

Resource utilization for the neurologically impaired patient

A compendium of available sources¹

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Of the estimated 32 million physically handicapped people in the United States, 500,000 are restricted to a wheelchair. It is the obligation of the medical profession to seek ways of adapting the home environment and the community in order to help these people regain functional capability. Toward this end, each physician should compile a referral list of appropriate services and information agencies. The author describes the basic books, governmental agencies, private enterprises, and charitable organizations which might serve as the backbone of such a resource file.

Index terms: Handicapped • Home care services • Self-help devices • Self-help groups

Cleve Clin Q 52:339-344, Fall 1985

It is estimated that there are 32 million physically handicapped people in this country, of whom some 500,000 are limited to a wheelchair.¹ Because of recent medical advances, patients with neurological impairments make up a sizable portion of this total. Unfortunately, it is difficult at times to provide for the needs of these people; frequently, their physical condition will not respond to drugs or surgery so that they are left with a chronic impairment that prevents them from carrying out even the most basic functions of daily living. These persons then come to the medical profession to learn how to adapt their homes and community environment in order to regain some functional capability, and at the same time, the feeling of self-worth which accompanies independence. A resource file containing information which provides such advice is an

¹ Department of Rheumatic and Immunologic Disease, Section of Physical Medicine and Rehabilitation, The Cleveland Clinic Foundation. Submitted Nov 1984; accepted May 1985.

0009-8787/85/03/0339/06/\$2.50/0

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Table. Home care resources

<u>Ohio State Agencies</u>	
Governor's Council on Disabled Persons	4656 Heaton Rd. Columbus, OH 43229 800-282-4536, ext. 1390 (in Ohio, activated by voice or TTY) 614-438-1392, ext. 1393 (outside Ohio)
Nursing Home Ombudsman Program	1468 W. 25th St. Cleveland, OH 44113 216-696-2719
Rehabilitation Services Commission	4656 Heaton Rd. Columbus, OH 43229 614-438-1200
<u>Housing Resources</u>	
Independent Living Research Utilization Project	P.O. Box 20095 Houston, TX 77225 713-797-0200
Services for Independent Living	Braeburn Bldg., #105 25100 Euclid Ave. Euclid, OH 44117 216-731-1529
<u>Transportation Resources</u>	
American Automobile Association	Traffic Safety Dept. 8111 Gatehouse Rd. Falls Church, VA 22047 703-AAA-6621
Regional Transit Authority (metropolitan Cleveland)	615 Superior Ave., N.W. Cleveland, OH 44113 216-431-1110
Rehabilitation International USA, Inc.	1123 Broadway, Ste. 704 New York, NY 10010 212-620-4040
Society for the Advancement of Travel for the Handicapped (SATH)	26 Court St., Ste. 1110 Brooklyn, NY 11242 718-858-5483
<i>The Itinerary</i>	Subscription Dept. P.O. Box 1084 Bayonne, NJ 07002 201-858-3400
<u>Volunteer Organizations</u>	
ACTION	806 Connecticut Ave., N.W. Washington, DC 20525 202-634-9282
National Organization on Disability	2100 Pennsylvania Ave., N.W., Ste. 234 Washington, DC 20037 202-293-5960 (voice) 202-293-5968 (TTY)
<u>Special Equipment</u>	
ABLEDATA	Catholic University of America 4407 Eighth St., N.E. Washington, DC 20017 202-635-5826 202-635-5885 (TDD)

Table—continued

Lifeline Inc.	One Arsenal Market Place Watertown, MA 02172 800-451-0525
Prentke Romich Co.	R. D. 2, Box 191 Shreve, OH 44676 216-567-2906
AT&T National Special Needs Center	2001 Rte. 46 Parsippany, NJ 07054 800-233-1222 (voice) 800-833-3232 (TTY)

inexpensive, yet invaluable tool in the care of the physically disabled patient. Though every health provider must seek out regional and local aid resources, most of these organizations and agencies have counterparts throughout the United States. Thus when specific Ohio agencies are described in this article, they serve only as examples of the resources available in many states throughout the country (*Table*).

