization and Standards of Care: SCI; Spinal Cord Injury Nursing Education - Suggested Content; and The Abstracts Digest from ASIA meeting proceedings. Ordering information and a price list can be obtained from ASIA. Taped proceedings (i.e. instructional courses) from the clinical meetings are available.

Association for Education and Rehabilitation of the Blind and Visually Impaired (AER) 206 North Washington Street Alexandria, VA: 22314 (703) 836-6060

Handicapping Conditions Served: Blindness, visual impairments, and deaf-blindness.

Users Served: Teachers and rehabilitation professionals.

The Organization: The Association for Education and Rehabilitation of the Blind and Visually Impaired (AER) is a membership organization of teachers and rehabilitators who work with blind and visually impaired children. AER establishes professional standards and certifies teachers and teaching assistants working in the field. Special interest groups of AER include teachers of the multihandicapped and deaf-blind children, orientation and mobility instructors, rehabilitation teachers and 16 others. AER meets biennially and also holds regional meetings to conduct educational workshops in the specialized fields.

Informational Services: The Association publishes an annual journal, a bimonthly newsletter and a monthly job exchange newsletter.

Association for the Care of Children's Health (ACCH) 3615 Wisconsin Avenue, NW Washington, DC 20016 (202) 244-1801

Handicapping Conditions Served: Disabilities resulting from chronic illness and/or requiring hospitalization of children.

Users Served: Health professionals and students, parents, teachers.

The Organization: The Association for the Care of Children's Health (ACCH) is a multidisciplinary organization dedicated to the psychosocial well-being of children and



families in health care settings. Membership includes health professionals and students in all disciplines as well as parents and teachers.

Information Services: ACCH publications, for which there is a charge, include titles on chronically ill and hospitalized children. A newsletter, <u>ACCH Network</u>, reports on new developments and activities of national and local organizations related to chronic illness in children. ACCH also publishes a quarterly peer review journal, <u>CHILDREN'S HEALTH CARE</u>.

Association of Medical Rehabilitation Directors and Coordinators, Inc. (AMRDC)
87 Elm Street
Framingham, MA 01701
(617) 877-0517

Handicapping Conditions Served: All handicaps.

Users Served: Administrators and directors of rehabilitation programs, agencies and services.

The Organization: Members of the Association are physicians in rehabilitation medicine and directors or coordinators of rehabilitation programs. The organization sets standards for professional practice, and provides professional certification to qualifying members. It offers continuing education courses in rehabilitation management in conjunction with its annual meeting, and it provides a job placement service for members. Eight regional divisions have been established to provide representation of the membership within the Executive Board and to sponsor regional meetings and activities.

Information Services: Information about professional certification and university programs in rehabilitation management is available from the Association. AMRDC publishes an annual membership directory and a quarterly newsletter, which covers Association activities, reviews publications relevant to the field, and includes articles on rehabilitation administration/management and activities in the field. Also available is the Education and Standards Manual which covers position requirements, suggested educational requirements and professional activities.

Association of Mental Health Administrators (AMHA) Suite 1103 W 840 N. Lake Shore Drive Chicago, IL 60611 (312) 943-2751

Handicapping Conditions Served: Mental and emotional disorders and developmental disabilities.

Users Served: Administrators, health services.

The Organization: The professional association disturbed, mentally ill, meas those with problems of

ociation of Mental Health Administrators (AMHA) is a dministrators of agencies and programs serving emotionally y retarded, and developmentally disabled individuals, as well ol and substance abuse The major goals of AMHA are to



promote excellence in administrative practice, to foster the professional growth of its members, and to provide recognition for noteworthy individual service in the field of mental health administration. The Association confers the Certificate of Certified Mental Health Administrator to qualified active members. The certification process includes both a written and oral review and covers various components, including competency-based assessments, continuing education and professional development:

Information Services: A three-day annual meeting and educational conference is held every fall. Registration is open to members and non-members. The AMHA Monthly Newsletter reports on relevant legislative developments, new information sources and publications, organizational issues, personal notes about accomplishments of Association members and empleyment information. The Journal of Mental Health Administration, issued in the spring and fall, publishes articles on new developments, innovations, and trends in the field of mental health management. Brochures about the Association and certification criteria are available. There is a nominal charge for services and publications.

Association of Rehabilitation Nurses (ARN) 2506 Gross Point Road Evanston, IL 60201 (312) 475-7300

Handicapping Conditions Served: All disabilities.

Users Served: Nurses, other interested health care professionals.

The Organization: The Association of Rehabilitation Nurses (ARN) was founded to advance the quality of rehabilitation nursing service throughout the community. Through the national office and 38 state chapters, the ARN offers educational opportunities to promote an awareness of and interest in rehabilitation nursing and to improve the expertise of personnel at all levels. The Association also facilitates the exchange of ideas in rehabilitation programs. Educational opportunities are provided through a variety of programs including: an annual national educational conference, a certification program, regional educational seminars, a self-study program and publications of the Rehabilitation Nursing Institute, the education and research foundation of ARN.

Under the Certified Rehabilitation Registered Nurse (CRRN) program, an examination is offered once yearly and certification is good for five years. Recertification is by examination or a combination of proof of continuing education, publication in a professional journal and submission of items for CRRN examination.

Information Services: The ARN has brochures available on membership, the certification program, education programs, and the self-study programs. The ARN News, a bimonthly newsletter primarily sent to members only, contains news about organizational activities. Rehabilitation Nursing, a bimonthly journal, contains professional manuscripts, organizational news, calendar listings of educational programs and other items of interest. Other publications available include a bibliography on rehabilitation nursing and a core curriculum covering rehabilitation nursing concepts. A self-study program on rehabilitation nursing topics consists of a study guide and cassette tapes and serves as both a learning tool and preparation guide for the certification examination. A membership fee includes subscriptions to the newsletter and the journal, and members are entitled to reduced prices on most materials and programs.



# Association on Handicapped Student Service Programs in Post-Secondary Education (AHSSPPE) P.O. Box 21192 Columbus, OH 43221 (614) 488-4972

Handicopping Conditions Served: All handicaps.

Users Served: Post-secondary education personnel.

The Organization: The Association on Handicapped Student Service Programs in Post-Secondary Education (AHSSPPE) provides a vehicle to strengthen the professionalism, expertise, and competence of personnel working with post-secondary handicapped students.

The Association has members throughout the U.S. and Canada representing residential and non-residential campuses, two and four year institutions. The Association sponsors a national conference each year.

Information Services: AHSSPPE publishes a newsletter, the ALERT, an annotated bibliography, proceedings from its national conferences and a quarterly bulletin, AHSSPPE. An Employment Exchange is also available to members. Telephone inquiries should be directed to Dr. Jane Jarrow, Executive Director.

#### Better-Hearing Institute (BHI) Box 1840 Washington, DC 20013 (703) 642-0580

Handicapping Conditions Served: Hearing impairments.

Users Served: Hearing-impaired persons, friends and family of hearing-impaired persons.

The Organization: The Better Hearing Institute (BHI) serves hearing-impaired persons through public information and public service programs, informing them about hearing loss and readily available medical, surgical, hearing aid, and rehabilitation assistance.

Information Services: BHI produces an extensive series of public service announcements on radio, TV and in magazines, which often fecture various celebrities with corrected hearing handicaps. The Institute also produces booklets, articles, and audio-visual presentations on hearing loss and what to do about it, which BHI sells to community organizations. Audio-visuals include "Listen Up With Norm Crosby," a 17-minute film on noise and hearing conservation, and three slide/cassette programs: "You and Your Hearing," for general audiences; "Silence is Lonely," targeted to the special needs of the senior citizen; and "We Overcame Hearing Loss," narrated by comedian Norm Crosby. (All four programs are also available on video). Printed materials on hearing loss, including noise-induced hearing loss, are also available from BHI. There is a charge for printed and audio-visual materials.

A Hearing HelpLine, (800) 424-8576, provides assistance to consumers in handling questions, suggestions and complaints about hearing loss, hearing aids, and hearing help services. BHI has national listings of hearing clinics, otolaryngologists, and certified hearing aid dispensers. Information from Hearing HelpLine is free.



Commission on Accreditation of Rehabilitation Facilities (CARF) 2500 North Pantano Road Tucson, AZ 85715 (602) 886-8575

Handicapping Conditions Served: All handicaps.

Users Served: Medical, vocational and psychosocial professionals, disabled persons, parents, teachers.

The Organization: The Commission on Accreditation of Rehabilitation Facilities (CARF) is the recognized accreditation authority for organizations serving people with physical and developmental disabilities. The Commission has established standards for and accredits organizations that provide the following programs: comprehensive inpatient rehabilitation, spinal cord injury programs, chronic pain management programs, brain injury programs, outpatient medical rehabilitation, infant and early childhood developmental programs, vocational evaluation, work adjustment, occupational skill training, job placement, work services, programs in industry, activity services, residential services, independent living programs, psychosocial programs and alcoholism and drug abuse treatment programs.

Information Services: Basic information about standards affecting all aspects of a rehabilitation facility's operation may be obtained from CARF's Standards Manual for Organizations Serving People with Disabilities. The Commission publishes separate pamphlets and booklets on program evaluation for specific facilities: hospital based facilities, vocational rehabilitation centers, work activity centers, and outpatient rehabilitation facilities. A list of accredited facilities is available upon request.

Conference of Educational Administrators Serving the Deaf (CEASD) 814 Thayer Avenue Silver Spring, MD 20910 (301) 585-4363

Handicapping Conditions Served: Deafness, hearing impairments, and deaf-blindness.

Users Served: Educational administrators serving deaf persons.

The Organization: The Conference of Educational Administrators Serving the Deaf (CEASD) was founded to promote effective management of schools, programs, and agencies providing services to the deaf. Its standing committees have developed position papers on topics related to the administration of elementary, secondary, postsecondary, and residential schools for the deaf. Administrative workshops are held throughout the year on these topics. CEASD evaluates and accredits elementary and secondary school programs, and certifies individuals who work in residential settings.

Information Services: The CEASD selects, reviews and evaluates captioned educational films. Actual distribution of captioned educational films and captioned general entertainment films is handled through Modern Talking Picture Service (see separate entry).



The Conference and the Convention of American Instructors of the Deaf jointly publish the American Annals of the Deaf, which includes a variety of articles relevant to the deaf and to professionals working with the deaf. Each April issue of the Annals is a Directory of Programs and Services for the Deaf in the United States, listing local education and rehabilitative services for the deaf, including the deaf-blind, in the U.S. and Canada. CEASD publishes the proceedings of its annual conference and copies of its administrative position papers. Members receive a newsletter. An extensive materials list of pamphlets and reprints from the Annals is available from the Conference.

Congress of Organizations of the Physically
Handicapped (COPH)
16630 Beverly Avenue
Tinley Park, IL 60477
(312) 532-3566

Handicapping Conditions Served: All physical handicaps.

Users Served: Organizations of the physically handicapped.

The Organization: The Congress of Organizations of the Physically Handicapped is an umbrella organization for about 50 organizations and associations of the physically handicapped. It serves these organizations by coordinating the joint activities of member organizations, and by representing the legislative objectives of member organizations at the national and state levels. COPH does not provide any direct services to handicapped individuals nor does it have information on scholarships and other concerns.

Information Services: COPH publishes a quarterly newspaper, the COPH Eulletin, with information on developments in rehabilitation research and on state and local legislation affecting the physically handicapped.

# Convention of American Instructors of the Deaf (CAID) P.O. Box 2605 Columbia, MD 21045 (301) 596-6722 (Voice and TDD)

Handicapping Conditions Served: Deafness, hearing impairments, and deaf-blindness.

Users Served: Professionals working with deaf persons.

The Organization: Members of the Convention of American Instructors of the Deaf (CAID) nelude teachers and support personnel working in a variety of educational settings. Through biennial conferences and regional workshops, CAID promotes the exchange of nformation among professionals. Topics for workshops range from diagnostic tools to sex iducation to psycholinguistics. Through its membership in the Council of Education of the Deaf, CAID helps to formulate standards of professional certification and accreditation of iducational programs.



Information Services: CAID and the Conference of Educational Administrators Serving the Deaf, (see separate entry), jointly publish the American Annals of the Deaf, which include a variety of articles relevant to the deaf and to professionals working with the deaf. Each April issue of the Annals is a Directory of Programs and Services for the Deaf in the United States, listing local educational and rehabilitative services for the deaf, including the deaf-blind, in the U.S. and Canada. Reprints from the Annals and a materials list containing pamphlets of interest to teachers, students, and parents are available from CAID. The organization publishes a newsletter for members, The Advocate for Education of the Deaf, and proceedings from its conferences.

Council of State Administrators of Vocational Rehabilitation (CSAVR)
1055 Thomas Jefferson Street, NW Suite 401
Washington, DC 20007
(202) 638-4634

Handicapping Conditions Served: All handicaps.

Users Served: State rehabilitation agency directors.

The Organization: The Council of State Administrators of Vocational Rehabilitation (CSAVR) is composed of the chief administrators of rehabilitation agencies in the states, the District of Columbia, and the U.S. territories. These agencies serve physically and mentally handicapped persons and are the state partners in the Federal-state program of vocational rehabilitation services provided under the Rehabilitation Act of 1973. In addition to providing a forum for discussion of relevant issues to its member administrators, the Council serves as an advisory body to the Rehabilitation Services Administration and the National Rehabilitation Association.

Information Services: CSAVR provides information to member agencies and to Federal agencies in coordinating rehabilitation services. It publishes a newsletter, <u>CSAVR MEMORANDUM</u>, which is issued on an as-needed basis: CSAVR also provides technical assistance to its members through its twelve standing committees. Information can be provided in braille, when needed.

Council on Rehabilitation Education, Inc. (CORE) 185 North Wabash Room 1617 ........ Chicago, JL 60601 (312) 346-6027

Handicapping Conditions Served: All disabilities.

Users Served: Disabled persons, parents, teachers, health care professionals, educators, postsecondary institutional officers.

The Organization: The Council on Rehabilitation Education (CORE) seeks to provide effective delivery of rehabilitation services to individuals with disabilities by stimulating and fostering continuing review and improvement of master's degree level programs. CORE's accreditation process promotes self-improvement rather than outside censure. A



further purpose of the accreditation process is to meet the manpower needs of both private and public rehabilitation agencies by providing graduates who have been equipped with the skills and knowledge necessary to help decrease dependence among persons with disabilities. CORE is involved in the development of standards for Rehabilitation Counselor Education (RCE) programs, the evaluation of compliance with established standards for RCE programs and consultation for program development.

CORE's membership is composed of persons appointed from five sponsoring organizations. They are: American Rehabilitation Counseling Association (ARCA), National Rehabilitation Counseling Association (NRCA), National Association of Rehabilitation Facilities (NARF), National Council on Rehabilitation Education (NCRE) and the Council of State Administrators of Vocational Rehabilitation (CSAVR).

Information Services: Annual publications include a brochure listing the recognized master's degree programs in rehabilitation counselor education and a fact sheet which includes current membership and planned activities for the current year. Also available is the Accreditation Manual for Rehabilitation Counselor Education Programs (1979 and 1983 editions). CORE offers limited distribution of bibliographies on information related to accreditation and/or rehabilitation counselor education program development. Statistical data based on responses to individual questionnaires from all RCE programs since 1979 is available. The questionnaire respondent groups include faculty/students, graduates, and employers/supervisors. Distribution of statistical data must be authorized by the CORE research committee.

There is a nominal charge for materials to cover reproduction costs.

## Foundation for Science and the Handicapped, Inc. (FSH) 154 Juliet Court - Clarendon Hills, IL 60514 (312) 323-4181

Handicapping Conditions Served: All handi aps.

Users Served: Disabled persons, parents, teachers, counselors, rehabilitation professionals.

The Organization: The Foundation for Science and the Handicapped was established in 1977 by a group of disabled scientists. The Foundation seeks to improve the quality and accessibility of the educational system for handicapped individuals, especially in the various areas of science. Major goals are to build a network that will support handicapped scientists throughout their lives, and involve Foundation members in advisory committees in academic institutions, government and industry. The Foundation works closely with the American Association for the Advancement of Science.

Information Services: FSH acts as a clearinghouse for information on science, education, technology and careers for handicapped persons. The Foundation publishes a newsletter six to eight times per year, reporting on varied news items of interest to disabled scientists and students. Free to members, it is also available on tape. A book ABLE SCIENTISTS - DISABLED PERSONS: Biographical Sketches by S. Phyllis Stearner, Ph.D. is also available through the Foundation. It describes the lives and achievements of 27 disabled scientists and students of science who are overcoming obstacles imposed by their disabilities and are carrying on careers and studies in their chosen fields. The book serves as an inspiration to disabled students and their parents, teachers and counselors. The Foundation also maintains the Student Grant Program, through which \$1,000 grants (three in 1985) are awarded to



physically disabled students accepted by or attending a college, university, graduate or professional school, majoring in an area of science, mathematics, medicine or engineering. Information about membership and services can be obtained by writing the Foundation at the above address.

# International Association of Psychosocial Rehabilitation Services (IAPSRS) P.O. Box 278 McLean, VA 22101 (703) 237-9385

Handicapping Conditions Served: Psychiatric disabilities.

Users Served: Facilities and professionals serving psychiatrically disabled persons.

The Organization: This organization was established in 1975 in response to increasing recognition of the need to upgrade community-oriented services for the psychiatrically disabled. As the community mental health center movement has gathered increased momentum, the importance of insuring adequate psychosocial rehabilitation services has assumed greater priority among planners, administrators, and service providers. The organization undertakes to establish improved communications among all levels of personnel active in this field.

IAPSRS assists agencies and practitioners in program development, evaluation and followup, staff utilization and training, management and administration, and in promoting understanding of the special needs of the psychiatrically disabled. Membership in the IAPSRS is open to facilities which offer vocational, residential, social/recreational, and/or educational services to disabled adults, and to professionals working in this area.

Information Services: Membership in the IAPSRS includes a free subscription to its newsletter and to the <u>Psychosocial Rehabilitation Journal</u>, current legislative updates, and reduced rates for attending state and national conferences.

National Accreditation Council for Agencies Serving the Blind and Visually Handicapped (NAC)
15 West 65th Street
9th Floor
New York, NY 10023
(212) 496-5880

Handicapping Conditions Served: Blindness and visual impairments.

Users Served: Facilities and agencies that serve blind individuals.

The Organization: The National Accreditation Council for Agencies Serving the Blind and Visually Handicapped (NAC) establishes and maintains accreditation standards for agencies and schools that specialize in serving blind children and adults. The Council accredits organizations that meet its standards and reviews services and management periodically to assure continued worthiness for accredited status.



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Information Services: NAC provides information about its standards which is published in the form of self-study and evaluation guides. They encompass the following subjects: governing structure and function, personnel administration and volunteer service, accounting, physical facilities, public relations and fund raising, orientation and mobility, social work and recreation, rehabilitation centers, vocational services, workshops, production of reading materials, low vision services and education services of schools for the blind. Print copies may be purchased from NAC; braille and recorded copies are available from the Library of Congress. Free periodicals are: The Standard-Bearer (includes a semiannual list of accredited members and an annual list of sponsors and supporters) and the Annual Report. Periodicals are available in print and on cassette.

### National Association for Music Therapy (NAMT) 505 Eleventh Street, SE Washington, DC 20003 (202) 543-6864

Handicapping Conditions Served: All disabilities.

Users Served: Music therapists, students, health professionals, personnel at facilities.

The Organization: The National Association for Music Therapy (NAMT) promotes the development of music as therapy by: (1) approving university curricula for music therapy programs; (2) approving clinical facilities for training music therapists; (3) certifying and registering professional music therapists; and (4) providing technical assistance to researchers in the field of music therapy. The Association has eight regional chapters.

Information Services: Free publications of NAMT include brochures about music therapy as a career, a yearly guide to conferences and workshops across the country, and an audiovisual catalog. Other publications of the Association, such as Music Therapy Clinical Training Facilities Handbook, Music in Therapy, Music Therapy: A Behavioral Guide for the Mentally Retarded, Developmental Music Therapy, The Use of Creative Arts in Therapy, and Handbook for Volunteer Workers in Hospital Music, are sold. A quarterly journal that contains reports of original investigations and theoretical papers pertaining to music therapy is free to members; subscriptions are sold to nonmembers. A bimonthly newsletter contains information on conferences, government relations news, basic music therapy information, and other items of interest. Additional membership materials may also be purchased by nonmembers. Disabled inquirers are referred to music therapists or to facilities which employ music therapists. Referral services for job placements, internship sites, and colleges and universities are available to members and students.

National Association of Activity Therapy and Rehabilitation Programs (NAATRP)
Nancy M. Schildgen, Membership Chairperson Director, Activities Therapy
Glen Eden Hospital
6902 Chicago Road
Warren, MI 48902
(313) 264-8875 X112

Handicapping Conditions Served: Primarily mental retardation and mental illness.



Users Served: Therapists (occupational, recreational, music, dance, etc.), rehabilitation and education specialists.

The Organization: The National Association of Activity Therapy and Rehabilitation Programs is an organization for professionals involved in occupational, recreational, music, dance, and similar therapies, and rehabilitation, educational and related fields. The Association holds an annual meeting. Its regional divisions offer other meetings and activities.

