



Information about Albinism

National Organization for Albinism and Hypopigmentation

Resources for Persons with Albinism

Many services and resources are available to help individuals and families with albinism, both on a national level and in local communities. This information bulletin first gives an overview of types of services available, and then tells how to access these services.

Types of Agencies

Agencies for the blind provide services and resources for persons with albinism. In the past, these agencies treated people with low vision as though they were blind. Today most agencies for the blind have staff members who are knowledgeable and skilled in working with people with low vision, including those with albinism. Some other agencies which can assist people with albinism are low vision services or clinics, libraries for the blind and handicapped, closed circuit radio reading and information for the blind, and special education services.

Independent living centers also provide services to people with various types of disabilities, including visual. Some communities have agencies which assist parents in advocating for the rights of children with various disabilities. Most communities have civic organizations which provide funding and services for people with disabilities. Lions Clubs are especially devoted to helping blind and visually impaired persons.

Written and Recorded Materials

The Library of Congress makes books available in large print and Braille, as well as on tape and disk through regional libraries for the blind. Bibles, hymnals, devotional booklets and other books and publications are available in large print and on cassette. Recording for the Blind and Dyslexic provides recorded and computerized textbooks, library services and other educational resources for people who cannot read regular print. Newspapers are read aloud and broadcast via closed circuit radio stations for the blind. Many newspaper publishers are developing telephone services through which blind and

The Definition of Legal Blindness

Some programs provide services only to individuals who qualify as "legally blind." A person is legally blind when visual acuity in the better eye after best correction is 20/200 or less or when visual fields are constricted to 20 degrees or less with a 3mm. test object.

Other programs provide services when a person has 20/60 or less corrected visual acuity in the better eye.

Since some individuals who have albinism are not legally blind, they are not eligible for some of the services listed in this information bulletin. However, they may be considered as covered or protected by the Americans with Disabilities Act (See page 5).

visually impaired persons can listen to the newspaper being read by computer. Audio descriptive services are being developed to provide descriptions of visual parts of plays, videotapes, television programs, and other entertainment.

Transportation

Special transportation services for people with disabilities and senior citizens are available in most communities through public transportation companies, agencies for the aging, and agencies serving persons with disabilities. These services usually consist of door-to-door paratransit services and reduced fare on fixed-route transportation. For persons who receive Medicaid or Medical Assistance, most communities reimburse for use of public transportation for medical purposes, or provide door-to-door transportation for individuals who are unable to use regular public transportation.

Counseling

Most communities have other services that provide individual and family counseling, such as family service agencies, child guidance clinics, and individual and group practitioners. If these counselors are not knowledgeable about problems related to albinism, NOAH can provide consultation. Usually, one or two telephone consultations as well as a NOAH Information Packet are sufficient to enable a good counselor to understand the problems related to albinism and put them into proper perspective in relation to other individual and family problems.

Other Low Vision Organizations

In addition to NOAH, there are several organizations for blind and visually impaired persons and/or their families. The major ones are Council of Citizens with Low Vision International, National Association for Parents of Visually Impaired, American Council of the

Blind, and National Federation of the Blind. There are also many organizations and agencies which provide information and services for people with various disabilities, such as the National Information Center for Children and Youth with Disabilities, the Job Accommodations Network, and assistive technology projects in all states.

Social Security

The Social Security Administration conducts two programs that benefit those eligible because of visual impairment. These programs are the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Because eligibility is based on many factors, the information presented here is only a very general overview. SSDI is available to individuals who have worked and paid Social Security for a specific period of time, are legally blind or otherwise disabled, and have become unemployed. SSDI benefits are also paid to legally blind and other disabled children if at least one of their parents has worked a certain amount of time under Social Security but is now disabled, retired, or deceased. SSI is targeted for individuals without assets, no income or low income according to federal criteria, and are legally blind or disabled.

Scholarships

The Council of Citizens with Low Vision International, American Council of the Blind, National Federation of the Blind and many other organizations and agencies give scholarships to visually impaired and blind persons. Most colleges and universities have an Office for Disabled Students, which provides special services, such as reader services, for persons with disabilities.