Encyclopedia of Associations

A basic resource file begins with a library book, the *Encyclopedia of Associations*,² which is a listing of national and international organizations arranged according to major subject headings. The medical section includes more than 1,000 listings of health-related organizations and agencies, each of them accompanied by a brief description of that agency's services. Such well-known organizations as the Muscular Dystrophy Association (MDA) and National Multiple Sclerosis Society are listed, along with lesser-known agencies such as the National Ataxia Foundation. The literature provided by these organizations often makes note of benefits which might otherwise be overlooked. For example, a pamphlet available from the MDA states that their services cover a number of diseases other than muscular dystrophy, including spinal muscular atrophy, myotonia, myasthenia gravis, Eaton-Lambert syndrome, Friedrich's ataxia, and Charcot-Marie-Tooth disease, to name just a few. If a patient has one of these diagnoses, among other services provided by MDA, certain durable goods, such as wheelchairs, walkers, hospital beds, braces, and ramps, can be obtained without cost.

The Source Book for the Disabled

Another basic resource which can be obtained at any library is *The Source Book for the Disabled*,³

which is intended to provide information that will allow the physically disabled person to lead a more independent life within his or her community. It covers such topics as home adaptations for the physically impaired person, the special problems faced by the disabled parent, and many small appliances helpful in achieving increased independence. This book and many others like it include names and addresses of mail-order companies and self-help equipment firms which supply aids for disabled persons. Listings in the Yellow Pages under "Hospital Equipment and Supplies" will also provide names of local resources for such items. However, local medical suppliers may not stock unusual pieces of equipment. If something out of the ordinary is needed, one might make use of ABLEDATA, part of the National Rehabilitation Information Center, an on-line computer data base containing more than 10,000 listings of commercially available rehabilitation equipment. It costs \$10 to search for approximately 100 items. The computer printout lists the available equipment brands and manufacturers, cost information, and informal evaluation data such as contraindications and factors which may affect safety. Those who perform the search find it useful to know as much as possible about potential users' functional abilities, limitations, and specific needs.

Financial aid

Unfortunately, there appears to be no general financial aid organization which supplies funds to disabled persons for the purpose of remodeling their homes to improve accessibility. However, veterans may be able to receive help from the Veterans Administration in an attempt to modify their homes or cars. The Rehabilitation Division of the Industrial Commission of Ohio may perform the same service for patients injured on the

job. Furthermore, the Rehabilitation Services Commission, an Ohio state agency, administers funds to provide for the vocational rehabilitation of physically and mentally disabled persons; for example, if ramp access in the home or modifications of one's car are needed to make a person employable, this agency will help provide appropriate funding.

On a more informal level, financial support can be sought from various volunteer organizations. The National Organization on Disability, a privately funded agency, has organized a network of Community Partnership Committees (CPC). These groups are located in more than 1,000 communities throughout the country. Their purpose is to solve the problems of local handicapped persons. Some of these groups have been known to save disabled individuals hundreds or thousands of dollars by calling upon local carpenters who donate their time to make structural adaptations to private homes. The CPC in any given area can be located by calling the National Organization on Disability in Washington, D. C. Smaller appliances and aids can sometimes be purchased through local organizations such as churches, synagogues, and service agencies. Medicare and Medicaid benefits will also cover part of the cost of various home features that improve either safety or accessibility for the disabled person; reimbursable items can be identified by obtaining the appropriate lists from the Department of Public Welfare, the local Blue Cross office, or large medical supply houses.

Home and environmental modification

Access for All

There are many organizations which supply free publications containing information for handicapped persons. For example, the Ohio Governor's Council on Disabled Persons offers pamphlets which explain how to remodel one's home to accommodate the disabled person. For \$5, the Council also provides a handbook called *Access for All* which is intended to educate the public in order to eliminate architectural barriers for disabled persons, not only in their homes, but in their communities as well. The book is filled with small but important details, such as where to put drapery pulls or electric plugs in order to make them accessible to a person in a wheelchair; how deep a closet should be (or how high a rod should be) so that a wheelchair-bound person can hang up his or her own clothes; and how large a

bathroom should be so that a wheelchair can turn 180°. All of this information can be useful to anyone who needs to use mobility aids.