Information Services: The Association publishes an informal newsletter for members ten times a year as a forum for the exchange of ideas.

### National Association of Physical Therapists, Inc. (NAPT) P.O. Box 367 West Covina, CA 91793 (818) 332-7755

Handicapping Conditions Served: All physical handicaps.

Users Served: Physical therapists, allied health personnel.

The Organization: This professional association of physical therapists certifies qualifications of members, establishes educational and training standards, accredits professional education programs, and conducts regional and state symposia and educational programs

Information Services: The Association disseminates information on schools which offer physical therapy programs and availability of products, and refers inquirers to other organizations. A booklet on NAPT, which contains basic information on physical therapy, is available at no charge. In addition, NAPT disseminates information to disabled persons all over the world on products and services. The NAPT Journal is the efficial publication of the organization and is published bimonthly.

National Association of Private Residential Facilities for the Mentally Retarded (NAPRFMR) 6269 Leesburg Pike Suite B-5 Falls Church, VA 22044 (703) 536-3311

Handicapping Conditions Served: Mental retardation, cerebral palsy, autism, epilepsy, and other developmental disabilities.

Users Served: Providers of private residential services, parents, professionals.

The Organization: The National Association of Private Residential Facilities for the Mentally Retarded (NAPRFMR) was founded in 1970 to improve the quality of life for developmentally disabled persons and their families by coordinating the efforts of providers of private residential services. Active membership is open to any state or locally approved facility or home serving primarily developmentally disabled persons. Associate membership is available to any interested person, organization, or facility not qualifying for active membership.



The Association offers comprehensive insurance protection for member facilities.

Information Services: NAPRFMR conducts conferences and studies, and issues bulletins and a monthly newsletter, LINKS, to keep its members informed of current legislation and regulations, safety and access standards, funding sources, social security benefits, the rights of disabled persons and their parents, staff development techniques, and topics of current interest. The newsletter is free to members; subscriptions are available to nonmembers for a charge. A Directory of Members, which lists facilities by state, may be purchased.

NAPRFMR responds to inquiries from members and the public. Information is strong in the areas of placement for developmentally disabled persons and government activities of interest to private operators of residential facilities.

National Association of Private Schools for Exceptional Children (NAPSEC) 2021 K Street, NW Suite 315 Washington, DC 20006 (202) 296-1800

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Handicapping Conditions Served: All disabilities.

Users Served: Administrators of private special education schools, parents, professionals.

The Organization: The National Association of Private Schools for Exceptional Children (NAPSEC) was founded in 1971 by a group of private special educators. It provides a national voice for private facilities regarding policies and programs affecting exceptional students and is dedicated to encouraging cooperation among educational facilities serving exceptional students. NAPSEC makes known to parents and to public and private referral sources the services of each of its member schools, so that all may work toward the best match of students and programs.

Membership in NAPSEC is divided into two categories, regular and affiliate. Regular membership is open to private facilities serving exceptional children in an educational/therapeutic setting; affiliation is open to organizations, agencies or individuals concerned with private special education but not eligible for regular membership.

Information Services: NAPSEC provides a free referral service to member schools serving all categories of exceptionality and located throughout the country. A <u>Directory of Membership</u> includes type of school, services offered, and population served. <u>THE NAPSEC VOICE</u> is a newsletter published three times per year which includes information on national issues and updates on NAPSEC activities. NAPSEC also publishes <u>Newsbrie's</u> an in-house publication focusing on member school events, programs and activities. The National Issues Service provides up-to-the minute briefings on major issues affecting the private special education community:



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### National Association of Rehabilitation Facilities (NARF) P.O. Box 17675 Washington, DC 20041 (703) 556-8848

Handicapping Conditions Served: All handicaps.

Users Served: Rehabilitation facilities and professionals.

The Organization: The National Association of Rehabilitation Facilities (NARF) was formed by a merger of the Association of Rehabilitation Centers and the National Association of Sheltered Workshops and Homebound Programs. Its membership is made up of institutions and individuals that offer rehabilitation services. The purpose of the Association is to strengthen rehabilitation services to handicapped persons by representing the interests of these services to the Federal government, and by providing field services and technical assistance to members. State chapters work to improve facilities at the state and local levels, through various representative committees (e.g., committees on vocational facilities, medical facilities, and developmental centers).

Information Services: NARF has information about Federal legislation affecting rehabilitation facilities. Although the National Association refers handicapped persons to facilities (educational, vocational, and medical), state chapters tend to have more complete local listings. NARF training seminars are held in various locations at all times of the year on subjects related to the management and operation of rehabilitation facilities. NARF publishes periodicals, bulletins, and newsletters for rehabilitation service administrators, including funding information for rehabilitation programs and the Rehabilitation Review, a weekly analysis of issues for rehabilitation facility professionals. Sample copies are provided free.

National Association of State Directors of Special Education (NASDSE) 2021 K Street, NW Suite 315 Washington, DC 20006 (202) 296-1800

Handicapping Conditions Served: All handicaps.

Users Served: State Directors of Special Education and other persons interested in special education.

The Organization: The National Association of State Directors of Special Education (NASDSE) is a nonprofit association representing personnel from state education agencies who have legal responsibility for the administration and supervision of special education programs in public schools.

Information Services: NASDSE has developed numerous products interpreting Section 504 of the Rehabilitation Act and Public Law 94-142, the Education for All Handicapped Children Act. Publications geared to education administrators cover management, training, legislation, and implementation of legislation. Materials for teachers and administrators on Individualized Education Plans (IEP's) and due process are also for sale. NASDSE also



publishes the <u>Liaison Bulletin</u>, a newsletter covering congressional action on legislation for disabled persons and its impact on state agency programs; activities of Special Education Programs, U.S. Department of Education, such as grant and contract announcements and regulations; and exemplary in-service training programs in special education.

In addition, NASDSE offers SpecialNet, an electronic mailbox service available to anyone who has access to a computer terminal or microcomputer. SpecialNet subscribers are able to communicate with a nationwide network of educators, resource organizations, advocacy groups, parents, and others interested in special education, and can send and receive information to improve programs and professional skills. SpecialNet also stores bulletin boards containing information on a variety of special education topics. NASDSE has also developed RehabNet, a similar service in the area of rehabilitation. There are subscription and access charges for SpecialNet and RehabNet.

National Association of State Mental Retardation Program Directors, Inc. (NASMRPD) 113 Oronoco Street Alexandria, VA 22314 (703) 683-4202

Handicapping Conditions Served: Mental retardation and developmental disabilities.

Users Served: Service providers, state MR/DD directors and staffs, legislators and staffs.

The Organization: The organization's membership consists of 53 state/territorial mental retardation (MR) program directors. NASMRPD facilitates the exchange of information among members on effective methods of providing care and treatment for the mentally retarded, and it represents the views of its members before Congress and Federal agencies.

Information Services: NASMRPD collects information about available services and model service programs for mentally retarded and developmentally disabled (DD) persons in each state. Areas of information include but are not limited to education, employment programs, public and private residential and day programs, foster care, early diagnosis and screening programs, recreation, and staff training programs. NASMRPD has Federal and state legislative information in all areas affecting the MR field, including health, education. welfare, Social Security, housing, employment, and transportation issues. Anyone may request information, but because of staff limitations, priority is given to members' requests. The Association publishes two monthly newsletters, one focusing on innovative programs throughout the country, New Directions; the other on Federal legislative and administrative developments affecting the mentally retarded, Capitol Capsule. It also publishes special reports analyzing legislation and other issues related to the MR/DD population. In addition, NASMRPD publishes a periodic series of reports called the Federal Funding Inquiry on Federal legislative, administrative and judicial issues and activities of interest to state MR/DD officials and service providers. National and regional meetings, featuring seminars on specific service-need categories, are held primarily for directors and staff of state MR programs, but anyone may attend. The Association operates an electronic communication network (currently for members only) which carries announcements of interest to MR/DD directors and staffs.

National Association of Vocational Education Special Needs Personnel (NAVESNP)
c/o Dr. David Kingsbury
Bridgeman Hall
Bemidji State University
Bemidji, MN 56601
(218) 755-2949

Handicapping Conditions Served: All handicaps.

Users Served: Special needs personnel, vocational counselors, vocational education and special education teachers.

The Organization: The National Association of Vocational Education Special Needs Personnel (NAVESNP) is a membership segment of the American Vocational Association (AVA) deveted to personnel working with handicapped and disadvantaged youth. Members include special needs personnel, vocational counselors, and vocational education and special education teachers, working at the secondary and postsecondary levels. NAVESNP attempts to provide services to special populations by acting as a communication network and information center for professionals working with such populations.

Information Services: NAVESNP publishes a professional journal and a newsletter (containing information on meetings, tips for teachers, and Federal legislation) three times a year; a directory of teachers; and other publications which relate to vocational education and handicapped youth.

NAVESNP holds regional workshops throughout the year. Topics range from jobs and careers for the handicapped, to teaching vocational reading and mathematics. While these workshops are mainly for professional education, parents of handicapped children are welcome to attend.

National Council for Therapy and Rehabilitation
Through Horticulture (NCTRH)
9220 Wightman Road
Suite 300
Gaithersburg, MD 20879
(301) 948-3010

Handicapping Conditions Served: All handicaps.

Users Served: Horticultural therapists and other professionals.

The Organization: The National Council for Therapy and Rehabilitation through Horticulture (NCTRH) acts as a consultant to institutions interested in establishing horticultural therapy programs. It also registers professional horticultural therapists and sponsors regional professional workshops in conjunction with its nine regional chapters and with university programs. NCTRH operates a job bank for members and non-members.



Information Services: Information is available on careers in horticultural therapy. Special publications are printed periodically to offer a means of continuing education to professionals on such topics as innovative programs and funding sources. NCTRH has bibliographic and audio-visual materials for persons to use in the field or to start a program. It also maintains a speakers' bureau. Members receive a monthly newsletter.

### National Council on Communicative Disorders (NCCD) 10801 Rockville Pike Rockville, MD 20852 (301) 493-4914

Handicapping Conditions Served: Deafness and hearing impairments, speech and language disorders.

Users Served: Speech-language pathologists and audiologists.

The Organization: The National Council on Communicative Disorders (NCCD) is a council of 22 national organizations representing persons with communication handicaps. The Council provides information to Congress, government agencies, and the public on issues relating to communicative disorders and seeks to encourage research in speech, language and hearing. One of the goals of the organization is to foster closer liaison with the private sector by recognizing individuals and/or corporations whose efforts benefit communicatively handicapped persons. To this end, the NCCD sponsors an annual awards banquet and seminar.

Information Services: The National Council on Communicative Disorders Newsletter highlights current developments in the communicative disorders field, including analysis of pertinent Federal legislation, judicial actions, reimbursement policies, organizational news and other items of interest. Materials and services are free to member organizations; there is a nominal charge to others.

## National Education Association (NEA) 1201 16th Street, NW Washington, DC 20036 (202) 833-4000

Handicapping Conditions Served: The NEA does not focus on information relating to handicaps. Information on P.L. 94-142 does, however, fall within its scope:

User: Served: Teachers.

The Organization: The NEA is a professional organization of elementary and secondary school teachers, administrators, and higher education faculty.

Information Services: The NEA informs its members about P.L. 94-142 and its implications for them and their students and gathers teacher testimony about the effects of the law. Members may obtain A Teacher's Reference Guide to P.L. 94-142 and information on training programs to help regular education teachers integrate handicapped students with non-handicapped students:



### National Eye Research Foundation (NERF) 899 Skokie Boulevard Northbrook, IL 60062 (312) 564-4652

Handicapping Conditions Served: Blindness and visual impairments.

Users Served: Ophthalmologists, opticians and other eye care professionals, general public.

The Organization: The National Eye Research Foundation is a membership organization for ophthalmologists, opticians, and other professional and lay people interested in the eye care field. With the objective of improving eye care for the general public, it sponsors research projects in the field of optometry, and disseminates research information on practical innovations and techniques to professionals. Dissemination is through international, national, and regional meetings, and through public service announcements.

Information Services: For lay inquirers, NERF provides free brochures defining specialists within the eye care profession and defining certain eye disorders, such as glaucoma, hyperopia, and myopia. The organization makes referrals to local eye specialists. NERF's bimonthly research journal on contact lenses, Contacto, is available to members only.

National Hearing Aid Society 20361 Middlebelt Road Livonia, MI 48152 (313) 478-2610 (800) 521-5247

Handicapping Conditions Served: Hearing impairment.

Users Served: Disabled persons, hearing health care professionals.

The Organization: The National Hearing Aid Society establishes training and ethical standards for professionals who test hearing, and fit and sell hearing aids. Its certification process outlines the educational, experience, and ethical requirements needed to become a Certified Hearing Aid Audiologist. The Society offers an independent, self-paced study course in hearing aid audiology. Other training courses are reviewed by the organization for suitability of course content. The Society accs as an intermediary between consumers and hearing aid specialists when consumers have problems with hearing aid transactions.

Information Services: A Hearing Aid Helpline, (800) 521-5247, has been established for consumers to receive basic information on hearing aid care and maintenance or assistance in resolving hearing aid transaction problems. A free consumer packet includes a directory of certified members and a Better Business Bureau booklet, Facts about Hearing Aids. Other general information pamphlets about hearing loss and hearing aids are available to the consumer. For the hearing health professional, the Society publishes a quarterly educational and research journal, a directory of members, and several pamphlets about standards of ethics, certification, and technical information. The national Society and its 50 chapters sponsor educational workshops for professionals on subjects such as fitting techniques, acoustics, hearing testing, and ear molds. The Society makes referrals to hearing aid specialists, support groups for hearing-impaired people, and other information sources, and provides information on assistive devices and manufacturers.



#### National HomeCaring Council 67 Irving Place New York, NY 10003 (212) 674-4990

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons and their families, homemaker-home health aide agencies and personnel.

The Organization: The goal of the National Council is to bring homemaker-home health aide services to families whose homes have been disrupted by illness, disability, and emotional and other problems. In all sections of the nation, in-the-home services are needed to help individuals and families in all economic brackets. To make these services available, the Council evaluates local agencies for accreditation, and encourages the formation of new services through a Federal and state advocacy project. It provides technical assistance to new agencies, and offers training workshops at the state and local level to administrators, supervisors, and aides.

Information Services: The Council has an extensive publications list of print and audio-visual materials relevant to the consumer needing homemaker-health aide services and the professional delivering those services. The organization's professional materials are particularly strong in the areas of establishing programs, training professionals, and providing services to particular populations (e.g., the elderly, children, mentally retarded, terminally ill, high risk infants, etc.). In 1981 two publications in the developmental disabilities area were produced: A Better Answer: Homemaker-Home Health Aide Services for the Person with Developmental Disabilities and Family: A Manual for Instructors and A Better Answer: Homemaker-Home Health Aide Services for the Person with Developmental Disabilities and Family: A Handbook for the Aide. Accompanying guidelines for the use of these two texts are also available.

The Council prepares two service directories: one, a comprehensive list of services in the U.S., Puerto Rico, and the Virgin Islands; and the second, a list of those services which are accredited by the Council. In addition, the Council operates a lending library, free to member agencies but with a nominal charge to nonmembers.

National Rehabilitation Association (NRA) 633 S. Washington Street Alexandria, VA 22314 (703) 836-0850

Handicapping Conditions Served: All handicaps.

Users Served: Rehabilitation professionals and consumers.

The Organization: The National Rehabilitation Association (NRA) was founded in 1925 as a membership organization for professionals and others interested in the advancement of rehabilitation services to all persons with disabilities. NRA's activities include: advocacy for state and Federal legislation; professional development through regular meetings and workshops, training sessions for continuing education credits, and publications; and public education via print and electronic media. NRA has chapters in all states, and seven divisions, which devote their efforts to carrying out the goals of the Association.



The National Rehabilitation Counseling Association (NRCA, 633 S. Washington Street, Alexandria, VA 22314, (703) 836-7677), is the largest NRA division and the only one with a paid staff. It is one of the sponsors of the Commission on Rehabilitation Counselor Certification. NRCA holds continuing education programs, publishes professional literature, and has a scholarship program for students in graduate rehabilitation counseling programs.

Other divisions include the Job Placement Division (JPD), National Association for Independent Living (NAIL), National Association of Rehabilitation Instructors (NARI), National Association of Rehabilitation Secretaries (NARS), National Rehabilitation Administration Association (NRAA), and the Vocational Evaluation and Work Adjustment Association (VEWAA).

Information Services: NRA publishes the <u>Journal of Rehabilitation</u> and a newsletter. The national office responds to general inquiries and directs specific questions to appropriate professional divisions.

All the divisions put out newsletters. NRCA publishes the <u>Journal of Applied Rehabilitation Counseling</u>. NRAA produces two quarterly journals: the <u>Journal of Rehabilitation Administration</u> and <u>Administration and Supervision in Rehabilitation</u>. VEWAA publishes the <u>Bulletin</u>. The national NRA office will supply inquirers with the current addresses of its division officers.

National Therapeutic Recreation Society (NTRS)
National Recreation and Park Association
3101 Park Center Drive
12th Floor
Alexandria, VA 22302
(703) 820-4940

Handicapping Conditions Served: All handicaps.

Users Served: Recreational therapists.

The Organization: The National Therapeutic Recreation Society is a membership organization for therapists who provide recreational activities to ill, handicapped, and institutionalized persons in direct care facilities and in the community. NTRS is a branch of the National Recreation and Park Association (NRPA). The Society acts as a professional licensing agency for recreational therapists. It offers consulting services to agencies, institutions, and individuals on new management techniques in the field.

Information Services: NRPA publishes books and brochures for the recreational therapist on providing services to specific populations. Titles include Standards of Practice for Therapeutic Recreation Service, Perspectives of Leisure Counseling, Recreation in Nursing Homes. NRPA sponsors regional and national conferences where special workshops are held for the recreational therapist on such topics as program design, facility design, and rehabilitation of special populations. A professional journal and a newsletter are available to members.



# Project on the Handicapped in Science (PHS) American Association for the Advancement of Science (AAAS) 1333 H Street, NW Washington, DC 20005 (202) 326-6400 (Voice and TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, teachers, rehabilitation engineers, and scientists.

The Organization: The Project on the Handicapped in Science was launched in 1975 as the AAAS advocate for disabled professionals and students engaged in science. The Project also acts as an information center for disabled individuals, parents, teachers and employers in areas pertaining to science education and careers. Through surveys, studies, symposia, and workshops, the Project has collected information about science education and employment opportunities for the handicapped. Using the information it collects, the Project consults with universities, professional scientific societies, and the Federal government to identify the accessibility and program needs of disabled scientists and students and to suggest strategies to meet those needs.

Information Services: The Project publishes reports, guides, and directories based on its activities, including: Barrier Free Meetings: A Guide for Professional Associations, a step-by-step system for achieving accessibility at professional meetings; a Resource Directory of Handicapped Scientists, containing names and biographical data of handicapped scientists who will consult with those working to improve science education and career opportunities for handicapped persons; Science for Handicapped Students in Higher Education, based on a study of barriers to post-secondary science education; Scientific and Engineering Societies: Resources for Career Planning, a listing of counseling, referral, and placement services of scientific professional associations and a source book on career counseling in science; A Research Agenda on Science and Technology for the Handicapped, the findings of a project and workshop researching science and technology for the handicapped; Out of School Programs in Science, a listing of science programs which take place outside of the traditional classroom; Within Reach: Out of School Science Opportunities for Youth, a guide for students with disabilities, their parents, teachers and counselors.

The Project publishes a quarterly bulletin which reports on the proceedings of workshops on science and technology for the handicapped, the latest developments in technology research, announcements of grants, brief articles on current projects/programs in the field, descriptions of technology, selected annotated resources, and a calendar of conferences and meetings.

Registry of Interpreters for the Deaf, Inc. (RID) 814 Thayer Avenue Silver Spring, MD 20910 (301) 588-2406 (Voice and TDD)

Handicapping Conditions Served: Deafness, hearing impairments, and deaf-blindness.

Users Served: Professional interpreters, interpreter referral agencies.

The Organization: The Registry of Interpreters for the Deaf (RID) is a membership organization of professional interpreters. Its main purpose is to certify interpreters and transliterators. RID and its state affiliates actively advocate for the use of interpreters for



hearing impaired people. The association provides technical assistance to employers of interpreters nationwide, in the development of position descriptions and standards and practices:

Information Services: RID provides information about interpreter training programs, professional development and job opportunities. The association also offers consumer information on national, state and local legislation related to interpretation. RID maintains a current list of all certified interpreters in the U.S. (by state), which is made available to over 160 interpreter referral service agencies.

Interpreter Views, published bimonthly, contains professional articles, organizational news, training program announcements, and job openings. Also available through RID is the "Introduction to Consecutive Interpretation" (1985) and the annual Journal of Interpretation with the latest in research and professional articles on interpreting.

RESNA: The Association for the Advancement of Rehabilitation Technology 1101 Connecticut Avenue, NW Suite 700 Washington, DC 20036 (202) 857-1199

Handicapping Conditions Served: All disabilities.