Agencies for the Blind and Visually Impaired

Every state has a vocational rehabilitation agency which provides services to persons with

disabilities with federal and state tax funds. Some states have a separate rehabilitation agency for the blind and visually impaired. Other states have a single rehabilitation agency which provides services to people with all kinds of disabilities. Some state agencies provide only services related to helping persons with disabilities become employable and find jobs. Such agencies may serve only individuals who are sixteen years of age and older and do not serve people who are beyond employment age, with some exceptions. However, some state agencies provide a wider variety of social services, independent living services, and rehabilitation services. These services are usually free of charge. Agencies that are not operated by federal, state or local governments are referred to as private agencies. They may receive some of their funding from government sources, such as through a contract with the state agency for the blind. They also receive funding from grants and contributions from foundations, industry, United Ways, and other organizations or individuals. They may charge a fee for some of their services, based on ability to pay. These agencies are governed by boards of directors composed of local citizens, some of whom are blind or have low vision. Services provided by state and private agencies vary from one state to another, and sometimes even within a state. Typical services are as follows: information and referral, professional counseling, peer counseling, early intervention programs to assist parents in stimulating their blind or visually impaired children to develop normally, financial help with visual aids, training in adaptive techniques for mobility (called Orientation and Mobility or O&M), training in daily living skills (referred to as Rehabilitation Teaching), reader services, volunteer services, vocational counseling, financial assistance with vocational training or college education, and job placement.

Services for Children

The state agency for the blind and visually impaired may provide special education services, or the local school system may provide them. Most communities have early intervention programs which start at infancy and work with the child throughout the preschool years. Many areas have transitioning programs designed to assist young people who do not plan to attend college to make the transition from high school to working and living independently in the community. These programs may be operated by state or private agencies in cooperation with the local schools.

Low Vision Services

Low vision services or clinics offer evaluation and training by ophthalmologists, optometrists, and other professionals specially trained in working with people with low vision. These services are designed to help people with low vision make the fullest use of their vision through prescribing, dispensing, and training in the use of optical and non-optical aids to enhance their visual function. Such services are found in agencies for the blind and visually impaired, colleges of optometry, eye hospitals, medical centers, and private offices.

Independent Living Centers

Independent Living Centers are directed and operated primarily by individuals with disabilities to help others with disabilities live as independently as possible in the community. These centers are usually private organizations, funded in part by the federal government and the state rehabilitation agency, but some are operated directly by the state rehabilitation agency. The services they provide are information and referral, peer counseling, advocacy, skills training, attendant care, and many others. Their government funding requires them to provide services to persons with all types of disabilities,

but in reality they vary in their interest and ability to provide services to individuals with low vision.

Other Services for People with Disabilities

NICHCY, the National Information Center for Children and Youth with Disabilities, provides information about disability and disability related issues. They produce publications on disability issues, including resource lists, as well as answer questions regarding specific disabilities and disability issues, make referrals, and provide technical assistance to parents and professional groups. The Job Accommodations Network (JAN) is an international consulting service that provides information about job accommodations that enable individuals to perform work more easily and more productively. Information is provided to individuals with disabilities as well as to employers. The technical assistance projects are sometimes referred to as Tech Act projects because they are funded by an act passed by Congress in 1988. Their aim is to increase awareness and accessibility of assistive technology, including computers and optical aids, for persons with disabilities. They also can provide information about how to obtain funding for assistive technology.

Finding Services and Resources in Your Community

To find agencies for the visually impaired and low vision services in a specific community, contact the American Foundation for the Blind. AFB provides information, consultation, and technical assistance related to blindness and low vision. They also publish books and other materials, maintain an extensive library, do research, and much more. To obtain a catalog of their publications and more information about their services, contact them at:

AFB

Eleven Penn Plaza, Suite 300
New York, NY 10001

Telephone: 212 502-7600 or
800 AFB-LINE (800 232-5463)
Fax: 212 502-7777
E-mail: afbinfo@afb.org
Internet: <http://www.afb.org>

Information about libraries for the blind and visually impaired, radio reading services, and many other services as well as organizations related to blindness and low vision can be obtained by contacting AFB or by contacting local agencies for the blind. Information about special transportation services can be obtained by contacting your local transportation company and your local agency for the blind or independent living center.