Independent Living Centers

It is sometimes difficult for people to translate suggestions from a book or pamphlet into actual modifications for their own home. Independent Living Centers (ILC) were created in part to help correct this problem. In Cleveland, this resource is administered through Services for Independent Living (SIL), a program operated for and by disabled consumers. An SIL representative will visit a disabled person's home to evaluate the physical layout and tell the person and his or her family what specific alterations are needed to make it more accessible, as well as estimate the cost of the necessary labor. If desired, SIL will also help find low-cost housing that will accommodate an individual's disability.

ILCs are just one type of independent living program found in the United States. Such programs provide many services to the disabled individual. There are three general types, each of which offers specific services. Some programs give peer counseling, advice on housing, information about barrier removal, and financial and legal advocacy for the disabled person. Others provide short-term goal-oriented training sessions in order to teach disabled individuals the skills necessary to attain educational and vocational goals, increased mobility, or even heightened awareness of their own sexuality. Still others maintain residential centers for the disabled individual. A directory of all of these programs and the services available can be obtained from the Independent Living Research Utilization Project for a small fee.

Environmental control systems

Patients who are so severely disabled that they are incapable of independence even within their own home can still be accommodated with the help of an environmental control system. This system can control most electrical conveniences at home, work, or school, including the room lights, television set and channel selector, telephone, and electric bed. The system is composed of a switch, a main control unit, and the devices to be controlled. The control unit can operate one device, such as a bell to summon someone for help, or it can be arranged to control many devices. Interaction between the unit and the

patient depends on his or her physical limitations. Someone with use of his or her hand can control the unit through a rocking lever or joystick; someone with only head control can use a tongue switch; and anyone with breath control can use a pneumatic stick to select the device he or she wants. Environmental control systems can be very expensive, costing thousands of dollars for a complete unit; however, a single unit such as a call bell may cost only about \$100–150. The type of unit desired depends on the severity of the person's handicap. These systems have been found to be useful for people with high-level spinal cord injury, multiple sclerosis, head trauma, and cerebral palsy. The Prentke Romich Co. of Shreve, Ohio, is one manufacturer of these units and can offer assistance in finding funding sources.

Emergency services

The thrust of the previous discussion has been to demonstrate that there are many devices available to physically accommodate the disabled person in the home. But can that person be left alone in the home for part or all of the day? If not, the concerned relative will want to seek attendant care. Most people will be referred to local nursing agencies which can supply home health aids, physical and occupational therapists, and registered nurses. But many cannot afford to pay for these specialized services, and yet their families believe that it is not safe for the patient to remain home alone all day. Fortunately, there are several services which allow a person left alone to contact the outside world in the event of an emergency. Lifeline Inc., a profit-making organization, rents a communication unit which operates through a telephone. The patient wears it as a pendant or bracelet, and if an emergency arises he or she activates it by merely pushing a button. A responder selected by the home-bound patient—a friend, relative, or local agency—is immediately sent to the home to assess the problem and, if necessary, call for emergency help. This type of unit is perfect for the patient who has slipped in the bathtub or fallen down in the backyard and cannot reach a phone. It costs \$15 per month and as yet is not third-party reimbursable. Lifeline can supply the name and location of the nearest provider agency. AT&T offers a similar service to those who wish to purchase a home emergency unit. It costs approximately \$230. Information about this and many more communication aids and services can be obtained by calling the AT&T Special Needs Center.

Attendant care

If some attendant care is required and need not necessarily be performed by a nurse or therapist, there are several agencies which offer such services. In Cleveland, SIL helps provide either part-time, full-time, or live-in care. Most care givers are laypersons who have been trained to help the homebound patients with their daily activities. In some areas, many of these same types of services are provided through local volunteer groups, in particular the federally funded ACTION project, which sponsors the Retired Senior Volunteer Program (RSVP) and Senior Companion Program (SCP). RSVP consists of 700 to 800 local organizations across the country, each made up of senior volunteers who will provide services to anyone they feel capable of caring for. SCP provides in-home care for other senior citizens. Each of these local community groups has their own rules as to what they will or will not do for homebound patients. Many provide volunteers who will keep the patient company, help him or her take medicine, and assist with other aspects of daily life; some also supply transportation to and from the doctor, shopping centers, and the like.