Users Served: Disabled persons, teachers, physicians, occupational and physical therapists, orthotists, prosthetists, rehabilitation engineers, service providers, manufacturers of rehabilitation technology.

The Organization: RESNA: The Association for the Advancement of Rehabilitation Technology is an organization concerned with the exploitation of science and technology in the rehabilitation process. Founded in 1979, its purpose is to promote and support the development, dissemination, integration, and utilization of knowledge in rehabilitation engineering and to assure that these efforts result in the highest quality of care and service delivery for all disabled citizens. RESNA's role is to serve as a catalyst and information center to address current issues that must be resolved so that disabled persons can enjoy independent living to the fullest extent possible.

RESNA's membership includes rehabilitation professionals drawn from all pertinent disciplines, providers and consumers. Interaction between these groups promotes understanding and better service to those who can benefit directly from the application of rehabilitation engineering technology. Membership benefits include: a central role in formulating and influencing policy relating to the delivery of technology to disabled citizens; a forum for information exchange; publications; and participation in regional and national conferences. RESNA's diverse discipline groups act as task forces to define their own objectives and roles in the service delivery process and interact with each other to assure effective functioning of the delivery system. Such task forces include consumers, health care practitioners, inventors and designers, researchers, manufacturers and distributors, authorizers and providers, and legislators. RESNA also sponsors the Easter Seal Society Student Design Competition (for able as well as disabled students) in conjunction with its annual conference.



Information Services: An organizational brochure and membership information are available from RESNA. The association publishes Rehabilitation Technology Review, a quarterly newsletter, as well as the proceedings of the RESNA annual conference. Other publications include: Technology for Independent Living Sourcebook; Choosing the Best Wheelchair Cushion, Revised Edition 1984; A Guide to Controls - Selections, Mounting, Applications; Wheelchair III Report of a Workshop on Specially Adapted Wheelchairs and Sports Wheelchairs. There is a charge for all publications, with a discount for RESNA members. The membership fee includes a subscription to the quarterly newsletter. The annual conference program is available in braille at the time of the meeting for registrants.

When possible, RESNA will refer people to experts residing in their local area, selected from the RESNA membership list.

Science for the Handicapped (SHA) c/o Ben Thompson, Secretary-Treasurer University of Wisconsin-Eau Claire/Brewer 275 Eau Claire, Wil 54701 (715) 836-4164

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, teachers.

The Organization: The Science for the Handicapped Association (SHA), which has as its main objective the promotion of science for all levels of handicapped students, organizes sessions on science for disabled people at conventions of the National Science Teachers Association. SHA cooperates with agencies and organizations which have similar goals.

Information Services: The Association has published a bibliography on science and disabled persons and publishes a newsletter several times a year covering science education programs, grants, aids and equipment, and containing annotated listings of current articles on science and the handicapped. In addition, SHA provides assistance to individuals who request help with special needs in science programs for handicapped students.

Sibling Information Network
Connecticut's University Affiliated Facility
University of Connecticut
249 Glenbrook Road U-64
Storrs, CT 06268
(203) 486-4034

Handicapping Conditions Served: All handicaps.

Users Served: Parents, teachers, physicians, physical therapists, educators, psychologists.

The Organization: The Sibling Information Network, a recently formed organization for professionals interested in siblings of handicapped children and their problems, offers support and assistance to those working in this area.



Information Services: The Network works to provide a common information base, serving as a clearinghouse for research and other professional activities related to siblings of handicapped children. The Network's quarterly newsletter, available free to members, reports on activities of member literature for siblings of handicapped children, and other topics of interest. The Network has published a collection of articles taken from the newsletter, a list of sibling groups and programs, a bibliography of journal articles on siblings, a bibliography of children's literature and a list of audio-visual materials about children with various disabilities. The newsletter and publications are geared toward the membership (nominal dues are charged), but materials are provided to others if requested.

Handicapping Conditions Served: All disabilities associated with head injury and related neurological disorders.

Users Served: Health care professionals, providers of services and products.

The Organization: The Traumatic Brain Injury Research/Education Association (TBI Association) is a nonprofit, multidisciplinary organization of professionals providing services and products to brain-injured persons and their families. The TBI was founded to: encourage research and education on the causes, prevention, and treatment of traumatic brain injury; provide a forum for exchange of information and ideas among providers of service and treatment; formulate and support the highest possible standards of care of brain trauma patients; and provide continuing growth and development of professionals furnishing services and products.

Case management services are available from the TBI Association to disabled persons and family members within the state of Michigan. Referrals to appropriate programs, treatment facilities and health care professionals are made nationwide.

Information Services: The TBI Association publishes a bimonthly newsletter which contains information about people and products, abstracts, new products and resources, classified ads, monograph listings, and a comment section. A quarterly journal covers research indings, field reports, features, book reviews, letters and reports on treatment programs and techniques. Both publications are available by subscription.

TBI Association members are invited to participate as presenters, faculty members and/or registrants at conferences and seminars, including international travel/education events. Other services offered to members include data and literature search through the Association's computer link-ups, a monograph distribution service and computer program exchange, a consultant's listing (for members wishing to provide consulting services in their areas of expertise), an information and referral file, an abstract service, and research grants, as they become available. Both individual/professional and corporate memberships are available. Members receive information services at cost; there is a small fee for nonmembers.



#### FACILITIES, SCHOOLS, CLINICS

These direct service organizations provide evaluation, rehabilitation, education, recreation and vocational services to individuals with various disabling conditions, often on a residential basis. In some cases, medical care is provided along with rehabilitative services. Many of these organizations design and adapt special aids and equipment to enable independent living and vocational adjustment. They also publish research materials and disseminate information about their particular training programs.



### FACILITIES, SCHOOLS, CLINICS

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#### Carroll Center for the Blind 770 Centre Street Newton, MA 02158 (617) 969-6200

Handicapping Conditions Served: Blindness and visual impairments.

Users Served: Disabled persons, professionals.

The Organization: The Carroll Center for the Blind is a residential and commuter rehabilitation center for visually disabled persons. The Center offers instruction in mobility, handwriting, braille, grooming and other activities of daily living, woodworking, and home mechanics, and operates a low vision clinic where aids are prescribed and clients are instructed in their usage. Orientation and mobility specialists offer instruction in mobility to visually handicapped persons in local communities throughout Massachusetts. An Outdoor Education Program expands the mobility instruction. New programs offered include CABLE, computer access training for adults and BYTE, a summer computer camp for teenagers.

Information Services: The Center has developed some free materials which it distributes nationally on request. Materials include: general information for newly blinded persons, elderly blind and blind children; Sighted Guide, a manual on ways the sighted person can help the blind; and tips for restaurant employees on serving the blind.

### Clovernook Home and School for the Blind (CHSB) 7000 Hamilton Avenue Cincinnati, OH 45231 (513) 522-3860

Handicapping Conditions Served: Blindness, visual impairments, multi-handicapped blindness.

Users Served: Disabled persons, parents, teachers, counselors.

The Organization: The Clovernook Home and School for the Blind (CHSB) provides rehabilitation, residential, and work facilities for blind and visually handicapped persons, aged 18 to 55. Work facilities include a sheltered workshop in printing, the Clovernook Printing House. The Printing House produces braille transcriptions of books, magazines, and other publications for government, religious, and nonsectarian organizations, including the Library of Congress. The workshop also employs blind men and women in the manufacture of file folders under a government contract.

Information Services: Information about programs of the Clovernook Home is provided free to all inquirers. A fee schedule for services and products is available upon request from potential clients or referral sources. A list of braille publications produced by the Printing House includes information about where to obtain free braille subscriptions to magazines such as Better Homes and Gardens, Ladies' Home Journal, Seventeen, and a variety of other publications. Braille calendars, writing paper, and a cookbook are available at nominal costs. The Printing House publishes a newsletter, The Clovernook Perspective, which provides general information about the organization, describes its programs of service and functions as an educational tool. It is available in braille. The Printing House also produces TACTIC, a braille publication for blind people interested in using computers.



#### Courage Center 3915 Golden Valley Road Golden Valley, MN 55422 (612) 588-0811

Handicapping Conditions Served: Physical disabilities, including speech, hearing and vision impairments and head injuries, developmental disabilities.

Users Served: Parents, health professionals.

The Organization: Courage Center is a nonprofit organization providing rehabilitation and independent living services to people with physical disabilities and speech, hearing and vision impairments. Some of the Center's approximately 70 programs are offered locally and regionally; others are available nationally. The Courage HANDI-HAM System, providing training, information, and radio equipment to disabled people interested in amateur radio, operates on an international level. Courage Residence, a transitional rehabilitation program, prepares disabled young adults for community living. The Courage Independent Living Home is a model for accessible single-family housing and serves as a working laboratory for developing and testing devices for independent living. The Center also offers comprehensive medical services, physical restoration, speech and hearing services, counseling and rehabilitation engineering services. Courage Center's recreation program includes Camp Courage, a residential camp program for ages 8 and up, other camping experiences, and various competitive and recreational sports and physical education and wellness programs. The Center's services are available regardless of a person's ability to pay.

Information Services: Brochures describing the Courage Center's programs are available at no charge. Requestors may also borrow a film, "On Their Way: The Courage Story," which documents the progress made by disabled people with the help of the Center's services. The Center publishes several newsletters, including the Courage News, published quarterly, and the bimonthly Meeting Ground.

Gallaudet College 800 Florida Avenue, NE Washington, DC 20002 (202) 651-5000 (Voice or TDD) (800) 672-6720

Handicapping Conditions Served: Hearing impairments, deafness, deaf-blindness.

Users Served: Disabled persons, parents, teachers, professionals, general public.

The Organization: Established by an act of Congress, signed by President Abraham Lincoln in 1864, Gallaudet remains the only accredited liberal arts college for the deaf in the world. The college offers bachelor degree programs in 30 subject areas, master's programs in nine, and a Ph.D. in special education administration. Students with normal hearing are admitted as exchange or graduate students, as well as to the two year Associate of Arts program in sign language interpreting. In addition to the College, a Division of Pre-College Programs, a Division of Graduate Study and Research, and a Division of College Relations now offer a wide range of services and information in the field of hearing impairments.

Pre-College Programs include the Kendall Demonstration Elementary School for the Deaf (KDES) and the Model Secondary School for the Deaf (MSSD). Both are authorized and funded by Congress to develop and evaluate innovative methods, curricula, and educational technology for the training of deaf children from infancy through secondary school. Both schools are located on campus and provide opportunity for classroom internships to the Gallaudet college students enrolled in programs of special education of the deaf and other professional training programs. MSSD has residential facilities, and accepts students from anywhere in the U.S., while KDES serves day students from the metropolitan Washington, DC area. For information on educational research and curricula, contact Pre-College Outreach at (202) 651-5048.

Continuing Education: An extensive demonstration program of classes for adults is offered. Curriculum information and assistance in organizing such services is available through the College of Continuing Education at (202) 651-5597 (Voice or TDD).

Sign Language and Interpreter Training: Instruction is offered in the areas of sign language, interpreting for the deaf, and in the teaching of sign language. An Associate of Arts Degree in Interpreting is offered for full-time students. An evening program offers courses in sign language and interpreting for local persons. Intensive summer programs in the above areas are offered on a national level with room and board being available on the Gallaudet campus during the summer. Summer brochures are available on request from the Department of Sign Communication, (202) 651-5630.

International Center on Deafness: Created in 1974 in response to requests from abroad, the Center offers an individualized program of study to persons from other countries who do not qualify for, or are not interested in pursuing, an academic degree. Application forms and a brochure may be requested from the Director (202) 651-5316 (Voice or TDD).

The Research Institute: The Institute assists faculty and graduate students in developing researchable ideas and exploring funding sources. It acts as a clearinghouse for coordination of and collaboration with other research efforts throughout the country. The Institute publishes a newsletter and catalog of publications. For further details, call (202) 651-5030.

Gallaudet College Library: Extensive holdings in all subject areas relating to deafness can be obtained through interlibrary loan. Bibliographies may be requested and assistance is available to organizations wishing to develop library services on the subject of deafness. Through the library, the Gallaudet Media Distribution Service distributes videocassettes, videotapes, and 16mm films on sign language instruction, signed educational films, and materials on deafness of interest to the general public as well as parent groups, psychologists, and educators. Catalogs and order forms are available from the library. Gallaudet's extensive collection of print and nonprint materials on deafness and communicative disorders is accessible to on-site researchers and through interlibrary loan. Requests for information should be directed to the information desk, (202) 651-5585 (Voice) or 651-5575 (TDD).

Center for Assessment and Demographic Studies: The conducting of national surveys was initiated in 1968 to gather information about hearing-impaired children and youth for research by educators, audiologists, psychologists, legislators, and others working in the field of hearing impairments. At present, data is collected on approximately 54,000 students in all types of educational programs throughout the country. Other special projects have included psychological and behavioral studies, and revision of the Stanford Achievement Test for hearing-impaired students. Data is available to independent investigators for research purposes, and to educational institutions, legislators and other groups devoted to



improving education and other services for the hearing-impaired. A publications list, bibliographies, and other information are available on request at (202) 651-5300.

National Center for Law and the Deaf: Established in 1975, the Center provides free legal services to the deaf and hearing-impaired community. The Center also acts as a clearinghouse of information about court decisions and current litigation associated with deafness, particularly in the areas of employment, income maintenance, insurance and tax benefits, and civil rights. Drafts of state and national legislation are prepared at the Center; petitions and briefs for presentation to administrative agencies are also drawn up, as need is indicated. The Center engages in advocacy and initiates class action suits of benefit to hearing-impaired citizens. Educational workshops are conducted for groups of deaf and hearing-impaired persons to inform them of their legal rights. Assistance is offered to hearing-impaired persons in preparing for legal careers. Lay or professional persons, including attorneys, may request information about deaf persons' interests. Brochures explaining services of the Center, and a quarterly newsletter that reports on legislation affecting hearing-impaired persons, are available on request. All services are free. Contact the Center for information at (202) 651-5454 (Voice and TDD).

Information Services: A quarterly magazine, Gallaudet Today, is distributed by the Office of Alumni Relations and Advancement. The College Bookstore catalog lists publications and curriculum materials in their stock. The Gallaudet College Press publishes two catalogs, the Gallaudet College Press Catalog and the Public Services Materials Catalog. Each division and program has publications and brochures, describing activities. Inquiries should be directed to the appropriate unit (see telephone numbers under each heading). For general information contact the National Information Center on Deafness (202) 651-5109 (Voice) or (202) 651-5976 (TDD) (see separate entry).

### Gesell Institute of Human Development 310 Prospect Street New Haven, CT 06511 (203) 777-3481

Handicapping Conditions Served: Learning and developmental disabilities, visual handicaps, allergies and nutritional problems, mental and emotional disorders.

Users Served: Disabled people, teachers, parents, health care professionals.

The Organization: Originally the Gesell Institute of Child Development, the Institute changed its name in 1979 and broadened its services to include adults in the medical and visual departments. In the child development clinic, children from two to thirteen are evaluated in a wide range of functions--physical (motor), adaptive, verbal and psychopersonal. Visual therapy is provided and parents of children with developmental difficulties may receive counseling.

The Institute advocates Gesell's philosophy of grouping school children according to behavioral maturation instead of chronological age. When learning disabilities appear to relate to perceptual or nutritional difficulties, appropriate diagnosis and treatment can be given through the Institute's vision and medical departments, or referrals made for treatment at local facilities. Postgraduate training in diagnosis and treatment of perceptual problems is offered to optometrists on grants from the National Optometric Foundation. Staff members give lectures, seminars and workshops at universities throughout the country to explain and help implement Gesell Institute methods.



Information Services: Brochures describing the services of the Institute, application forms for evaluation, and a publications list of books written by staff members can be requested. On-site use of library materials and films is open to interested persons. Professionals, parents, handicapped persons and their families are welcome to inquire by phone or mail about services, or request referrals to local resources. While most information is free of charge, there is a nominal cost for publications. Fees for direct services vary.

Goodwill Industries of America, Inc. (GIA) 9200 Wisconsin Avenue Bethesda, MD 20814 (301) 530-6500

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, vocational and rehabilitation specialists, employers.

The Organization: Goodwill Industries of America, Inc. (GIA) is an International, nonprofit organization. The members of GIA are 174 community-based, autonomous, nonprofit organizations in the United States and Canada that use the Goodwill Industries name. Additionally, there are 45 affiliated members in 31 nations outside North America.

Local Goodwill Industries organizations provide vocational evaluation, training, employment and job placement services for handicapped persons. Direction for each agency is provided by local volunteers, with programs designed by professional staff members to meet the needs of both the individual client and the community.

Information Services: Manuals, statistical data, and other administrative information, as well as consultation, are available from the national office to assist local organizations or groups interested in establishing new Goodwill centers. Brochures explaining Goodwill services to employers and business contractors may be ordered.

Hadley School for the Blind 700 Elm Street Winnetka, IL 60093 (312) 446-8111

Handicapping Conditions Served: Blindness and deaf-blindness.

Users Served: Disabled persons.

The Organization: The Hadley School, which offers correspondence courses free for blind persons, was founded in 1921 by William A. Hadley, a blind high school teacher. The first college level courses were added in the early 1940's. Hadley now has offices in South America, Europe, India, and Africa, offering courses appropriate to the locale and in the native language. Both credit and self improvement courses are offered at no charge to blind or deaf-blind students through braille or cassettes. One-to-one tutoring by correspondence or telephone supplements the lesson materials. Hadley courses are accredited by the North Central Association of Schools and Colleges, and it is possible to earn a high school diploma by correspondence. College courses are arranged in cooperation with the extension services



of selected universities and colleges. A two-week intensive training course is offered on site on use of the Optacon, a print reading device.

Information Services: Catalogs in large print, braille, or on cassette list secondary level and self-improvement courses ranging from career planning to classical Greek. College level course information can be requested from the Coordinator of the College Program.

Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) 111 Middle Neck Road Sands Point, NY 11050 (516) 944-8900

Handicapping Conditions Served: Deaf-blindness with accompanying disabilities.

Users Served: Disabled persons, parents, teachers, social workers, rehabilitation counselors, interpreters, and other professionals.

The Organization: Operated by Helen Keller Services for the Blind, formerly the Industrial Home for the Blind, under an agreement with the Rehabilitation Services Administration of the U.S. Department of Education, the Center was authorized by a 1967 Amendment to the Vocation Rehabilitation Act and is funded by annual Congressional appropriations. Extensive evaluative and rehabilitative services are provided to deaf-blind youths and adults, 18 or older. Individualized pre-vocational training in orientation and mobility, communication and life skills, as well as in other areas, is conducted in a residential setting for up to 50 clients at a time, for periods ranging from several months to several years. A major effort is made to develop and assist in the appropriate placement of clients in work settings, when training is completed. Mobility and orientation to both work and residential settings is similarly provided. The Center conducts research in personal adjustment, education and rehabilitation techniques; and offers training in the field and at headquarters to new and prospective professionals who plan to work with the deaf-blind population.

HKNC operates an extensive nationwide network of field services through its ten regional offices and its many affiliated programs. The regional offices provide consultation and technical assistance to deaf-blind persons and their families, and to public and private agencies in their regions. They locate, assist and refer deaf-blind individuals to the most appropriate program for comprehensive services. The ten offices, listed in the telephone directories, are found under "Helen Keller National Center" in Sands Point, NY; Philadelphia, PA; Atlanta, GA; Chicago, IL; Dallas, TX; Kansas City, MO; Denver, CO; Seattle, WA; Boston, MA; and San Francisco, CA.

Information Services: Consultations and referrals may be requested from the national or regional offices. For information on direct services, contact the Supervisor, Direct Services, at the Sands Point address. A reference library at the Helen Keller National Center may be used by appointment. Rehabilitation activities of the Center are described in brochures, a periodical, NAT-CENT NEWS, published three times a year, and two captioned films, "Raising the Curtain" and "The World at His Fingertips". The Center also publishes the Directory of Agencies Serving the Deaf-Blind and Curriculum Models.

Pamphlets, fact sheets, bibliographies, indexes and abstracts of articles on deaf-blindness and rehabilitation for professionals and laymen are available. Some information is available in braille. Demographic information and results of the Center's research on personal adjustment, education and rehabilitation may be requested from the research



department in New York. There is a charge for some materials. Application forms for referral to the Center may be obtained from the local regional office or from the Intake Coordinator, Helen Keller National Center, 111 Middle Neck Road, Sands Point, New York 11050.

Human Resources Center I.U. Willets Road Albertson, NY 11507 (516) 747-5400

Handicapping Conditions Served: All physical handicaps and learning disabilities.

Users Served: Disabled persons, parents, teachers, rehabilitation counselors, administrators, employers.

The Organization: The Human Resources Center, founded in 1952 by Dr. Henry Viscardi, Jr., a pioneer in the rehabilitation and special education fields, is a private, nonprofit organization dedicated to providing educational, vocational, social, and recreational opportunities for the severely disabled. The Center's programs encompass work demonstration; vocational evaluation, job training and placement; academic, career, and adult education; independent living services; and research and information dissemination. The Center is composed of four coordinated units: (1) Abilities Inc., which runs a work demonstration center that employs disabled adults in industrial operations; (2) Human Resources School, which offers tuition-free education to over 230 severely disabled children; (3) the Research and Training Institute, which conducts research relating to severely disabled persons, initiates and develops demonstration projects in rehabilitation and professional training, and disseminates information and model programs nationally; and (4) Rehabilitation Services, which conducts programs of work evaluation, training, job development and career placement for the disabled.