For information about independent living centers in a specific community, contact your local agency for the blind or Independent Living Research Utilization at:

ILRU

2323 S. Shepherd, Suite 1000
Houston, Texas 77019
Telephone: 713 520-0232
Fax: 713 520-5785
E-mail: ilru@ilru.org
Internet: <http://www.bcm.tmc.edu/ilru>

To contact a local Lions Club, first locate a Lions Eye Bank or other eye bank. These are usually found in eye hospitals or medical centers. Ask for a referral to a local Lions Club or contact:

International Association of Lions Clubs

300 W. 22nd Street
Oak Brook, Illinois 60523-8842
Telephone: 630-571-5466
Fax: 630-571-8890
E-mail: it@lionsclubs.org
Internet: <http://www.lionsclubs.org>

To locate counseling services, look in your telephone directory for human services and counseling, or call your local United Way and ask for the telephone number of your local community information and referral agency. Health insurance

may cover counseling as well. Some plans will cover services only at specific clinics or through a referral process; check your policy or call the member services department of the plan.

For more information about **Social Security**, call 800 772-1213. To obtain information about scholarships for visually impaired students, contact the student aid office and the office for disabled students at your college or university. Also contact your vocational rehabilitation agency, your local library for the blind, the American Council for the Blind, the American Foundation for the Blind, Citizens with Low Vision International, the National Federation of the Blind, and any other agencies or organizations they suggest.

The American Council of the Blind
1155 Fifteenth Street NW, Suite 1004
Washington, DC 20005
Telephone: 202 467-5081
800-424-8666

Fax: 202 467-5085
E-mail: info@acb.org
Internet: <http://www.acb.org>

Citizens with Low Vision International
1155 15th St. NW, Ste. 1004
Washington, DC 20005
Telephone: 800-733-2258
Internet: <http://www.cclvi.org>.

National Federation of the Blind
1800 Johnson Street
Baltimore, MD 21230
Telephone: 410 659-9314
Fax: 410 685-5653
E-mail: nfb@nfb.org

Internet: <http://www.nfb.org> For information about services and agencies in Canada, look in the phone book for the local office of the Canadian National Institute for the Blind, or contact:

The Americans With Disabilities Act (ADA)

The ADA, passed by Congress in 1990, prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications. It also applies to the United States Congress. The ADA also mandates that employers, governments, public accommodations, commercial facilities, transportation and telecommunications provide reasonable accommodations for persons with disabilities. In the ADA, an individual with a disability is defined as a person who has a physical or mental impairment that substantially limits one or more major life activities; a person who has a history or record of such an impairment; or a person who is

perceived by others as having such an impairment. Since seeing is considered to be a major life activity and people with albinism have low vision, people with albinism are covered under the ADA if the low vision substantially limits them. For more information about the ADA and other disability rights information, contact the following resources:

- **Regional Disability and Business Technical Assistance Centers:**
Telephone 800 949-4232
<http://www.ada-infonet.org>
- **U.S. Department of Justice**
ADA Information Line: 800 514-0301
Internet: <http://www.usdoj.gov>

**The Canadian National Institute
for the Blind - National Office**

1929 Bayview Avenue
Toronto, Ontario, M4G 3E8
CANADA
Telephone: 416 480-2500
Fax: 416 480-7677
E-mail: irc@lib.cnib.ca
Internet: <http://www.cnib.org>

For information about services for visually impaired persons in other countries, contact:

The World Blind Union

c/o CBC ONCE
La Coruna, 18
28020 Madrid, SPAIN
Telephone: 34-1-571-36-85
Fax: 34-1-571-57-77
E-mail: umc@once.es

**Association for Education
and Rehabilitation of the Blind
and Visually Impaired**

4600 Duke St. #430
PO Box 22397
Alexandria, VA 22304
Telephone: 703-823-9690
Fax: 703-823-9695

The National Information Center for Children and Youth with Disabilities can be contacted at:

NICHCY

PO Box 1492
Washington, DC 20013-1492
Telephone: 800 695- 0285
Fax: 202 884-8441
E-mail: nichcy@aed.org
Internet: <http://www.nichcy.org>

The Job Accommodations Network can be contacted at:

Telephone in the United States: 800 526-7234
In Canada: 800 526-2262
Internet: <http://www.jan.wvu.edu>
Locate your local Tech Act Project by calling:

RESNA Technical Assistance Project

1700 N. Moore Street, Suite 1540
Arlington, VA 22209-1903
Telephone: 703 524-6686
Fax: 703 524-6630
E-mail: info@resna.org
Internet: <http://www.resna.org>

For information about other resources for persons with disabilities, contact your local center for independent living or search the Internet. There are many interesting resources to be found on the Internet.

Ask NOAH

There are many other resources that are helpful to individuals and families with albinism. NOAH News provides information about many of these. NOAH is willing to help locate resources. We can be contacted at the address and telephone number below.

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