If the primary care giver wishes to leave the home for an extended period of time, arrangements must be made to provide an alternate system of support for the disabled person. The Ohio Department of Aging funds a Nursing Home Ombudsman Program, which can supply a current list of facilities that provide respite care. Not all these facilities are nursing homes; many boarding houses now provide respite care as well. Currently, boarding houses are not licensed in the state of Ohio; however, one of the purposes of the Ombudsman Program is to maintain up-to-date files on the quality of care provided by boarding homes as well as nursing homes around the state so that a family can find out more about the care being received. Funding of respite care is usually not third-party reimbursable.

Travel

National travel

It is not necessary to leave a disabled person at home if the family is traveling. The Society for the Advancement of Travel for the Handicapped is a non-profit organization whose members include health professionals, government officials, and commercial transportation providers who work to fulfill the needs of the handicapped

traveler. They send out a newsletter at frequent intervals during the year which reports on upcoming tour programs designed especially for the disabled person and also tells of accessible hotels and travel services. It specifically names tour companies which specialize in travel arrangements for the wheelchair-bound person. There is also a magazine known as *The Itinerary*, which reports on the accessibility of various sightseeing areas and hotels in a given vacation area and contains ads that offer discounts to traveling companions. The *International Directory of Access Guides*, available from Rehabilitation International USA, Inc., is also a useful resource on the subject of travel for handicapped persons. Its bibliography of 458 entries provides information about the accessibility of recreation areas, hotels, motels, airports, railroads, and bus travel services for people with impaired mobility.

Local travel

Less exciting but equally essential is travel which allows the disabled person to get around town. Community transportation in Cuyahoga County (Ohio) is provided through the Regional Transit Authority (RTA), offering a door-to-door transit service to take the elderly and disabled person between community centers and shopping centers as well as homes of friends and relatives. This type of travel is limited to specified neighborhood areas. The disabled person may have an escort who accompanies him or her onto the bus for full fare (or, with special identification, a reduced fare). The RTA also provides a service known as the Extralift Program, providing regular curb-to-curb transportation to work, college, or vocational training. Provisions for escorts can be made, as ground-level assistance is limited. The RTA also provides a cross-county medical service which provides door-to-door transportation to 12 major medical facilities in Cuyahoga County.

The Handicapped Drivers Mobility Guide

The ability to drive independently provides the greatest freedom of mobility for the physically disabled person. Some persons, even with severe disabilities, can learn to drive by making various

modifications to their cars. Information on this subject is most readily obtained from the American Automobile Association (AAA), which provides a pamphlet called *The Handicapped Drivers Mobility Guide*. This pamphlet contains state-by-state listings of driver training facilities, adaptive equipment manufacturers, and organizations that provide transportation services to drivers with handicaps. It also lists appropriate car modifications for those paralyzed on either the right or left side, as well as those who are quadriplegic or paraplegic.

Conclusion

The above, then, is an overview of resources available to the impaired patient, but is by no means exclusive. Many important topics have not been mentioned; however, information about vocational training, education, and various recreational resources can be obtained from many of the agencies and books already discussed.

It is important to realize that while the community of agencies and professionals who work with handicapped persons is a relatively small one, most organizations are very generous with their information. If one agency does not supply a given service, someone within that agency may know of another more appropriate referral. It is not difficult to put together a resource file for the impaired person; granted, it does take time, but it is time well spent. With the help of such a file, any member of the medical profession can provide information to the physically handicapped person which will allow them to achieve a new level of independence: and that, after all, is the primary goal of the medical profession.

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References

1. Worst handicaps are other people's attitudes. Cleveland Plain Dealer, 17 Aug 1984.
2. Akey DS, ed. Encyclopedia of Associations. Detroit, Gale Research, 7th ed, 1983.
3. Hale G, ed. The Source Book for the Disabled. New York, WB Saunders, 1982.