In addition, the National Center on Employment of the Handicapped was established in 1977 on the campus of the Human Resources Center with the objective of enhancing employment opportunities for disabled persons through (1) conducting research in such areas as career education, independent living, job placement, and attitudes toward disabled persons; (2) giving seminars and conferences; (3) providing technical assistance; and (4) publishing monographs, textbooks, and multimedia training modules.

The nucleus of the National Center on Employment of the Hyndicapped is the Industry-Labor Council, an outgrowth of the White House Conference on Handicapped Individuals. The Industry-Labor Council unites industry/labor and rehabilitation, directing efforts toward developing employment opportunities for the handicapped population through serving the needs of the employer community. The Council conducts seminars of interest to employers concerning awareness, affirmative action, and the medical and legal aspects of employing disabled workers. Technical assistance (consultations, literature distribution, onsite visits, and specialized training) is available to employers. A newsletter reports on the activities of the Council and its members.

Information Services: The main information dissemination arm of the Human Resources Center and the National Center on Employment of the Handicapped is the Research Library, which responds to inquiries on all aspects of the Center's programs and on handicapping conditions and related services. When appropriate, requestors are referred to a staff member at the Center or to an outside organization. Publications available from the Center include titles on employment, placement, attitudes, driver education, and recreational



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boating. Recent publications include a handbook for professionals on vocational rehabilitation for learning disabled adults and a reference manual for managers responsible for implementing corporate affirmative action and equal employment opportunity programs. For details, write to the Products Manager and request the Catalog of Publications. Any lay or professional person may request information from the Center. Frequent inquirers include professionals in education and vocational rehabilitation, and members of business and industry.

John Tracy Clinic 806 West Adams Boulevard Los Angeles, CA 90007 (213) 748-5481 (213) 747-2924 (TDD)

Handicapping Conditions Served: Deafness, hearing impairments, and deaf-blindness.

Users Served: Preschool deaf and deaf-blind children, parents, teachers, audiologists, physicians.

The Organization: The Clinic is an educational center for deaf and hard-of-hearing preschool children and their parents. One of the Clinic's prime concerns is the training of parents of young hearing-impaired children in helping their children to understand language and to speak. Parents may visit or write the Clinic for information, encouragement, and training in coping with a deaf child and in helping the child acquire language, lipreading, and speech skills. Clinic services are available to hearing-impaired children and their parents and include: consultation services for the audiological and psychological evaluation of deaf children; parent classes in child development, parent attitudes, and communication skills; psychological counseling for parents; a demonstration nursery school where children and parents are enrolled; summer sessions for parents and children; a teacher training course; and referrals for appropriate educational needs of preschool deaf children and their parents.

Information Services: Correspondence courses for parents of preschool deaf and deaf-blind children are offered by the Clinic. They emphasize parent attitudes, communication, motor development, and self-care skills. They are available in English and Spanish.

The Clinic makes available the following educational materials: "Vocabulary List"; Language Guide (a detailed description of a four-year language program for preschool deaf children); My Child (helps to explain your child's deafness to others); Getting Your Baby Ready To Talk, a home study plan for infant language development, designed for use with "high risk" infants whose language development may be inhibited; and special materials for teacher education. In addition, the Clinic publishes a bulletin two times a year.

All services of the John Tracy Clinic are given free of charge to children and their parents. Educational materials are available for a charge as a convenience to professionals.



#### Joseph Bulova School 40-24 62nd Street Woodside, NY 11377 (718) 424-2929

Handicapping Conditions Served: All physical and emotional handicaps.

Users Served: All interested persons.

The Organization: The Joseph Bulova School was founded in 1945 to serve returning disabled veterans. Since 1950, the School has accepted disabled civilians, and more recently, nondisabled persons, although 80 percent of its graduates are disabled. The School offers watchmaking, watch repair, precision technology and jewelry repair on an individualized basis to students. In addition to vocational training and rehabilitation, some job counseling and placement services are offered. A course in digital electronic computer repair has recently been added. Residential students receive health services, counseling, and recreation. Financial aid for tuition and living expenses is available to qualifying students.

Information Services: The Bulova School provides free brochures about its services to any interested person. A film about the school, "To Live On," is available on loan.

### National Jewish Center for Immunology and Respiratory Medicine 1400 Jackson Street Denver, CO 80206 (303) 388-4461

Handicapping Conditions Served: Chronic respiratory and immunologic disorders including asthma; chronic bronchitis, emphysema, tuberculosis, systemic lupus erythematosus, and juvenile rheumatoid arthritis.

Users Served: Disabled persons, health care professionals, researchers.

The Organization: The National Jewish Center for Immunology and Respiratory Medicine (formerly the National Jewish Hospital/National Asthma Center) maintains treatment and research facilities where patients can be referred who need specialized care beyond the means of local families. Treatment facilities include medical care and psychological, social, occupational, physical and recreational therapy for patients with chronic respiratory and immunological disorders. Treatment is available to patients of all ages, beliefs and backgrounds. An outpatient program and short-term treatment for children with less severe illnesses are also available. The National Jewish Center program blends patient care and research and teaching. Areas of research include basic investigations in molecular and cellular biology and basic and applied research in respiratory and immunological diseases. The Center is affiliated with the University of Colorado Health Sciences Center. The Center also offers postdoctoral training in respiratory diseases, immunology and allergies. Short courses are offered in other specialty areas related to respiratory diseases and immunology.

Information Services: The National Jewish Center publishes four booklets which discuss in lay language the causes, diagnosis, and treatment of specific diseases. Available at no charge, they are: Understanding Asthma, Understanding Allergy, Understanding Tuberculosis, and Understanding Chronic Bronchitis and Emphysema. A fifth booklet, Understanding Immunology, describes the body's immunological system and possible



immunological dysfunctions. Also available is <u>Management of Chronic Respiratory Disease</u>. A quarterly newsletter, <u>New Directions</u>, is available to those who make a contribution to the Center.

The Center provides a toll-free information service called LUNG LINE R at (800) 222-LUNG. Registered nurses are available to answer questions Monday-Friday from 8:30 a.m.-5:00 p.m. Rocky Mountain time. Off hours and weekends an operator will take messages or send information.

# National Music Information Center for the Handicapped Settlement Music School Program for the Handicapped 3745 Clarendon Avenue Philadelphia, PA 19114 (215) 637-1502

Handicapping Conditions Served: All disabilities except for severe-profound mental retardation and mental illness.

Users Served: Disabled persons, therapists, educators.

The Organization: The Settlement Music School is a community school offering quality music instruction to children and adults regardless of race, ethnic background, religion, disability or ability to pay. Its specialized Program for the Handicapped is open to all students with disabilities who show musical inclinations and could benefit from the school's educational/therapeutic approaches and social/recreational activities. One goal of the program is to integrate all disabled students into regular classes of the school.

In response to the lack of availability of information for professionals on the subject of music for disabled persons, the National Music Information Center for the Handicapped was conceived. Goals of the Information Center include providing information on replicating a program like that of the Settlement Music School and assembling all available printed matter (books, journal/magazine articles, directories, etc.) on the topic "Music for the Disabled" into a collection at one central location. The services of the Information Center are open to all therapists and educators, researchers in the field of creative therapies and special education, and the general public.

Information Services: Brochures and pamphlets are available on issues pertaining to music for disabled persons. The Program for the Handicapped is responsible for the 1983 publication of the Guide to the Selection of Musical Instruments with Respect to Physical Ability and Disability, the first reference book of its kind on the subject.

The Information Center has available a collection of large print and braille music, textbooks and supportive materials on all areas of teaching music to disabled persons. The use of the Center is free and open to the public; however, there is a nominal fee for duplication and mailing. The Center is gathering a smaller collection of video-tapes and records which are not for loan outside the school. Computer searches, bibliographies, folders containing periodicals, newsletters, conference data and scholarship information are also being assembled. In addition, a manual outlining the philosophy, policies and procedures which govern the use of the Program for the Handicapped is available upon request to assist in program development elsewhere. For a nominal fee, Information Center staff members of fer consultation to institutions interested in developing or improving their services for disabled persons.



National Technical Institute for the Deaf (NTID)
Rochester Institute of Technology (RIT)
One Lomb Memorial Drive
P.O. Box 9887
Rochester, NY 14623
(716) 475-6400 (Voice)
(716) 475-2181 (TDD)

Handicapping Conditions Served: Deafness and severe hearing impairments.

Users Served: Hearing-impaired students, their parents and teachers, and miscellaneous others who serve deaf people:

The Organization: The National Technical Institute for the Deaf (NTID) was established by an act of Congress and is funded through the U.S. Department of Education. Since 1968, it has provided a two to three-year technical education to deaf and severely hearing-impaired students. Staff research in speech therapy, educational methods, and vocational training and placement is reported in professional journals as well as in publications of the Institute. Sign language interpreter training, teaching internships, and workshops for employers, educators, and rehabilitation professionals are offered both on and off campus. The Institute is one of nine colleges of Rochester Institute of Technology, and "mainstreaming" deaf students in classes elsewhere on campus has been accomplished with significant success.

Information Services: The Division of Public Affairs provides curriculum materials; communication packages for speech pathologists; orientation manuals and information on hearing aids for audiologists and consumers; special bibliographies and other data requested by researchers; and the NTID catalog, an Institute magazine, and an educational resources catalog. There is a nominal charge for some materials. Videotapes are captioned or interpreted.

The National Center on Employment of the Deaf at NTID offers services in employee development, training, and information services. Information and training are available to employers interested in hiring qualified deaf people. Workshops are conducted on-site, or employers may attend seminars at NTID. Consultation is also available in the areas of job analysis, accommodation in the workplace, and access to upward mobility for deaf employees. Training and consulting are provided for placement professionals working with deaf persons concerning successful placement strategies for qualified deaf persons.

Perkins School for the Blind 175 N. Beacon Street Watertown, MA 02172 (617) 924-3434

Handicapping Conditions Served: Blindness, deaf-blindness, and multi-handicapped blind.

Users Served: Disabled persons.

The Organization: The Perkins School was chartered in 1829 to educate blind and deaf-blind children. It is a private residential school, serving blind students, and clients age 0 to adult, and is accredited to award a high school diploma. Additional services include a rehabilitation program in which older persons or Perkins School graduates learn daily living



and employment skills; a nonresidential preschool; a special program for learning disabled blind children; a deaf-blind program; and a program for severely impaired students. A teacher training program is offered in cooperation with Boston College. The Howe Press, a division of Perkins, manufactures the Perkins Brailler as well as other appliances and materials for blind students. An historical museum on campus is open to the public. While Perkins is a private school, tuition is usually paid by the state or local agency which refers the student.

Information Services: Nineteen curricula in areas such as academics, self-care, home economics, mobility and physical education are available through the Perkins School. In addition, many publications are available through the Howe Press. The Howe Press has lists of curriculum materials and of publications for educators and parents including a Bibliography of the Deaf-Blind, Speech againings for the Deaf-Blind Child, and the Perkins Sign Language Directory. Frice lists for appliances (including the braille typewriter) and for publications are available on request. Public education films, brochures, and books are available from the public relations office; there is a nominal charge for some materials. Information is available in braille, large type, cassette and disk. Information is also available in Spanish. A research library is open for on-site use and an annual newsletter is prepared by the research librarian.

Rubella Project
Developmental Disabilities Center
St. Luke's Roosevelt Hospital Center
428 West 59th Street
New York, NY 10019
(212) 554-6565

Handicapping Conditions Served: Rubella, and conditions arising from its complications.

Users Served: Disabled persons cents, physicians.

The Organization: The Rubella Project was established for research, training and service in prevention and management of rubella and congenital rubella, and for research in rubella vaccines. The Project provides medical and allied services to children with congenital rubella in the New York metropolitan area and is a national referral center for unusual complications associated with rubella and rubella vaccines.

Information Services: The Rubella Project responds to telephone and mail inquiries related to the disease and current management techniques. It makes referrals to diagnostic centers located in the northeastern United States. A bibliography of scientific articles related to congenital rubella and rubella vaccine is available from the Project. Some information is available in Spanish.

Shriners Hospitals for Crippled Children 2900 Rocky Point Drive Tampa, FL 33607 (813) 885-2575

Handicapping Conditions Served: Children's orthopaedic or burn disabilities.

Users Served: Disabled children up to age 18.



The Organization: The Shriners' first children's orthopaedic hospital opened in 1922 as the official philanthropy of the fraternal order. There are now 19 Orthopaedic Hospitals and three Burn Institutes serving children up to age 18 in the U.S., Mexico, and Canada. Diagnosis and treatment are offered solely on the basis of medical and financial need, at no charge to the patient's family. The Burn Institutes accept children who need immediate care or those needing plastic surgery and rehabilitation ("healed" burns). Research on the causes of crippling and scarring and on methods of treatment is conducted at each Shrine Hospital. Members' assessments, charitable bequests, and a variety of fund-raising activities support this network of patient care and research facilities.

Information Services: Application forms for hospital admission, brochures on the hospitals and Burn Institutes, and donation and bequest forms are available from local Shrine Temples or from the International Head marters. Eligibility for treatment is determined on the basis of applications which are completed by parents or guardians, the referring polician, and a local Shrine sponsor. For emergency admission to Burn Institutes or hospitals, call Shriners Hospitals for Crippled Children in Tampa, Florida, (813) 885-2575. To be free numbers: (800) 237-5055; for Florida, (800) 282-9161.

Sister Kenny Institute
Division of Abbott-Northwestern Hospital
800 E. 28th Street at Chicago Avenue
Minneapolis, MN 55407
(612) 874-4457
(612) 874-4482
(612) 874-5163 (TDD)

Handicapping Conditions Served: Musculoskeletal and neurological disorders.

Users Served: Disabled persons, parents, physicians, physical therapists, occupational therapists, nurses, health educators, disabled groups.

The Organization: The Institute was established in 1942 by Sister Elizabeth Kenny, an Australian nurse who revolutionized the treatment for polio. Her method has been adapted and treatment expanded to include comprehensive rehabilitation for persons with spinal cord injuries, strokes, brain injury or other physical disabilities. Since 1975 the Institute has been a division of Abbott-Northwestern Hospital, where it cares for patients coming out of the acute care facility or other hospitals, and offers a continuum of rehabilitative services. Departments include physical medicine, rehabilitation nursing, and occupational, recreational, and physical therapy; speech pathology and audiology; psychological and social services; a day hospital and day center; a residential treatment center for chronic pain; and vocational rehabilitation, evaluation, training and job placement.

Patient and family education programs and services such as the resource room are part of programs. Outpatient clinics and therapies are offered in: brain injury follow-up, cardiac rehabilitation, chemical dependency/physical disability, chronic pain rehabilitation, low back care, polio residuals, spinal cord injury follow-up, and stroke (CVA) follow-up. Exercise and recreation programs include bowling, golf, sports training, swimming and wheelchair basketball.



A department of research and education offers both graduate and continuing education courses for health professionals in long term care, nursing and rehabilitation. These courses can be given at other locations by arrangement.

Information Services: A wide variety of health care materials are prepared and published by the Institute for health professionals, patients and their families. The catalog lists publications and audio-visuals on range of motion exercises; managing specific hand problems; patient care; transfers and positioning; pain, stroke, heart, back, bowel and bladder, hand and leg care; and patient education and community education. A newsletter, Kenny Scope, is published two to three times per year and contains about 30% external information of interest to disabled persons and others. The Institute also publishes the Educational Materials Catalog twice a year. Some information is available as a computer program or audio-visual. There is a charge for services and products other than simple questions.

Vinland National Center P.O. Box 308 3675 Ihduhapi Road Loretto, MN 55357 (612) 479-3555 (Voice and TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons and family members, physical and recreational therapists, adapted physical educators.

The Crganization: Patterned after the Beitostolen Health Sports Center in Norway, Vinland National Center is a healthsports center for persons who are disabled. Vinland offers comprehensive on-site programs that enable participants to improve their physical, social and emotional fitness, develop medical self-care skills, and enhance their employability. In Vinland's healthsports program, participants and instructors design individualized programs tailored to personal needs and abilities. A wide variety of sports and recreational activities are included in the curriculum.

Vinland activities also include research on the effect of exercise and sports on energy output and stamina, and educational services for professionals in a wide variety of fields, for example, health care, education, sports, recreation, and architecture.

Information Services: Vinland serves as a national information service on recreation and sports for disabled persons, and puts inquirers in touch with local, regional and national groups interested in health and sports. Referrals are also made to local rehability ion/recreation facilities. Vinland training manuals are available in areas such as the following: skiing and several other sports, adventure, health skills, fitness, and relaxation. There is a charge for the manuals. Information is available in braille and on tape. Vinland also has available for loan or purchase a 25-minute film, "Equal Victors," explaining the Vinland concept, present accomplishments and future plans.



#### SERVICE ORGANIZATIONS

Service organizations can be divided into two distinct categories—those that offer services for handicapped persons as a part of their general activities and those that provide a very narrow and specialized service for handicapped individuals, often in the form of communication aids. Organizations in the the first category include groups concerned with adoption, foster care, camping and recreational activities such as scouting. Some of the specialized services provided include braille books and recordings for the blind, captioning of television programs and shoe and glove exchanges for amputees.



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### AASK AMERICA/Aid to Adoption of Special Kids 595 Market Street San Francisco, CA 94105 (415) 543-2275

Handicapping Conditions Served: All handicaps.

Users Served: Prospective adoptive parents, adoption agencies.

The Organization: Aid to Adoption of Special Kids helps to place older children, minority children, and emotionally, mentally, and physically handicapped children in permanent adoptive homes. AASK is a licensed adoption agency. It serves the national adoption scene by acting as an intermediary between adoption agencies and parents seeking to adopt "special kids." AASK AMERICA is headquartered in San Francisco with offices throughout the U.S. and serves all 50 states. It also sponsors, through its affiliate in Dawson, MN, a program placing children from Brazil. Generally, no fees are charged.

Information Services: AASK maintains files of available children, referred by caseworkers of adoption agencies throughout the U.S., and a registry of families seeking to adopt difficult to place children. When AASK can match a request of adoptive parents with a specific child listed in its files, the parents are referred to the appropriate adoption agency. Individual requests for information on the availability and needs of adoptable handicapped children, financial resources available to adoptive families, and proper adoption procedures are answered by phone or letter.

### Adventures in Movement (AIM) for the Handicapped, Inc. 945 Danbury Road Dayton, OH 45420 (513) 294-4611

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons.

The Organization: Adventures in Movement (AIM) for the Handicapped was founded in 1958 to promote the teaching of movement using the AIM method, a series of rhythmical exercises involving gross and fine motor movements. The purpose of the method is to improve muscle control and coordination, and thereby enhance self-image. The program can be adapted for instruction to all handicapped persons and all age groups. The organization's major activity is the training of classroom teachers and volunteers in the AIM method. Workshops are planned to meet the particular needs of sponsoring groups.

Information Services: Brochures describe the AIM method and the organization's workshops. A handbook, Adventures in Movement for the Handicapped, illustrates the exercises used in AIM classes. "Maybe Tomorrow", a film of the AIM method in actual classroom use, is available for rent or purchase. The organization will provide a list of school systems with AIM programs upon request. For further information, contact the Education Department of AIM. The AIM Water Program transposes the AIM Method to the water, where exercise and movement, rather than actual swimming instruction, are emphasized. An annual newsletter informs interested parties about developments within the organization. There is no charge for information or services.



### American Camping Association (ACA) Bradford Woods Martinsville, IN 46151 (317) 342-8456

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons and their families, professionals.

The Organization: The Association inspects and accredits camps throughout the country according to standards of hygiene, safety, and program. An annual guide for parents lists camps which mainstream physically or mentally retarded children and others which serve children with epilepsy, diabetes, asthma and learning disabilities, and children, youths and adults who are deaf, blind, and physically, emotionally or mentally handicapped. The primary focus of the Association, however, is not on services to the handicapped.

Information Services: Camping Magazine is the official journal of the Association. The annual Parents Guide to Accredited Camps lists all ACA camps around the country. An ACA publications catalog is updated annually containing titles of more than 400 books and pamphlets on various topics related to organized camping (including how to serve the handicapped through mainstreaming and special programs).

American Printing House for the Blind (APHB) 1839 Frankfort Avenue P.O. Box 6085 Louisville, KY 40206-0085 (502) 895-2405

Handicapping Conditions Served: Blindness and visual handicaps.

Users Served: Disabled persons, parents, teachers.

The Organization: Chartered in 1858, the Printing House is the oldest and largest publishing house for the blind in the world. Since 1879 Congressional appropriations have supported publication of textbooks in braille, large print, or recorded format for all blind students under college age. In cooperation with the National Library Service for the Blind and Physically Handicapped, Library of Congress, the Printing House produces braille recreational reading material and records, "Talking Books." APHB also contracts with private agencies or individuals to publish books and periodicals for study or recreational reading by the blind. Other instructional materials produced include more than 250 special educational aids and tools.

A research department conducts basic studies relevant to the education of the blind, and applies this information to the design of new educational materials. A milestone in this department is the development of the talking edition of the World Book Encyclopedia.



The Printing House has established a central catalog of volunteer-produced books which coordinates the services of volunteers who produce a large number of special materials, to make interchange of these materials possible and avoid duplication. Requests for information about volunteer and commercially produced materials should be directed to the Instructional Materials Reference Center.

Information Services: Catalogs include braille publications, braille music, large type (textbooks, high interest/low vocabulary textbooks, cookbooks); educational aids; lists of print books for parents and professionals working with the blind; and brochures describing the Printing House.

American Red Cross National Headquarters 17th and D Streets, NW Washington, DC 20006 (202) 737-8300

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, parents, teachers, professionals.

The Organization: The American Red Cross was established in 1881 by Clara Barton. Some of its areas of service are disaster services; blood services; services to the armed forces and veterans; safety services; nursing and health services; and youth services. Handicapped persons are given priority transportation, shelter, food, clothing, and medical assistance in case of disaster. Through 3000 local chapters, and depending on the needs of the community, volunteers offer transportation services, hot meal programs, and assistance at community rehabilitation and recreation centers for handicapped persons. In addition to programs initiated at the local level, the national headquarters has designed programs for handicapped persons which are implemented by the chapters.

An adapted aquatics program is available through many Red Cross chapters. The Red Cross trains swimming instructors to teach handicapped persons.

A course for the care of multiple sclerosis patients is offered through local Red Cross and National Multiple Sclerosis Society chapters.

Information Services: Books, manuals, and audio-visuals on adapted aquatics are available from chapters. A publications list and publications are also available from local chapters. Some chapters publish their own materials. Charges are nominal, primarily to cover the cost of materials.

"Breaking the Barriers," a film about four disabled young people, is available on loan from the Audiovisual Loan Library at the above address. Some publications can be obtained in braille, large type, or tape editions through national headquarters. Some information is available in Spanish.



### Amputee Shoe and Glove Exchange Dr. and Mrs. R. E. Wainerdi 1635 Warwickshire Drive Houston, TX 77077

Handicapping Conditions Served: Amputation.

Users Served: Disabled persons.

The Organization: The Amputee Shoe and Glove Exchange provides a free service to facilitate the exchange of unneeded shoes and gloves among amputees.

Information Services: The Exchange maintains a list of amputees with information on their age, size, style preferences, and side needed. This information is sent to an amputee with similar tastes and the opposite side amputated. All mailings of shoes or gloves are between the amputees themselves.

### Associated Services for the Blind (ASB) 919 Walnut Street Philadelphia, PA 19107 (215) 627-0600

Handicapping Conditions Served: Blindness, visual impairment, deaf-blindness.

Users Served: Disabled persons, professional training schools, health care professionals.

The Organization: Associated Services for the Blind (ASB) (formerly Volunteer Services for the Blind) strives to support independence and self-determination of visually impaired people by providing needed equipment, materials, training, support, and education of the public. ASB provides braille, large type, and recordings of a variety of reading material to blind and partially sighted persons, and transcribes printed materials on request from blind individuals. ASB also transcribes materials for government agencies, including the Library of Congress. Each fall, ASB offers a braille transcriber training program free to those who wish to do volunteer transcribing. Persons who successfully complete the course are certified by the Library of Congress, National Library Service for the Blind and Physically Handicapped. ASB trains handicapped persons to use the Optacon (a tactile scanning device that "reads" print), and makes the device available at cost. ASB also provides training and consultation in the use of other advanced electronic aids.

The organization provides instruction for blind or visually impaired persons preparing to enter or re-enter the workforce, for older persons with failing vision seeking to retain independence and for blind persons desiring to update their skills. In addition, ASB teaches adaptive skills to newly blind individuals. ASB also provides counseling for visually impaired persons and their families and supportive services such as escort service, reader's services, volunteer visitors and telephone companions. To improve public understanding of blindness, ASB provides educational and 'taining programs to community organizations, agencies, professional students in social work and health care, and elementary and secondary school students.



Information Services: More than 200 volunteers across the country transcribe textbooks, professional materials, music, and recreational materials. ASB regularly records certain magazines and journals, and will fill individual requests for periodicals not available from other sources. Transcription Services have a minimal charge for materials. A list of recorded periodicals is available; periodicals must be subscribed to and are on a loan basis. ASB operates a retail store, Sense-Sations, which sells a variety of specialized items for blind and visually impaired persons. Purchases can be made in the store or by mail order. A catalog is available on request. ASB also operates a radio station which broadcasts news and information to visually impaired persons in the Philadelphia area via special radio receivers.

# Association of Radio Reading Services (ARRS) 1330 20th Street Washington, DC 20049 (800) 255-2777 ARRS Information Number

Handicapping Conditions Served: Visual and physical handicaps, problems associated with aging.

Users Served: Disabled persons.

The Organization: The Association of Radio Reading Services (ARRS) was established in 1977 to promote the growth of such services throughout the country, and to provide for the development and sharing of advanced technology and for a unified effort towards legislation supportive of Radio Reading Services.

Radio Reading Services are independently operated broadcasts of news and information for visually and physically handicapped persons who cannot read printed materials for themselves. Broadcasts are presented by trained volunteers and include readings of newspapers, magazines and books. Now on the air in more than 110 communities throughout the country, these services operate on a closed channel basis (an FM station simultaneously broadcasts the service along with its regular programming to designated listeners via special receivers) or on an open channel basis (local stations interrupt their regular programming for the service and no special receiver equipment is required).

Information Services: ARRS publishes brochures on Radio Reading Services and how to establish them. Memos on issues affecting the broadcasts of special programs, such as regality one of the Federal Communications Commission or the Office of Telectinunications, are periodically distributed to member services. Information is available about possible funding sources and broadcast and receiver equipment. ARRS will reconsultation or referrals to other consultants. In addition, ARRS has a free tape exchange for new and established services, providing loan copies of tapes of books and feature programs. A newsletter, Hearrsay, is published quarterly, as is the ARRS Tape Exchange Program Catalog which is also available on cassette. A Directory of Radio keeding Services in braille and large; in free of charge to ARRS members.



# Association of Rehabilitation Programs In Data Processing (ARPDP) P.O. Box 2404 Gaithersburg, MD 20879

Handicapping Conditions Served: Severe physical disabilities.

Users Served: Disabled persons.

The Organization: The ARPDP represents 31 programs across the country which train severely handicapped individuals as computer programmers. Graduates of these programs are placed in competitive employment. As of December, 1984, 1,265 out of 1,500 students were successfully placed.

Information Services: The Association responds to inquiries concerning the specific needs of disabled programmers. Persons desiring detailed information are referred to the training program nearest to them. The Association publishes a quarterly newsletter, Viewpoint.

Boy Scouts of America (BSA) Scouting for the Handicapped Service 1325 Walnut Hill Lane Irving, TX 75038-3096 (214) 659-2127

Handicapping Conditions Served: All disabilities.

Users Served: Disabled persons, parents, teachers, schools, service clubs and community organizations.

The Organization: In 1970 the BSA established a handicapped service in its Relationships Division. A National Advisory Committee on Scouting for the Handicapped (NACOSH) was formed in 1974. In addition, more than 150 of the 413 local Scouting councils have established their own advisory committees on Scouting for the Handicapped. Scouting for the Handicapped is designed to include young handicapped people in regular units or in groups at schools and homes for handicapped youth, when inclusion in ongoing scouting activities is not possible. National voluntary organizations with expertise in specific handicapping conditions assist Scouting for the Handicapped in devising special programs and materials.

Information Services: Audio-visual and print publications for scout leaders contain specific activities for handicapped scouts and ways to involve handicapped persons in regular scouting activities. Scouting manuals are available on persons who are mentally retarded, physically handicapped, deaf, emotionally disturbed, or visually impaired. For visually impaired scouts, a list of braille scouting books and their suppliers is available from the service. A giveral bibliography of reading for mentally retarded boys is also available. In addition, curriculum materials have been developed to supplement reading, writing, and math skills taught by classroom teachers. Some information is available in Spanish and all information is provided free of charge:



# Child Welfare League of America (CWLA) 440 First Street, NW Washington, DC 20001 (202) 638-2952

Handicapping Conditions Served: All handicaps.

Users Served: Child welfare professionals.

The Organization: The Child Welfare League of America (CWLA) is a federation of about 400 public and private social service agencies in Canada and the United States. The member agencies provide a variety of child welfare services to children and their families. The agencies' services include, but are not limited to, foster care, counseling, day care, adoption, and services for unmarried parents. The League offers consultation to agencies on day-to-day and long range problems in policy, program, and practice. It establishes standards, provides consultation, conducts research, holds regional workshops and training conferences for professionals, offers a personnel referral service for top administrators only, and acts as an advocate for child welfare issues in Washington and in 27 state capitals.

Among the League's several specialized programs is the Permanent Families for Children Unit, which provides special assistance for child welfare agencies and advocates to improve their procedures for reversities children with their biologic families when possible or for funding appropriate permanent foster homes. PFC includes the North American Center on Adoption to amazing and referral resources.

Under a separate grant partment of Health and Human Services (HHS), CWLA conducted a develoging develoging of the severely handicapped. A resource available,

Through grants from HHS, the League has developed three curricula for foster parent education: <u>Introduction to Foster Parenting</u>; <u>Foster Parenting a Retarded Child</u>; and <u>Foster Parenting an Adolescent</u>. Brochures detailing the materials, and consultation on the use of the materials are available upon request.

Information Services: The League's Informational Resource Service acts as a clearinghouse for information about child welfare services and related subjects. It has a national videotaped lending library for agencies, organizations, and individuals.

A publication catalog includes titles of more than 120 books on foster parenting and administration of foster care agencies. Final reports on League studies are also available. CWLA publishes a professional journal, Child Welfare, as well as newsletters covering administrative, legislative, and parenting topics. Fees are charged for all publications.

The Children's Campaign, founded in 1985, is an attempt to organize individuals around children's issues. This network is used for advocacy, education and communication.



Eye Bank Association of America, Inc. (FBAA) 1511 K Street, NW Suite 830 Washington, DC 20005-1401 (202) 628-4280

Handicapping Conditions Served: Blindness and visual impairments.

Users Served: Ophthalmologists, eye researchers, and researchers of eye-related problems, e.g., diabetes.

The Organization: The main purpose of eye banks is to secure eye tissue and to preserve it until it is needed for corneal transplants or eye research. The Eye Bank Association of America (EBAA) was founded in 1961 by the American Academy of Ophthalmology and Otolaryngology (AAO) for the purpose of promoting and standardizing eye banks. The EBAA has 88 associated eye bank members in 41 states, Puerto Rico, and Canada which meet the criteria set by the Association's medical advisory committee. This committee also certifies technicians working in eye banks.

Information Services: The Association distributes promotional materials to its eye bank members intended to inform the public of the needs of eye banks. The EBAA answers inquiries from the public on how to donate eyes for corneal surgery and provides national statistics on eye banking and tissue supplied for corneal surgery and eye research. The EBAA publishes abstracts of scientific papers delivered at the annual meetings of the EBAA and the AAO, four eye banking manuals, and Foresight, a quarterly magazine. There is a charge for the eye-banking manuals.

Girl Scouts of the U.S.A. Services for Girls with Disabilities 830 Third Avenue New York, NY 10022 (212) 940-7500

Handicapping Conditions Served: All disabilities.

Users Served: Girls, ages 5 through 17.

The Organization: Girl Scouting is open to all girls ages 5 through 17 (or kindergarten through grade 12). Girl Scouts of the U.S.A. does not have a separate program for girls with disabilities. The aim of its services for girls with disabilities is to make the troop and camp experience of girls with disabilities as much like that of other girls as possible. This is achieved by mainstreamed troop situations for girls with disabilities when the situation indicates this placement, and flexible adaptation of program resources based on individual strengths of each girl in all situations. There are no "special" or different activities in Girl Scouting for girls with disabilities; regular activities such as camping, sports and recreation, arts, service and learning skills are adapted to suit the abilities and limitations of individual girls.



The Girl Scouts of the U.S.A. is a private, nonprofit organization with a national headquarters and three field centers serving 336 Girl Scout Councils chartered by the National Board of Directors. Membership includes approximately 3,000,000 girls. The overall aim of GSUSA is to inspire each girl to develop her own sense of values and sense of worth as an individual.

Information Services: The Girl Scouts organization publishes various literature, including Girl Scout Leader Magazine. A publications and audio-visuals catalog is available. A spring 1985 program membership training packet, Serving Girls With Disabilities, can be obtained from the national headquarters.

Institute of Art and Disabilities 233 South 41st Street Richmond, CA 94804 (415) 620-0290

Handicapping Conditions Served: All disabilities.

Users Served: Disabled persons, parents, teachers, artists, art therapists, art educators, counselors.

The Organization: The Institute of Art and Disabilities is a nonprofit organization which operates a demonstration visual arts program, provides professional training and consultation, helps establish art centers and art programs for children and adults with disabilities and conducts research. The Institute is founded on the belief that artistic expression is a means of promoting community involvement and integration for disabled individuals, as well as personal expression. The Institute offers creative opportunities in painting, sculpture and print-making to adults who are physically handicapped, emotionally disturbed or mentally retarded. Students come to the center from throughout a two-county area, as an alternative to sheltered workshops and work activity programs. Training is provided in prevocational and vocational skills related to remunerative employment in the art field. Counseling and training in independent living skills are also integrated into the program. Opportunities are provided for observation, practice teaching and research for professionals and students at the Institute.

The Institute promotes exhibitions of creative art of people with disabilities in art galleries, museums and public places. The philosophy of the Institute is disseminated nationwide through publications, conferences, public education and advocacy.

Information Services: The Institute publishes brochures on the programs and services it offers, as well as a quarterly newsletter. Publications include Art and Disabilities, Disabled Artists at Work - Photography by Judy Dater (Exhibition Catalog), Exhibition - Artists With Disabilities (Exhibition Catalog).

The Institute consults with individuals and groups in establishing and operating art centers and art programs for people with disabilities. It also develops programs for children and adults in schools, sheltered workshops, convalescent hospitals and state institutions. Professional training is provided through courses, participatory workshops, and conferences for artists, teachers, social workers, nurses, museum personnel, parents, etc. To further public education, the Institute conducts lectures, conferences, radio, television, film and media presentations.



#### International Handicappers' Net (IHC NET) P.O. Box 59 Oregon, MO 64473 (816) 446-2902

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons.

The Organization: Any handicapped person (including the deaf, blind and mute, who operate radios using the Continental Code and/or voice) who is a qualified amateur radio operator is eligible for membership in the International Handicappers' Net (IHC NET). The international membership of 2:00 communicates via radio at the appointed frequency (14287 MHz upper sideband) at 1600 Greenwich Time (1500 during daylight savings time). Monday through Friday. While members use the Net for communicating with other members, they also handle public service messages and are trained to handle emergency communication in the event of disasters. IHC NFT provides instruction and assistance in qualifying for and obtaining an FCC license to operate privately owned radio stations. The organization encourages the skills learned to be applied towards preparation for future employment.

Information Services: Information about the organization is provided to any inquirer upon request. New members are referred to members in their locales for assistance and information about the operation. To obtain membership and a certificate, send a legal size or an 8x10 self-addressed stamped envelope with 2 stamps postage along with your call letters and nature of handicap. Information is available in print and on cassette tape, but referrals can be made for braille. The organization publishes a quarterly newsletter, IHN NEWS, to provide news about members, IHC NET activities and other information of interest to members.

Jewish Guild for the Blind (JGB) 15 West 65th Street New York, NY 10023 (212) 595-2000

Handicapping Conditions Served: Blindness and visual impairments.

Users Served: Disabled persons and their families.

The Organization: The Jewish Guild for the Blind (JGB) is a nonprofit voluntary agency whose mission is to assist blind and visually impaired persons to achieve their optimum potential as members of society. The Guild offers a wide range of services to blind and visually impaired persons and their families without regard to religion, race, or age. Clients are charged for services based on their ability to pay. Direct services encompass rehabilitation in a number of areas (including daily living skills, vocational and mental health con seling, job training and placement), activities in the arts, a school for meltihandicapped students 5 to 21 years of age, a residential facility for the aged blind, and other programs.

The Calle offers field training experience to grad late students of social work, vocational rehabilitation, and special education.



Information Services: JGB is the world's largest circulator of taped best sellers and other recorded books to blind and disabled persons. More than 800 best selling books have been recorded by volunteers. The Guild distributes more than 250,000 cassettes yearly in the U.S. and abroad.

Brochures describing JGB services are available. The Guild provides information and referral to its own and other community services, when appropriate. Information is provided in braille upon request. Information and consultation concerning visual impairment and blindness are also offered.

Modern Talking Picture Service, Inc.
Captioned Films/Video for the Deaf Program
5000 Park Street North
St. Petersburg, FL 33709
(800) 237-6213 (Voice/TDD)
(813) 541-7571 (Voice/TDD)

Handicapping Conditions Served: Deafness and hearing impairment.

Users Served: Deaf and hearing impaired persons and persons involved in the education of deaf and hearing-impaired persons.

The Organization: The Captioned Films/Video for the Deaf Program provides captioned educational and enterainment films to deaf and hearing-impaired persons on a free-loan basis. The program is operated by Modern Talking Picture Service, Inc. under a contract with the Office of Special Education Programs, U.S. Department of Education. The educational captioned films collection numbers over 1400 titles and covers a wide variety of topics, e.g. science, math, and computers. These films are used at residential and lay schools for deaf and hearing-impaired students and in mainstreamed programs at all educational levels. The entertainment collection numbers about 1800 titles and ranges from adult education and short subjects to feature length films. These films are used throughout the deaf and hearing-impaired communities.

Information Services: The services of the Captioned Films/Video for the Deaf Program are available only to approved, authorized users. Persons wishing to borrow films must apply to the program to open an account. Anyone involved in the education of deaf/hearing-impaired persons is eligible for an account to borrow educational films. Groups of six or more deaf individuals are eligible for an account to borrow entertainment films. Once an application is approved, the account holder receives information on catalogues and other distribution information. The program has 58 distribution libraries around the country.

There is no charge to account holders for the processing of applications or for catalogues. The only cost involved in the service is the cost of return postage for films which have been borrowed.



#### National Adoption Center 1218 Chestnut Street Philadelphia, PA 19107 (215) 925-0200

Handicapping Conditions Served: Developmental disabilities and social and environmental deprivation.

Users Served: Disabled children with special needs.

The Organization: The mission of the National Adoption Center is to promote adoption opportunities for children with special needs. These include children with emotional, physical, or developmental disabilities or groups of siblings who need homes together. Many of the children are older or come from minority cultures. The Center does not determine where children will be placed, but works cooperatively with adoption agencies around the country on the children's behalf. The Center operates a computer-based exchange that allows it to "match" a child from one part of the country with a family from another. The Center maintains an information and referral service on adoption and related issues, conducts professional training and does extensive recruitment for adoptive families. The Federal government estimates that there are approximately 35,000 "legally free" children in the country who wait for permanent families.

Information Services: The Center publishes a quarterly newsletter, available at no charge. It also produces a Family Album quarterly which contins photographs and description of many of the children around the country awaiting adoption. The Center has public service announcements about adoption and has produced a film, "The Challenge of Caring," a 30 minute presentation on adoption of special needs children. Interested groups may borrow or purchase the them from the Center:

The Center, partially federally funded, welcomes inquiries from people who want to know more about adoption, in particular, from families who want to explore the possibilities of adopting a special needs child.

#### National Braille Association, Inc. (NBA) 1290 University Avenue Rochester, NY 14607 (716) 473-0900

Handicapping Conditions Served: Blindness and visual impairments.

Users Served: Disabled per as, volunteers and professionals who serve the blind.

The Organization: The National Braille Association, Inc. (NBA) was formed to unite volunteers and professional workers for the visually impaired in one national organization to develop, provide and coordinate volunteer services in the production and distribution of reading materials in braille, tape and large type. NBA is unique in that it is an international organization without any local units. Its thousands of members work through philanthropic, religious and service groups in their own communities.

The NBA's Braille Materials Production Center is a central source for braille readers. Over 1800 book titles, including music scores, supply college students, professionals, and other adults with technical and non-technical materials for school, work and recreation. The



collection is continuously updated. Personal items of general interest that are helpful in work, recreation and daily living are also translated by certified braillists. NBA's Disk Output Service enables transcribers and braille readers to send 5 1/4 inch disks, compatible with NBA's personal computer system, to NBA for output in braille form. This service is not restricted to NBA-prepared materials.

NBA provides continuing education for members and non-members through its national conferences, regional meetings and Robert S. Bray Community Workshops conducted by NBA specialists. NBA publications are used by volunteers and state agencies throughout country to train transcribers. The NBA also serves as a clearinghouse for the exchange of ideas and suggestions for improvement of transcription techniques.

Information Services: Catalogs of the NBA collection of book titles and standard technical tables are available for a fee. The NBA <u>Bulletin</u> is published quarterly in print, braille and audio formats. It contains skills columns and articles about new materials and equipment, braille code changes and activities of outstanding individuals and groups. A subscription to the <u>Bulletin</u> is included in the cost of membership. NBA also publishes skills maguals and guidelines for transcribing procedures, format and uniform standards which are available for or at reduced prices to member.

National Captioning Institute, Inc. (NCI) 5203 Leesburg Pike Suite 1500 Falls Church, VA 22041 (703) 998-2400 (Voice or TDD)

Handicapping Conditions Served: Deafness and hearing impairments.

Users Served: Disabled persons, parents, teachers.

The Organization: The National Captioning Institute (NCI) is a nonprofit organization which captions television programs for the Public Broadcasting Service (PLS), ABC, CB3, NEC and independent producers. ABC and PBS played major roles in developing the captioning system. The Institute's primary goal is to increase the number of captioned programs available, and to expand the audience benefiting from the service.

Closed captioning converts the TV program dialogue into subtitles that are shown on the viewer's television screen. The captions are encoded and transmitted by the broadcaster on a part of the television signal that does not ordinarily carry picture information. Unlike "open captions" which are seen by all viewers, "closed captions" are seen only on television sets equipped with a special device. The equipment needed to receive closed captions is sold by Sars, Roebuck and Co. (catalogue only), J. C. Tonney (catalogue only) and Hearing Aid Dispensors. As of January, 1986, over 96 hours of captioned programs, predominantly prime time, are broadcast each week. Further increases in the number of captioned programs will depend largely on the demand by television viewers for the special equipment. Over 120,000 units are already in use.

Information Services: The Institute's Public Affairs and Development Office provides information on the history of the captioning project and NCI's activities. NCI has two publications: <u>CAPTION</u>, a newsletter for viewers, and the NCI MARKETING MEMO, an update sheet for producers and sponsors.



National Industries for the Blind (NIB) Rehabilitation Services Division 524 Hamburg Turnpike Wayne, NJ 07470 (201) 595-9200

Handicapping Conditions Served: Blindness, deaf-blindness, multi-handicapped blindness.

Users Served: Agencies and workshops for the blind.

The Organization: National Industries for the Blind (NIB) was established in 1938 to act as the designated liaison between workshops for the blind and Federal government procurement representatives. Approximately 100 workshops, employing more than 5,000 blind and multihandicapped blind persons, are associated with NIB, and their activities involve producing goods and services for government and private industry. NIB's main functions are to allocate government purchase orders among qualified workshops and to provide training and consultation to workshop boards and personnel in the areas of workshop management, mechanical and industrial engineering, quality assurance, product research and development, vocational rehabilitation services and subcontract procurement. NIB works with new workshops, helping them to meet the special requirements of both NIB and the Committee for Purchase from the Blind and Other Severely Handicapped, and with representatives in industry to create employment opportunities for blind persons. There are no fees or dues for association with NIB.

Information Services: Information available through NIB relates to the standards and requirements for association with NIB. as well as assistance in establishing new workshops for blind and multihandicapped blind persons. General information about NIB and a list of associated workshops are available to any individual. A nominal fee may be charged for some materials. A limited number of NIB annual reports are available in braille.

National Industries for the Severely Handicapped, Inc. (NISH) 2235 Cedar Lane Vienna, VA 22180 (703) 560-6800

Handicapping Conditions Served: All handicaps, when severe.

Users Served: Sheltered work center personnel.

The Organization: National Industries for the Severely Handicapped (NISH) is the non-profit agency that provides technical assistance to sheltered work centers interested in securing Federal contracts under the mandatory procurement provisions of P.L. 92-28, the Javits-Wagner-O'Day (JWOD) Act. NISH was established in 1974. Its three major functions are: (1) conducting research and development to identify commodities and services that are feasible for work centers to provide to the Federal government; (2) providing technical assistance in the form of industrial engineering, production planning, quality control, inventory management, cost analysis, pricing, contract administration, and regulatory processing; and (3) acting as liaison between work centers and the Presidentially appointed Committee for Purchase from the Blind and Other Severely Handicapped, the Federal agency charged with oversight of the JWOD program. More than 1,000 work centers are verified for participation in the program; and more than 200 are producing commodities or providing services to the Federal government.



Information Services: An information packet outlines the preliminary steps involved in obtaining verification for participating in the JWOD program and provides information about the JWOD Act and the kinds of assistance NISH offers. NISH publishes a quarterly newsletter distributed to all work centers employing the severely handicapped that have Department of Labor certificates. It also distributes its Work Center Manual which details operational requirements of participation in the JWOD program. NISH holds an annual National Conference in the spring, which provides training in cost analysis, production methods, compliance with JWOD and Labor Department regulations, and other areas.

New Eyes for the Needy 549 Millburn Avenue Short Hills, NJ 07078 (201) 376-4903

Handicapping Conditions Served: Visual impairments.

Users Served: All interested persons.

The Organization: New Eyes for the Needy provides funds for new prescription glasses, artificial eyes, and lenticular contact lenses (for cataract patients) to medically indigent persons who are not eligible for other sources of financial assistance. New Eyes solicits metal frames in any condition, unbroken plastic frames with single vision lenses, sunglasses, brown artificial eyes, soft eyeglass cases, and any precious metal scrap such as old jewelry or silverware. The organization ships reusable glasses to medical missions and welfare agencies abroad for redistribution. Metal framed glasses and metal scrap are sent to be refined, and the proceeds furnish the funds to provide glasses for the needy in the United States.

Information Services: New Eyes has organizational brochures describing its history, function, how a community group can organize a collection drive, and how donors should package and send materials to New Eyes. Information about qualifying for financial assistance from New Eyes is given to lay and medical inquirers:

Organization for Use of the Telephone, Inc. (OUT) P.O. Box 175
Owings Mills, MD 21117-0175
(301) 655-1827

Handicapping Conditions Served: Hearing impairments.

Users Served: Disabled persons, parents, teachers, audiologists, advocates.

The Organization: The Organization for Use of the Telephone (OUT) was founded in 1973 as a consumer advocacy group for hearing-impaired people. Its main concern, as its name implies, is to make the telephone an accessible instrument of communication to those who are "phone deaf." To this end, OUT has held a major role in persuading telephone companies to convert coin operated, business and home phones to make them electronically compatible with telephone pick-ups in hearing aids. At this writing, there are more than 145 million hearing aid compatible phones in the U.S.; 45 to 50 million are incompatible.



OUT is also an active advocate for the installation of Induction Loop Amplification (ILA) systems in places of public gatherings. Induction loops, when used with hearing aid telephone pick-ups, provide added amplification and clarity to hearing-impaired people, making hearing and understanding possible without the need for lipreading.

Information Services: OUT provides inquirers with organizational materials, information on the use of hearing aids with telephones, and copies of relevant news articles, congressional bills and testimony. The OUT-Line, published quarterly, informs the membership and other interested persons of national and local efforts to improve communication technology for hearing-impaired people. Individual mail and phone inquiries relating to problems with telephone usage are answered by OUT. OUT intervenes with telephone companies to acquire compatible phones for hearing aid users. All information is provided free.

P.R.I.D.E Foundation (Promote Real Independence for the Lisabled and Elderly)
71 Plaza Court Groton, CT 06340
(203) 445-1448

Handicapping Conditions Served: All disabilities.

Users Served: Disabled persons, parents, teachers, and professionals.

The Organization: The P.R.I.D.E. Foundation is a nonprofit organization whose primary objective is to provide assistance for handicapped and elderly persons in the areas of homemaking, independence in dressing, personal grooming, and fashionable apparel.

Information Services: For a fee, P.R.I.D.E. provides technical assistance to health agencies, social service groups, and voluntary organizations in the areas of clothing design and other homemaking skills. Direct services to disabled and elderly persons and their families include sewing assistance, adapting patterns and designs to meet the clothing needs of persons with specific disabilities, training in sewing machine operation, and the provision of household devices for use in the kitchen, bedroom and bathroom. Many of these services are offered through the mail.

P.R.I.D.E. makes available a clothing exhibit, "The Travel Trunk," for a rental fee of \$50. This exhibit contains approximately 30-50 same a garments, which have been especially designed for persons with various disabling conditions.

P.R.I.D.E. provides brochures on dressing, grooming, home management and fashionable apparel for disabled and elderly persons. The Foundation also disseminates a number of publications which include a curriculum guide for advanced inservice training for homemaker/home health aides; sewing instruction manuals; pattern design and clothing modification manuals; a bibliography of resources; an information sheet for scoliosis patients; a clothing lesson plan for training of care givers who provide assistance in dressing and grooming; and other materials designed to teach the disabled homemaker or service provider. There is a charge for all items except brochures.



Recording for the Blind (RFB) 20 Roszel Road Princeton, NJ 08540 (609) 452-0606

Handicapping Conditions Served: Blindness and visual impairments; physical and perceptual handicaps that prevent the person from reading normal printed material.

Users Served: Print-handicapped persons, as well as counselors, teachers, parents, and health care professionals who act on their behalf.

The Organization: Recording for the Blind (RFB) supplies taped educational books in cassette form, free on loan to handicapped students, elementary throug' graduate school, whose objective is to earn diplomas and academic degrees. RFB also serves adults who require specialized taped educational texts to maintain business and professional roles or who desire such material for self-study and personal enrichment. RFB accepts requests to tape textbooks which are not already contained in its Master Tape Library. Those titles are then added to the library's approximately 63,000 titles at the average rate of 350 each month. Tapes are produced at 29 recording studios nationwide. RFB makes referrals to alternative sources for taped material and/or visual aid assistance as necessary.

Information Services: A 1984-85 RFB catalog, listing books available on tape as of May, 1984, can be requested for a charge. Each year a supplement to the catalog is printed. Also available is a Subject Reference System which provides subject access to RFB's entire library. A telephone voice response system for searching and ordering books is scheduled to be implemented in July, 1985. Taped books are available in numerous languages. RFB provides information and instructions for borrowers, as well as information on volunteering. A newsletter, RFB News, is published 2-3 times per year. There is no charge for any of RFB's services; borrowers are billed for postage only if they request tapes not to be sent via Fice Matter for the Blind. Taped books are available only to registered borrowers (certified as print-handicapped). Borrower applications will be sent upon request.

Telecommunications for the Deaf, Inc. (TDI) 814 Thayer Avenue Silver Spring, MD 20910 (301) 589-3786 (301) 589-3006

Mandicapping Conditions Served: Deafness, hearing impairments, deaf-blindness and speech impediments.

Users Served: Disabled persons, parents, teachers, people with normal hearing and speech, general public with telecommunications interests and concerns.

The Organization: Telecommunications for the Deaf, Inc. (TDI) serves members, people with deafness and hearing impairments and the general public with their needs of telecommunications: providing public information about telecommunications and deafness/hearing impairment; assuring equal access to telecommunications technologies and services; supporting legislation affecting Telecommunications Devices for the Deaf (TDD) users; installing TDD's in all public places; monitoring telecommunications issues and concerns across the country.



Information Services: TDI publishes the <u>International Telephone Directory of TDD Users</u>, annually, which includes the TDD numbers of Federal, state, local agencies, businesses and organizations that serve deaf and hearing-impaired persons and individuals. TDI also publishes <u>GA-SK Newsletter</u> quarterly for TDI members. Nominal dues entitle members to the Directory and <u>GA-SK Newsletter</u>.

# Voice Indexing for the Blind, Inc. (VIB) 9116 St. Andrews Place College Park, MD 20740 (301) 935-5772

Handicapping Conditions Served: All disabilities that make it difficult or impossible to use printed reference materials.

Users Served: Disabled persons, teachers, librarians and agencies serving the blind and visually handicapped.

The Organization: Voice Indexing for the Blind (VIB) is a nonprofit organization of volunteers devoted to increasing access by print-handicapped persons to published reference works and informal personal files, address lists, recipes, etc. through a technique called voice indexing. Voice indexing provides "headlines" to direct the blind reader to specific portions of recorded material. Using a 4-track cassette player, the tape is scanned at "fast forward" speed by index term, thus saving much time in locating items within a reference work or in less formal personal files. VIB is involved in developing procedures for voice indexing, instructing individuals and groups in the technique, publishing a list of voice-indexed materials that are generally available and preparing oice-indexed recordings of reference materials on contract for wide distribution.

Information Services: VIB produces a brochure which gives an introductory description of the nature and purpose of voice indexing. A series of procedures for informal sequential voice indexing is in preparation. Other publications available include Voice Indexing Manual, a detailed technical procedure for producing voice-indexed cassettes, and Voice-Indexed Cassettes: A List of Titles that are Generally Available (1985 edition in preparation). VIB will consult by letter, phone or in person on the suitability of materials for voice indexing and methods of doing the voice indexing. There is a nominal fee for consultation and/or preparation of voice-indexed tapes and for the manual. Most cassettes that VIB produces have braille labels. The bibliography is widely distributed on a voice-indexed cassette:

Whole Person Tours, Inc. P.O. Box 1084 Bayonne, NJ 07002-1084 (201) 858-3400

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons and their families and friends, teachers, health care professionals, senior citizens:

The Organization: Whole Person Tours, Inc. provides accessible tours by disabled persons for disabled persons. Individuals from throughout the USA and Canada have participated,



along with their friends and families. 1986 tours to Europe, Canada and Hawaii are planned. The 1987 schedule will include USA tours via accessible motorcoach.

Information Services: In addition to brochures about its tour offerings, Whole Person Tours publishes The Itinerary Magazine. Begun in 1981 as a newsletter to promote the tours of the organization, since 1982 it has evolved into a full-service magazine for travelers with disabilities. It is one of the few (if not the only) magazines dedicated to this specialized group worldwide. The magazine covers numerous topics including: consumer reports, travelogues, how-to features, travel-book reviews, resources, feature stories, hotel and transportation surveys, new products, accessible tour offerings by numerous companies, helpful hints and more. Subscriptions are available from The Itinerary Magazine at the above address.



#### ENTERNATIONAL INFORMATION

medical and technologic. developments and programs for handicapped persons on an international basis. In developing countries, attempts are made to integrate research and intervention projects into primary health care programs and to provide technical assistance. Some organizations perform comparative studies of programs between countries. Information is shared through publication of reports, newsletters and other periodicals and through participation in international seminars and conferences.



### INTERNATIONAL INFURMATION

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Helen Keller International, Inc. (HKI) 15 West 16th Street New York, NY 100 (212) 620-2100

Handicapping Conditions Served: Blindness and visual impairment.

Users Served: Officials, government agencies and private voluntary agencies concerned with blindness.

The Organization: Helen Keller International (HKI), founded in 1915 by Helen Keller and other Americans, assists governments in their efforts to prevent blindness; to educate children, with an emphasis on mainstreaming; and to rehabilitate blind aduits so that they can live independently. HKI concentrates its efforts in developing nations with the goal of strengthening the ability of each country to establish indigenous programs. HKI is also engaged in research and intervention projects to control xerophthalmia, an eye disease caused by malnutrition and lack of vitamin A. and trachoma and other infectious eye diseases. The agency also establishes surgical services that restore sight to the cataract-blind. HKI's blindness prevention projects are being integrated into primary health care programs wherever feasible.

Information Services: HKl shares its expertise with officials and private voluntary agencies from nations everywhere who need information on the prevention of blindness, services for the blind, and the education of visually handicapped children. The HKI Report, published periodically, contains articles on HKI activities and overseas projects. Brochures on the organization's programs are available free of charge.

Mobility International USA (MIUSA) P.O. Box 3551 Eugene, OR 97403 (503) 343-1284 (Voice and TDD)

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, parents, teachers, recreation therapists, travel agents.

The Organization: Mobility International USA (MIUSA), a nonprofit membership organization for disabled people and other interested persons, is affiliated with Mobility International, an organization founded in London to help integrate disabled persons into international educational exchange programs and travel. MIUSA works to expand opportunities for disabled people in these areas through advocacy, international conferences, international work camps, workshops and development and distribution of new publications, in addition to conducting international educational exchange programs.

Information Services: MIUSA members receive information and referral services in the areas of travel and placement in international work camps and educational exchange programs. A quarterly newsletter, Over the Rain jow, is available to members. MIUSA also publishes A World of Options: A Guide to International Educational Exchange, Community Service and Travel for Persons with Disabilities, 1985-86, and A Manual for Integrating Persons with Disabilities into International Educational Exchange Programs. A slide/tape presentation about MIUSA, "Challenge Yourself and Change the World," is available for rental or purchase. The newsletter and books can be obtained on cassette; there is limited



information available in Spanish. Specific information on program opportunities is limited to members only, but publications, the audio-visual and workshops are available to the public.

Partners of the Americas
PATH (Partners Appropriate Technology for
the Handicapped) Americas Program
1424 K Street, NW
Suite 700
Washington, DC 20005
(202) 628-3300

Handicapping Conditions Served: All handicaps.

Users Served: Disabled persons, parents, teachers, professionals.

The Organization: Partners of the Americas promotes economic and social development through 56 bilateral partnerships linking U.S. states with countries or areas of Latin America and the Caribbean. Volunteers on both sides vor together in community projects to improve agriculture, economic development, employment opportunities for low-income citizens, health and nutrition, services for disabled persons, and emergency preparedness.

The PATH Americas Program involves a network of people and programs addressing the needs of disabled persons, their families and communities. Partner volunteers disseminate information, provide training and implement projects aimed at improving the lives of disabled persons. Priority areas include: teacher training, materials development, early detection, resource center development, development of self-help and parent groups, public awareness campaigns and vocational development. All exchanges take place between one of 44 U.S. states and 27 countries in Latin America and the Caribbean where linkage has been established.

The PATH Americas Program provides for the exchange of teachers/therapists for shortrm training activities in the partnership area, opportunities for advanced leademic/technical training in the U.S. partner state for up to two years, and small grants (up to \$5000) available to partnerships for community projects benefiting and involving disabled persons. Also, 17 Resource Centers on disability have been established in Latin America and the Caribbean to provide practical information about preventing, treating and working with disabilities.

Information Services: Brochures are available for program areas including emergency preparedness, PATH, International Training Program and Fellow Program (leadership training). The PATH Resource Centers publish newsletters from time to time and Partners publishes a quarterly newsletter. Other publications available include concept papers, project descriptions, project report abstracts, and special education/rehabilitation resource packets. The PATH Americas Program has also compiled a bibliography of appropriate technology resources, listing people, programs, publications, ideas and technologies which are low cost/community based. Some publications are available in Spanish and Portuguese. Technical assistance is provided through the exchange of professionals between partnerships.



# People to People Committee for the Handicapped 1111 20th Street, NW Washington, DC 20036 (202) 523-9447

Handicapping Conditions Served: All handicaps.

Users Served: International rehabilitation organizations.

The Organization: The People to People Committee for the Handicapped exchanges information about technical developments and programs for the handicapped between organizations in the U.S. and similar groups in other countries. The Committee provides technical assistance to developing countries in setting up rehabilitation facilities for the handicapped, and works closely with the President's Committee on Employment of the Handicapped and with many other major Federal agencies and private sector international and national organizations.

Information Services: The Committee publishes the <u>Directory of Organizations Interested in the Handicapped</u> containing lists and abstracts of national organizations involved in services to the handicapped. A quarterly newsletter uports on current developments or organizations for the handicapped and on relevant Federal legislation.

Rehabilitation International (RI) 25 East 21st Street New York, NY: 10010 (212) 420-1500

Handicapping Conditions Served: All handicaps.

Users Served: Organizations in the disability field and government ministries.

The Organization: Founded in 1922, Rehabilitation International (RI) is the major world organization for disability prevention and rehabilitation with more than 125 member organizations in 80 countries and 10 international member organizations. RI assists member organizations in establishing and improving rehabilitation programs, cooperates with other international organizations in advancing the welfare of disabled people, and organizes international and regional conferences and seminars. RI has consultative status with the United Nations and its specialized agencies such as UNESCO, UNICEF, ILO, and WHO.

Information Services: RI edits the International Journal of Rehabilitation Research, which contains articles on research projects, methodological problems and solutions in rehabilitation research, and basic theoretical aspects of rehabilitation. RI's quarterly newspaper, International Rehabilitation Review, reports on international, regional and national developments. The Newsletter of the Secretary General of Rehabilitation International is published three or four times per year to provide organizational news to member groups and key associates. Also available is ONE-IN-TEN, a quarterly newsletter on childhood disabilities, their prevention and rehabilitation, produced by the Joint Technical Support Program of UNICEF, and RI. This RI/UNICEF Technical Support Program is an ongoing project to help UNICEF field offices and personnel in developing countries to integrate rehabilitation and disability prevention services within their primary health care programs. RI also makes available the Compendium on the Activities of World



On anizations Interested in the Handicapped, which contains descriptions of members of the Council of World Organizations Interested in the Handicapped, a coordinating group of nearly 50 international organizations. Recent RI publications include The Economics of Disability: International Perspectives, a discussion of the costs of disability in 30 countries; The Charter of the 80's, an outline of objectives in the field for the next decade; and the proceedings of its 15th World Congress, held in 1984. A publications list and organizational description are available free of charge. Many publications are available in languages other than English.

NOTE: See separate entry for Rehabilitation International USA, the U.S. representative of RI.

#### Rehabilitation International, USA (RIUSA) 1123 Broadway New York, NY 10010 (212) 620-4040

Handicapping Conditions Served: All handicaps.

Users Served: Organizations concerned with disabilities and rehabilitation, disabled persons, health care and rehabilitation professionals.

The Organization: Rehabilitation International, USA (RiSA) is a private voluntary organization that represents the United States in a worldwide network (Rehabilitation International, see separate entry) of 130 organizations in 80 nations and works for a more equitable life for 500,000,000 people with disabilities throughout the world. National agencies work with RIUSA through its Council of Organizations, whose members include rehabilitation organizations and facilities, professional associations, government agencies and others.

Information Services: RIUSA's quarterly publication, R illitation/WORLD, emphasizes international information. Each issue is theme-oriented d ludes relevant articles from world experts, in addition to feature columns about general news items, book reviews, science/technical news, product listings and an ational calendar of meeting Rehabfilm Newsletter is a quarterly magazine devoted to media and the disabled, covering film reviews, reports on major festivals and exhibitions, specialized listings of audio-visual materials and articles on all aspects of nonprint communication elated to disabilities. RIUSA also periodically publishes two newsletters, one to provide carerage of national and international developments in the field of disability prevention and reliabilitation and the other on up-to-date information about its Access to the Skies Program, which seeks to make air travel accessible to disabled and elderly travelers. Other publications include the International Directory of Access Guides (1981, Third Edition), which is a listing of 458 Access Guides available in over 20 nations that provide detailed information about accessible hotels, restaurants, transportation and places of interest, and the Rehabsilm Catalogue, which describes over 160 films and videotapes available for rental from RIUSA's film library.



World Rehabilitation Fund, Inc. (WRF-IEEIR)
International Exchange of Experts and Information
in Rehabilitation Project
400 East 34th Street
New York, NY 10016
(212) 679-2934

Handicapping Conditions: All disabilities.

Users Served: Rehabilitation specialists, physicians, other health care professionals.

The Organization: The World Rehabilitation Fund, Inc. (WRF) offers training programs and consultation services in prosthetics, orthotics, and other rehabilitation-related disciplines in developing countries, and provides fellowships for physicians from developing countries for advanced training in rehabilitation medicine. Through the International Exchange of Experts and Information in Rehabilitation Project, funded by the National Institute of fundicapped Research, fellowships are provided for U.S. experts to study abroad at sites they select whose programs and practices meet a priority need for the rehabilitation community in the United States. In addition, foreign authors are commissioned to write monographs are distributed in United States. Some authors are brought to this country to participate in meetings and seminars.

Information Services: WRF provides programmatic descriptions of the International Exchange of Experts and Information in Rehabilitation. Monographs developed by WRF foreign actions and fellowship reports are available. Requestors may obtain a list of titles; a fee is charged to cover postage, handling and duplication costs. Tapes of WRF monographs for visually impaired, learning disabled and physically disabled persons are available from Recordings for the Blind (see separate listing). The WRF newsletter, INTERCHANGE, is published three or four times per year, covering news on fellowships, monographs, seminars, conferences and other topics of interest in the rehabilitation field.



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### RELIGIOUS ORGANIZATIONS SERVING DISABLED PERSONS

Board for Parish Services
Ministry with Persons Who Are Disabled
1333 S. Kirkwood Road
St. Louis, MO 63122-7295
(314) 965-9000

An administrative unit of the Lutheran Church-Missouri Synod, this board equips congregations to minister with persons who are disubled and their families. Seminars are conducted for pastors, teachers, and other congregation leaders. Curricular resources are prepared for hristian education classes for persons with serious learning difficulties. The Board has a number of audio-visuals an ations available for rental/purchase in the area of remuse special education.

Christian Record Braille Foundation, Inc. (CRBF) 4444 South 52nd Street Lincoln, NE 68516 (402) 488-0981 (402) 488-1902 (TTY)

The Christian Record Braille Foundation (CRBF) provides services to visually and physically handicapped persons in the U.S. and Canada who cannot read normal print. Magazines in English braille are also available to other countries. Services include limited scholarship assistance when funds are not available from other sources, glaucoma screening clinics, camps for blind children, and Bible correspondence courses. Materials include talking magazines and tapes, cassettes, records and large print books on a variety of subjects. CRBF maintains an extensive lending library of books on cassettes and in braille and large print, and cooperates with regional and other libraries in serving the visually impaired. All services including publications are free to legally blind individuals, to state schools for the blind, and to teachers of blind studences.

Ephphatha Services
Ministry with Persons with Disabilities
American Lutheran Church
P.O. Box 15167
Minneapolis, MN 55415
(612) 330-3537 (Voice and TDD)

Ephphatha Services is the American Lutheran Church's national office which encourages, enables and facilitates the inclusion of persons with disabilities in the overall life of the church. Ephphatha Services provides special materials including braille and cassette tape services, awareness-raising materials, information and referral services, consultation, educational events, special grants for ministry with deaf persons and other special projects. American Lutheran Church materials and publications in braille and on audio-cassette tapes are available free of charge to blind, vision-impaired and physically disabled persons. Ephphatha publishes PARTNERS, a general information new letter, awareness-



raising materials and printed resources related to specific disabilities, bibliographies, and curriculum materials.

Episcopal Guild for the Blind 157 Montague Street Brooklyn, NY 11201 (718) 625-4886

The Guild provides blind or visually impaired individuals with the teachings and devotional literature of the Episcopal Church through braille, large-type books and cassettes. The Guild also acts as an information center in areas pertinent to blindness, such as public and private resources and facilities, and assists blind persons and their families and friends in making application to appropriate facilities. Services available to blind and physically handicapped persons include: the Braille Circulating Library offering Prayer Book services and other materials; the Cassette Program of Person to Person Recording; the Cassette Library of books, articles, sermons and music for borrowing; and Tape-Spondence providing personal counseling via cassette by the Guild's Director, who has been blind since birth.

The Gospel Association for the Blind, Inc. P.O. Box 62
Delray Beach, FL 33447
(305) 409-8900

The Gospel Association for the Blind furnishes religious material in braille and cassettes to blind individuals throughout the U.S. and 47 other countries. The Association conducts a summer camp for blind teenagers and adults, and provides temporary direct aid to newly blinded persons while helping them to locate more permanent sources of income, welfare, or rehabilitation. It also sponsors weekly religious radio broadcasts and has monthly followship meetings for blind individuals.

John Milton Society for the B" d 475 Riverside Drive Room 832 New York, NY 10115 (212) 870-3335

The John Milton Society for the Blind publishes Chistan literature in braille, on records (talking books), and in large type on behalf of most Protestant denominations. The literature is intended for children and adults and is sent free to anyone who cannot read ordinary printed material. The Society gives small grants to church-related schools and homes for blind children.



Lutheran Braille Evangelism Association (LBEA) 660 East Montana Avenue St. Paul, MN 55106 (612) 772-1681 (612) 776-8430

The Lutheran Braille Evangelism Association (LBEA) publishes and distributes Christian literature for blind and visually impaired persons. Bible materials, including the complete Bible, New Testament, and Psalms, are available in braille, cassettes, and large print. Devotional magazines are available in braille and large print. Sunday school lesson materials and evangelism materials in braille are also available. No blind person is denied materials because of inability to pay.

Lutheran Braille Workers, Inc. (LBW) P.O. Box 5000 32999 Yucaipa Boulevard Yucaipa, CA 92399 (714) 790-2901

The Lutheran Braille Workers (LBW) produce large print and braille religious (primarily Biblical) materials for free distribution to all who need them. Braille materials are produced in three grades of English braille and in 40 foreign language brailles. Targe-print materials are available in 15 languages.

Lutheran Library for the Blind 1333 South Kirkwood Road St. Louis, MO 63122-7295 (314) 965-9000

The Lutheran Library for the Blind has a large collection of religious materials for the blind and visually impaire. Its materials (in braide, talking-book form, tapes, and large print) are loaned throughout North America and some foreign countries. Catalogs are available from the Library, as is information about the services provided by other agencies for the blind. Braille catalogs listing books in traille are available on loan from the library. All Library services are free, with the exception of the Lutheran hymnal.

Ministries to the Deaf and Blind (MDB)
Division of Home Missions
General Council of Assemblies of God
1445 Boonville Avenue
Springfield, MO 65802
(417) 862-2781

Ministries to the Deaf and Blind (MDB) produces religious literature for blind and deaf persons and trains religious workers to carry out the ministry. Among MDB's materials are: pamphlets and Bible study manuals illustrated in sign language; books, pamphlets and hymnals in braille and on cassette. Fees are charged for some materials; others are free or available on loan.



National Catholic Educational Association (NCEA) Special Education Department 1077 30th Street, NW Washington, DC 20007 (202) 293-5954

The Special Education Department of the NCEA serves as a clearinghouse of information on developments in legislation and in mainstreaming of handicapped children into regular classrooms. NCEA publishes the Directory of Catholic Special Facilities and Programs in the United States for Handicapped Children and Adults, bibliographies of research, and a newsletter. Also available are Into the Christian Community: Religious Education with Disabled Persons and a videotape program, Mainstreaming: Responding to the Individual Needs of Children Within the Regular Classroom. Users of the clearing! ouse are Catholic schools and dioceses which provides: ial education services.

National Catholic Office of the Deaf 814 Thayer Avenue Silver Spring, MD 20910 (301) 587-7992

The National Catholic Office of the Deaf provides teaching materials for religious education and organizes training programs for hearing-impaired individuals, teachers, and parents. It organizes workshops which provide orientation and training in work with hearing impaired-persons. Information relating to the religious education of the hearing impaired is available from the Office. A pastoral journal entitled <u>Listening</u> is available by subscription. A summary of every journal issue is available in Spanish. There is a charge for most products.

ional Congress of Jewish Deaf (NCJD) 9192 Edmonston Cours Greenbelt, MD-29770 (301) 345-8612 (TTY Only)

The National Congress of Jewish Deaf (NCJD) is a parent organization, advocating religious and cultural ideals and fellowship. NCJD conducts conventions, orientation seminars and workshops, assists in religious classes, supports a youth camp program, and is involved in religious publication. The Congress maintains an endowment fund which provides grants to tutor rabbis in sign language. A book of instruction on the proper signs of Jewish ritual words is in preparation.

The Congress is affiliated with the World Organization of Jewish Deaf (home base in Tel-Aviv).



### SPORTS ORGANIZATIONS BY AND FOR DISABLED PERSONS

American Athletic Association for the Deaf-10604 E. 95th Street Terrace Kansas City MO 64134

American Blind Bowling Association, Inc. 3500 Terry Drive Norfolk, VA 23518 (804) 857-7267

American Blind Skiing Foundation 610 S. William Street Mt. Prospect, IL 60056 (312) 253-4292

American Wheelchair Bowling
Association
N54 W 15858 Larkspur Lane
Menomonee Falls, WI 53051
(414) 781-6876

Blind Outdoor Leisure Development (BOLD) 533 E. Main Street Aspen, CO 81611 (303) 925-8922

Blind Sports 1939-16th Avenue San Francisco, CA 94116 (415) 681-1939

Handicapped Boaters Association P.O. Box 1134, Ansonia Station New York, NY 10023 (212) 877-0310

Indoor Sports Club 1145 Highland Street Napoleon, OH 43545 (419) 592-5756

International Committee of Sports

for the Deaf

Gallaudet College

800 Florida Avenue, NE

Washington, D. 20002

(202) 651-5430 (Voice or TDD)

National Amputee Golf Association 5711 Yearling Court Bon. a, CA 92002 (619) 479-4578

National Archery Association 1750 E. Boulder Street Colorado Springs, CO 80909 (303) 578-4576

National Association of Sports for Cerebral Palsied c/o Craig Huber 56 East 34th Street www.York, NY 10016 (212) 481-6359

National Deaf Bowling Association 9244 E. Mansfield Avenue Denver, CO 80237 (303) 771-9018

National Foundation for Happy
Horsemanship for the
Handicapped, Inc.
P.O. Box 462
Malvern, PA 19355
(215) 644-7414

National Foundation of Wheelchair Tennis 3857 Birch Street Newport, CA 92660 (714) 851-1707

National Handicapped Sports and Recreation Association Farragut Station P.O. Box 33141 Wasnington, DC 20033 (202) 429-0595

National Wheelchair Athletic Association 2107 Templeton Gap Poad Suite C Colorado Springs, CO 80907 (303) 632-0698



National Wheelchair Basketball
Association
110 Seaton Center
University of Kentucky
Lexington, KY 40506
(606) 257-1623

National Wheelchair Softball

Association
P.O. Box 737
Sioux Falls, SD 57101
(605) 334-0000

North American Riding for the Handicapped Association, Inc. P.O. Box 100 Ashburn, VA 22011 (703) 471-1621

3ki for Light, Inc. 1455 West Lake Street Minneapolis, MN 55408 (612) 827-3232

Special Olympics 1350 New York Avenue, NW Suite 500 Washington, DC 20005-4709 (202) 628-3630

U.S. Association for Blind Athletes 55 West California Avenue Beach Haven Park, NJ 08608 (609) 492-1017

United States Deaf Skiers Association 159 Davis Avenue Hackensack, N 07601 (201) 489-3777 United States Wheelchair Sports Fund 1550 Franklin Avenue Suite 29 Mineola, NY 11501 (516) 294-7610

Vinland National Center P.O. Box 308 3675 Induhapi Road Loretto, MN 55357 (612) 479-3555 (See Directory Entry)

Voyageur Outward Bound School P.O. Box 250 Long Lake, MN 55356 (612) 473-5476 (800) 328-2943 (Outside MN)

Wheelchair Motorcycle Association, Inc 101 Torrey Street Brockton, MA 02401 (617) 583-8614

Wheelchair Tennis Play: ssociation 3857 Birch Street
Newport Beach, CA 92600
(714) 669-1453



### LIST OF PERTINENT DATA BASES

The following table lists many of the data bases available for computer-based research which are relevant to disabled persons and professionals who work with them. In most cases, the data bases are produced by an organization or agency found in the <u>Directory</u>; the abstract of the organization contains additional details about its data base, including access information. Some of the first bases listed are reduced by organizations not included in the <u>Directory</u>, but they are generally available to bugh the commercial data base vendors. Information Technologies, <u>DIALOG</u> In mation Services, Inc., and/or System Development Corporation (SDC) (See Directory able to assist with computer-based research.



Data Base	Producer, Access	Description					
Education							
ECER (Exceptional Child Education Resources)	Council for Exceptional Children/BRS, DIATOG	Education materials for handicapped and gifted children					
ने हों <u>चें</u> द्र के	JWK International 7617 Little River Turnpike Annandale, VA 22003	Technical assistance to state and local educational agencies educators and others interested in special education					
ERIC (Educational Resources Information Center)	National Institute of Education/BRS, DIALOG. SDC	Educational documents					
Clearinghouse on Adult, Career, and Vocational Education	National Center for Research in Vocational Education	Adult and continuing education, career, wocational and technical education and work					
Clearinghouse for Counseling and Personnel Services (CAPS)	University of Michigan School of Education	Professional resources					
Clearinghouse on Elementary and Early Childhood Education	University of Illinois College of Education	Child development and resources through age 12, day care, early childho and elementary education					
• Clearinghouse on Handicapped and Gifted Children	Cauncil for Exceptional Children	r ducation of handi- capped and gifted children and youth					
Clearinghouse on Reading and Communication Skills	National Council of Teachers of English	Educational informa- tion in language arts					
• Clearinghouse on Tests, Measurement and Evaluation	Educational Testing Service	Tests, measurement and evaluation					



Data Base	Producer/Access	Description						
Education (Continued)								
RIVE (Resources in Vocationa! Education)	National Center for Research in Vocational Education/BRS	Curriculum development projects and research in vocational education						
SPIF (School Practices Information File)	Educational Services Group at PRS/BRS	Currently used educational practices, software, teacher-developed materials and inservice training materials						
SpecialNet	National Association of State Directors of Special Education	Communication and in- formation network for special education per onnel						
VECM (Vocational Education Curriculum Materials)	National Center for Research in Vocational Education/BRS	Vocational and technical education curriculum materials						
Law and Government								
Federal Register Abstracts	Capital Service Interna- tional, Washington, DC/ DIALOG	Coverage of Federal regulatory agency actions as published in the Federal Register						
Legal Resource Index <sup>TM</sup>	Information Access Company/DIALCO	Indexing of law journals, newspapers, legal monographs and other sources						
NCJRS (National Criminal Justice Reference Service)	National Institute of Justice/DIALOG	Centralized clearing- house on law enforce- ment, juvenile justice and court administration						
Life Sciences								
AGRICOLA (Agricultural Online Access)	National Agricultural Library/BRS, DIALOG	Agriculture-related fields						



Data Base	Producer/Access	Description					
Medicine and Biosciences							
Cancer Information Clearinghouse	Office of Cancer Communications, National Concer Institute	Cancer education ma- terials for patients public and profes- sionals					
CHID:	Combined Health Information Data Base/BRS	Resources for health professionals, patients and general public					
• Arthritis subfile	Arthritis Information Clearinghouse	Arthritis and related musculoskeletal diseases					
• Diabetes subfile	National Diabetes Infor- mation Clearinghouse	Diabetes					
• Digestive Diseases subfile	Digestive Diseases Clearinghouse (Sponsored by National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases)	Digestive diseases					
High Blood Pressure	National Heart, Lung and Blood Institute	High blood pressure					
• Health Education subfix	Center for Health Promotion and Education (Centers for Disease Control)	Health education lit- erature and program methodology					
CRISP (Computer Retrieval of Informatics, on Scientific Projects	Statistics and Analysis Branch, Division of Research Grants, National Institutes of Health	Research projects sponsored by Public Health Services or with National Insti- tutes of Health and National Institute of Mental Health					
EMBASF	Elsevier Scientific Publishing Group, Amsterdam, The Netherlands, /BRS.DIALOG	Comprehensive indexing and abstracting of medical literature					



Data Base	Producer/Access	Description
Medicine and Biosciences (C	ontinued)	
MEDLINE/MEDLARS (Medical Literature Analysis and Retrieval System)	National Library of Medicine/BRS, DIALOG	Citations on over 40 biomedical areas
Cumulatie Index to Nursing and Allied Health Literature (NAHL)	CINAHL Corp., Glendale, CA,/BRS, DIALOG	Index to current peri- odical literature re- lating to nursing and allied health topics
Technical Information Center Data Base	Office of Smoking and Health, U.S. Public Health Service	All aspects of smoking and health
Reference/Multidisciplinary		
Books in Print	R.R. Bowker, New York, NY/BRS, DIALOG	Books currently published and in-print in U.S.
Dissertation Abstracts Online	University Microfilms International/BRS, DIALOG	Access to over 750,000 published dissertations accepted at North American colleges and universities
GPO Monthly Catalog	Superintendent of Docu- ments, U.S. Government Printing Office/ BRS, DIALOG	Wide variety of public documents produced under U.S. government sponsorship
GPO Publications Reference File	Superintendent of Documents, U.S. Government Printing Office/DIALOG	Indexes public docu- ments currently for sale by Superintendent of Documents
LC MARC	U.S. Library of Congress/ DIALOG	Bibliographic records for all books cataloged by U.S. Library of Congress since 1968



Data Base	Producer/Access	Description
Science and Technology		
COMPENDEX	Engineering Index Inc./ 345 E. 47th Street New York, NY 10017 BRS, DIALOG	Rehabilitation-related information, patent- searching and standards for engineers
Federal Research in Progress	National Technical Information Service/ DIALOG	Ongoing research projects in the social, life, and physical sciences
HRIS (Highway Research Information Service) Access Through TRIS (Transporta- tion Research Information Service)	Transportation Research Board, National Academy of Sciences/DIALOG	Bibliographic information on transportation-related issues
NTIS	National Technical Information Service/BRS, DIALOG, SDC	Reports on government- sponsored research, developments and engineering projects
Social Sciences/Humanities		
ABLEDATA	National Rehabilitation Information Center (NARIC)/BRS	Lists over 12,000 commercially available aids and devices for people with disa- bilities
Accent on Information	Accent on Information	Over 5,000 entries of assistive aids and devices, organizations, information on adapting and making equipment
ADDS (Assistive Device Data Base System)	American International Data Search, Inc. 2326 Fair Oaks Boulevard Suite C. Sacramento, CA 95825	Information on com- mercial and custom- made adaptive equip- ment, programs and resources
AGELINE	National Gerontology Research Center, American Association of Retired Persons 1909 K Street, NW Washington, DC 20049	All aspects of social Gerontology



Data Base	Producer/Access	Description
Social Sciences/Humanities		
Family Resources Data Base	National Council on Family Relations/BRS, DIALOG	Information concerned with functioning of the family
Handicapped Users' Data Base	CompuServe Information Services (800) 848-8199 P.O. Box 20212 Columbus, OH 43202	Compendium of information for and about handicapped people
HUD User	Aspen Systems for Department of Housing and Urban Development	Research, testing and demonstration projects related to housing and community development
JAN (Job Accomoda- tion Network)	President's Committee on Employment of the Handi- capped/(800) JAN-PCEH	Listing of accommoda- tions employers have made for employees with handicaps
Language and Language Cohavior Abstracts	Sociological Abstracts, Inc./BRS, DIALOG	Linguistics and re- lated disciplines, including learning disabilities
Project SHARE	Berul Associates, Ltd. for the National Clearinghouse for Improving the Manage- ment of Human Services	Human services plan- ning, administration and evaluation for human services managers
PsychiNFO	American Psychological Association/BRS, DIALOG, SDC	Abstracts of litera- ture in psychology and related behavioral and social sciences
REHABDATA	National Rehabilitation Information Center (NARIC)/BRS	Information about rehabilitation and related subject areas



Data Base	Producer/Access	Description
Social Sciences/Humanities		
SCAN (Shared Communi- cation and Assistance Network)	American Association of University Affiliated Programs for Persons with Developmental Disabilities	Electronic information and referral system on resources and services for disabled persons
Social SCISEARCH	Institute for Scientific Information/BRS, DIALOG	Social sciences literature
Sociological Abstracts	Sociological Abstracts, Inc./BRS, DIALOG	Sociology and related disciplines



# NATIONAL DIRECTORIES OF SERVICES AND RESOURCES FOR DISABLED PERSONS

#### Access Guides

The International Directory of Access Guides: 1981-82, 64 pages, single copies free. Rehabilitation International, U.S.A., 1123 Broadway, New York, NY 10010. Tel.: (212) 620-4040.

A listing of 458 access guides available in over 20 nations that provide detailed information about accessible hotels, restaurants, transportation, and places of interest.

## Amputation

Amputee Medical Service Directory, 1985, 400 pages, \$25. American Amputer Foundation, Inc., 210 Linwood, Little Rock, AR 72205. Tel.: (501) 666-2523.

Information on services for amputees throughout the United States.

## Amyotrophic Lateral Sclerosis

Why Didn't Somebody Tell Me About These Thing: 1984, 139 pages, \$7.50. Kansas City Patient Services Fund, 5350 West 94th Terrace, Suite 207, Prairie Village, KS 66207.

A collection of information and illustrations of equipment, aids, clothing, skills and other things of interest to the ALS patient and patients with similar diseases and handicapping conditions.

#### Autism

Directory of Programs Serving Children and Adults with Autism, 1985, 19 pages, \$3 includes postage and handling. National Society for Children and Adults with Autism, 1234 Massachusetts Avenue, NW, Suite 1017, Washington, DC 20005. Tel.: (202) 783-0125.

State listings with brief descriptions.

## Blind/Visually Impaired

Coping with Sight Loss: The Vision Resource Book, 1984, 219 pages, \$11 in large print or \$12 for four voice-indexed cassettes. Vision Foundation, Inc., 818 Mt. Auburn Street, Watertown, MA 02172. Tel.: (617) 926-4232. Orders must be prepaid.

Lists benefits, resources, names and addresses for blind and visually impaired persons.

Directory of Agencies Serving the Visually Handicupped in the United States, 1984 (22nd edition), 547 pages, \$20. American Foundation for the Blind, 15 West 16th Street, New York, NY 10011. Tel.: (212) 620-2000.



Biannual resource directory listing agencies and other organizations which provide services for blind and visually impaired persons.

Volunteers Who Produce Books: Braille, Tape, Large Type, 1984, 73 pages, free. Consumer Relations Section, National Library Service for the Blind and Physically Handicapped, Library of Congress, Washington, DC 20542. Tel.: (202) 287-5100.

Lists (by state) special education agencies, resources for visually impaired persons, certified proofreaders and producers of braille, recorded and large print books.

## Children/Youth

Directory for Exceptional Children, 1984-85, \$40 plus \$2 4th class postage. Porter-Sargent Publishers, Inc., 11 Beacon Street, Boston, MA 02108. Tel.: (617) 523-1670.

Over 3,000 schools, treatment centers, speech and hearing societies, state and private residential facilities, and other services for disabled children are described and listed for each state.

National Directory of Children and Youth Services: 1986-87, 570 pages, \$49 plus \$3 shipping and handling. Bookmakers Guild, 1430 Florida Avenue, Suite 202, Longmont, CO 80501. Tel.: (303) 772-7322.

This book contains more than 20,000 listings (by state and county) of public and private agencies serving children and youth including those who are handicapped. Descriptive information is included.

National Directory of Federally Funded Parent Information and Training Centers, 1985, 36 pages, free while supplies last. National Information Center for Handicapped Children and Youth, Box 1492, Washington, DC 20013.

Listing of federally funded parent information and training centers across the country.

National Directory of Personnel Preparation Programs, 1983, 50 pages, tree while supplies last. National Information Center for Handicapped Children and Youth, Box 1492, Washington, DC 20013.

State listings of personnel preparation programs.

#### Deaí

American Annals of the Deaf: Reference Issue: 1985, 196 pages, \$16.50. American Annals of the Deaf, 814 Thayer Avenue, Silver Spring, MD 20910. Tel.: (301) 585-4363.

This Reference Issue, published annually in April, supplies information on programs and services for deaf persons in the United States including educational, rehabilitational, social, and recreational resources. Most information is listed by state.

International Directory of Services for the Deaf: 1980, 231 pages, \$6.25. Bookstore, Gallaudet College, 800 Florida Avenue, NE, Washington, DC 20002. Tel.: (202) 651-5176.

Lists schools, organizations, athletic associations, federations, social agencies, and rehabilitation agencies for deaf persons in foreign countries.



International Telephone Directory of TDD Users: 1986, approximately 120 pages, \$10 fee includes directory, a listing in the directory and a newsletter subscription. Telecommunications for the Deaf, Inc., 814 Thayer Avenue, Silver Spring, MD 20910. Tel.: (301) 589-3006.

Lists TDD numbers for agencies and organizations, and those of individual members of TDI.

## Deaf/Blind

Directory of Agencies Serving the Deaf-Blina, 1980, 77 pages, \$5. Ms. Anna Beck, Librarian, Helen Keller National Center, 111 Middle Neck Road, Sands Point, NY 11050. Tel.: (516) 944-8900.

Agencies are listed by state with descriptions of services.

## Dentistry

Academy of Dentistry for the Handicapped Membership Referral Roster. New edition will be available in 1986. Academy of Dentistry for the Handicapped, 211 E. Chicago Avenue, 21st Floor, Chicago, IL 60611. Tel.: (312) 440-2660.

State listings of dentists and hygienists interested in improving the quality of dental care for handicapped persons.

## Developmental Disabilities

Resource Guide to Organizations Concerned with Developmental Handicaps: 1984-85 (annually), 186 pages, no charge. American Association of University Affiliated Programs for Persons with Developmental Disabilities, 8605 Cameron Street, Suite 406, Silver Spring, MD 20910. Tel.: (301) 588-8252.

Listing of university affiliated programs (including names of personnel and project titles), satellite centers, mental retardation research centers, selected government agencies and programs, and other resources.

#### Down Syndrome

Directory of Programs and Services for Children with Down Syndrome, Ages 0-6, 1985, approximately 100 pages, free to individuals. National Down Syndrome Society, 70 West 40th Street, New York, NY 10018. Tel.: (212) 764-3070 and (800) 221-4602.

Listing of programs, services and age group served.

Parent Group Network, April, 1985, 50 pages, \$3. National Down Syndrome Congress, 1640 W. Roosevelt Road, Chicago, IL 60608. Tel.: (312) 226-0416 (IL), (800) 446-3835 (outside IL).

Listing of names, addresses and telephone numbers of parent groups/contacts throughout the U.S. and in other countries who are willing to serve as resources within their geographical area.



## Drug Abuse/Alcoholism

National Directory of Alcohol and Drug Abuse Treatment and Prevention Programs, 1985, approximately 400 pages, single copy free. National Clearinghouse for Drug Abuse Information, P.O. Box 416, Kensington, MD 20795. Tel.: (301) 443-6500.

Nationwide listing of the location of programs. (Does not include descriptions of services provided by the programs.)

#### Genetic Diso ders

Clinical Genetics Service Centers: A National List, 1985, approximately 120 pages, no charge. National Center for Education in Maternal and Child Health, 38 and R Streets, NW, Washington, DC 20057. Tel.: (202) 625-8400.

Centers are listed by state. Includes sickle cell and hemophilia treatment programs.

## Handicapped Scientists

Resource Directory of Handicapped Scientists, 1985. Project on the Handicapped in Science, American Association for the Advancement of Science, 1333 H Street, NW, Washington, DC 20005. Tel.: (202) 326-6400 (Voice/TDD).

A reference listing of over 500 disabled scientists, many of whom are available to consult in areas such as laboratory and curriculum adaptations for handicapped students, architectural and program accessibility, and on their particular scientific disciplines.

## Head Injuries

Resource Directory for Head Injury Rehabilitation Services, 1985, 223 pages plus additional pages on Canadian resources, \$63.50 until March, 1986, \$30 for quarterly supplement until March, 1986. National Head Injury Foundation, P.O. Box 567, Framingham, MA 01701. Tel.: (617) 879-7473.

Listing of treatment facilities, programs, state agencies and research programs that deal with traumatic head injuries.

#### Homemakers

Directory of Homemaker, Home Health Aide Services, \$4 for each state, \$3 for New York City list. National HomeCaring Council, 67 Irving Place, New York, NY 10003. Tel.: (212) 674-4990.

Separate state listings of service units providing home care.

Directory of Homemaker, Home Health Aide Services: Approved and Accredited Agencies, 9 pages, \$2. National HomeCaring Council, 67 Irving Place, New York, NY 10003. Tel.: (212) 674-4990.



Nationwide listings of agencies that provide homemaker and/or home health aide services which are approved by the National HomeCaring Council.

## Independent Living

Annotated Registry of Independent Living Programs in the U.S., 1985, 187 pages, \$12.50. Independent Living Research Utilization Project, P.O. Box 20095, Houston, TX 77225. Tel.: (713) 797-1440 Ext. 504.

Provides annotated profiles of independent living programs in the U.S. and other countries.

Technology for Independent Living, 1984, 265 pages, \$25 (members deduct 20% discount). RESNA (Rehabilitation Engineering Society of North America), Suite 700, 1101 Connecticut Avenue, NW, Washington, DC 20036. Tel.: (202) 857-1199.

Covers information services and resources and equipment selection; educational and vocational technology; the workplace; recreation and leisure; personal mobility; control, communication and sensory aids; and computer applications to funding, models, policy and statistics.

#### International

A World of Options: A Guide to International Education Exchange and Travel for Persons with Disabilities, 1985, 196 pages, \$11 for members, \$13 for nonmembers (includes postage and handling). Mobility International USA, P.O. Box 3551, Eugene, OR 97403. Tel.: (503) 343-1284.

Describes over 70 international educational exchange programs which serve people of different age groups and interests in addition to information on travel options and resources available to disabled persons.

## Learning Disabilities

Directory of Educational Facilities for Learning Disabled Students. 1985-86, 145 pages, \$1 (plus 10% postage/handling or \$1 minimum). Association for Children and Adults with Learning Disabilities, 4156 Library Road, Pittsburgh, PA 15234. Tel.: (412) 341-1515.

Programs are listed by state with descriptive information.

The FCLD Guide for Parents of Children with Learning Disabilities. 2nd Edition, \$5 for postage and handling. Send check or money order to the Foundation for Children with Learning Disabilities, P.O. Box 2929, Grand Central Station, New York. NY 10163. Tel.: (212) 687-7211.

State by state listing of organizations, preschool programs, special education programs, school-related summer programs, diagnostic or counseling services, and special recreational activities for LD children.



List of Colleges/Universities that Accept Students with Learning Disabilities, 1985, 43 pages, \$3 (plus 10% postage/handling or \$1 minimum). Association for Children and Adults with Learning Disabilities, 4156 Library Road, Pittsburgh, PA 15234. Tel.: (412) 341-1515.

Higher education institutions are listed with descriptive information.

National Directory of Four-Year Colleges, Two-Year Colleges, and Post High School Training Programs for Young People with Learning Disabilities: 1984, 97 pages, \$15.95 plus \$1 postage. Partners in Publishing Company, P.O. Box 50347, Tulsa, OK 74150. Tel.: (918) 584-5906.

Facilities are listed by state, with brief descriptions of curricular modifications. A contact person is also listed for each facility, where possible.

Summer Camp Directory for Children with Learning Disabilities, 1986, 54 pages, \$2.50 (plus 10% postage/handling or \$1 minimum). Association for Children and Adults with Learning Disabilities, 4156 Library Road, Pittsburgh, PA 15234. Tel.: (412) 341-1515.

Programs are listed by state with descriptive information.

## Legal Resources

Legal Resources for the Mentally Disabled: A Directory of Lawyers and Other Specialists, 1983, 30 pages, \$5. American Bar Association, 1800 M Street, NW, Washington, DC 20036. Tel.: (202) 331-2200.

State by state listing of public and private attorneys serving mentally and developmentally disabled persons.

#### Maternal and Child Health

National List of Voluntary Organizations in Maternal and Child Health, 1985, 60 pages, no charge. National Center for Education in Maternal and Child Health, 38 and R Streets, NW, Washington, DC 20057. Tel.: (202) 625-8400.

Organizations are listed by state with descriptive information.

Starting Early: A Guide to Federal Resources in Maternal and Child Health, 1984, 86 pages, no charge. National Center for Education in Maternal and Child Health, 38 and R Streets, NW, Washington, DC 20057. Tel.: (202) 625-8400.

Federal resources are listed by state with descriptive information.

#### Mental Retardation

Directory of Members: National Association of Private Residential Facilities for the Mentally Retarded: 1984, \$15. National Association of Private Residential Facilities for the Mentally Retarded, 6269 Leesburg Pike, Suite B5, Falls Church, VA 22044. Tel.: (703) 536-3311.

State listings with descriptive information on members' services.



## Organizations of and for Handicapped Persons

Directory of Organizations Interested in the Handicapped: 1986, approximately 100 pages, no charge. People to People Committee for the Handicapped, 1111 20th Street, NW, Suite 660, Washington, DC 20036. Tel.: (202) 523-9447.

Lists and describes over 200 national organizations that serve disabled persons, state vocational rehabilitation agencies, developmental disabilities programs, and employment security offices.

Postsecondary Education and Handicapped Individuals 1985-86 HEATH Resource Directory, 24 pages, single copies are free, bulk orders are free but must include distribution information. HEATH Resource Center, The National Clearinghouse on Postsecondary Education for Handicapped Individuals, One Dupont Circle, Suite 670, Washington, DC 20036-1193. Tel.: (202) 939-9320 or (800) 54-HEATH (both Voice/TDD).

Annotated listing of over 100 national organizations which can provide additional information about postsecondary education and handicapped individuals.

#### Rehabilitation Facilities

National Association of Rehabilitation Facilities Membership Directory: 1985, \$30 for members, \$40 for nonmembers. National Association of Rehabilitation Facilities, P.O. Box 17675, Washington, DC 20041. Tel.: (202) 556-8848.

Over 2500 member facilities and potential members are listed by state, city and facility name with descriptions of programs and services.

National Resource Handbook: A Guide to Vocational Rehabilitation Services in the United States: 1981, 75 pages, \$22.50. Vocational Rehabilitation Center, 1323 Forbes Avenue, Pittsburgh, PA 15219. Tel.: (412) 471-2600.

Lists accredited rehabilitation facilities by state and region.

1982-83 Host Directory: U.S. Rehabilitation Facilities which Welcome Foreign and American Professional Visitors: 1982, single copies free. Rehabilitation International, USA, 1123 Broadway, New York, NY 10010. Tel.: (212) 620-4040.

Facilities are listed by state, with descriptions of programs and services.

Resources for Physically Handicapped Persons Buyer's Guide, 1984-85 (1986-87 published Dec. 1985), 135 pages, \$10 plus \$.70 shipping. Accent on Information, Accent Special Publications, P.O. Box 700, Bloomington, IL 61702. Tel.: (309) 378-2961. Prepayment or purchase order number required.

Listing of products, publications, organizations and addresses of interest to physically handicapped people.

#### Sickle Cell Disease

HELP!, 1983, 158 pages, free. National Association for Sickle Cell Disease, Inc., 3460 Wilshire Boulevard, Suite 1012, Los Angeles, CA 90010. Tel.: (213) 731-1166 and (800) 421-8453.



A guide to sickle cell disease programs and services in the U.S., Bahamas, Puerto Rico, the Virgin Islands, Canada, Jamaica and England.

## Special Education, See also Children/Youth

Special Ware Directory. 1983, approximately 100 pages, \$16.95. Oryx Press, 2214 N. Central at Encanto, Phoenix, AZ 85004.

Software for special education.

## Speech/Language/Audiology

The Guide to Professional Services in Speech-Language Pathology and Audiology: 1985, 240 pages, \$20 to members, \$28 to non-members. American Speech-Language-Hearing Association (ASHA), 10801 Rockville Pike, Rockville, MD 20852. Tel.: (301) 897-5700.

Contains profiles of clinical services programs accredited by the Boards of Examiners in Speech Pathology and Audiology, and lists ASHA Certified private practitioners, state resource personnel, and industrial hearing conservation specialists.

## Spinal Cord Injuries

National Resources Directory. August, 1985, 150 pages, free to persons with spinal cord injuries (ask for price to others). National Spinal Cord i jury Association, 149 California Street, Newton, MA 02158. Tel.: (617) 964-0521.

Topics covered include medical equipment, independent living, psychology, sexuality, education, employment, transportation, legal rights, sports and recreation.



## NATIONAL DIRECTORIES THAT INCLUDE RESOURCES OF IMPORTANCE TO HANDICAPPED PERSONS

Directory of Agencies: U.S. Voluntary, International Voluntary, Intergovernmental: 1980, 104 pages, \$6. National Association of Social Workers, 7981 Eastern Avenue, Silver Spring, MD 20910. Tel.: (301) 565-0333. Note: This publication is going out of print.

Provides information on the membership, purpose, and programs of over 300 agencies offering various services including services to persons with disabilities.

Encyclopedia of Associations: National Organizations of the U.S.: 1985, 2215 pages in 3 volumes, \$210. Gale Research Company, Book Tower, Detroit, MI 48226. Tel.: (313) 961-2242.

This publication serves as a comprehensive guide to national organizations and associations including: trade, business, legal, governmental, educational, technical, health and medical, and others. Pertinent descriptive information is provided.

The Foundation Directory: 1985, approximately 800 pages, \$65. The Foundation Center, 79 Fifth Avenue, New York, NY 10003. Tel.: (212) 620-4230.

This directory lists and describes over 4400 foundations throughout the United States, and includes information on grant application procedures. Many of these foundations have supported programs for disabled persons.

National Directory of State Agencies, 1984-85, \$85. National Standards Association, 5161 River Road, Bethesda, MD 20816. Tel.: (301) 951-1389.

Contains listings of state governmental agencies, including lists of state government information telephone numbers, and addresses of associations of state government officials.



## HOW TO USE THE INDEX

The index is a guide to organizations and agencies relevant to your area of interest. It cannot substitute for careful review of the description in the Directory to determine if it meets your information needs.

Organizations which cover a disorder or group of disorders have been indexed to the term used for the disorder and, where applicable, to a broader category such as genetic diseases, neurological disorders, etc. The description will tell you if the organization has information relating to education, employment, recreation or other topics of interest to individuals with this disorder or whether it is simply a source of information on the disorder and how to cope with it.

Operations which are sources of information on all or many aspects of a field such as medicine or behavioral sciences have been indexed only to these broad terms. Additional information, particularly of a technical nature, can be obtained on specific disorders and diseases under these inclusive categories.

Organizations are listed under those index terms which indicate a primary focus of the group. For example, organizations which emphasize advocacy activities, civil rights, legislation, parent groups and similar activities are listed under those index terms. Many other organizations also participate in the same activities as part of their general operations. Likewise, organizations which deal with a specific population, such as children or severely disabled persons, are listed under that term.

Groups and agencies whose information covers broad subject areas such as education or employment with respect to all handicapping conditions are indexed under the subject area and not under specific disorder terms. If you want all information related to epilepsy, for example, you would have to consider organizations indexed under epilepsy and under all subject areas such as education, employment, etc.

All Federal agencies are marked with an asterisk for easy identification.



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All Federal agencies are asterisked for easy identification.

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Page 50: Juvenile Diabetes Foundation International (212) 889-7575

Page 52: Lupus Foundation of America, Inc.
National Headquarters
1717 Massachusetts Ave., N.W., #203
Washington, DC 20036
(202) 328-4550

Page 100: Arthritis Information Clearinghouse changed name to:

National Arthritis & Musculoskeletal and Skin Diseases Information Clearinghouse

Page 104: Center for Residential and Community Services (612) 624-6328

Page 137: National Health Information Clearinghouse and National Information Center for Orphan Drugs and Rare Diseases
(202) 429-9091

Page 141: National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases changed name to:

National Institute of Arthric's and Musculosketal and Skin Diseases

Page 228: National HomeCar ng Comcil 10 Columbus Circle New York, NY 1001 (212, 582-1022

Page 261: Association of Radio Reading Services
1133 20th St., NW
Washington, DC 20036
(202) 659-KNOW

