

## Deafblind Resource Reference Sheet

*Current Information as of July 13, 2016*

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### Missouri Deafblind Technical Assistance Project

#### Address:

Missouri School for the Blind  
3815 Magnolia Avenue  
St. Louis MO 63110-4099  
**Switchboard:** (314) 776-4320  
**Fax:** (314) 773-3762

**Contact:** Susan Bonner  
**Title:** Project Coordinator  
**Email:** [susan.bonner@msb.dese.mo.gov](mailto:susan.bonner@msb.dese.mo.gov)  
**Phone:** (314) 633-1553 direct  
(314) 776-4320 switchboard

#### Contact:

**Title:** Project Director  
**Email:**  
**Phone:** (314) 633-1587

**Contact:** Jessica Hall  
**Title:** Family Specialist  
**Email:** [jessica.hall@msb.dese.mo.gov](mailto:jessica.hall@msb.dese.mo.gov)  
**Phone:** (660) 785-2317

**Website:** <http://www.msb.dese.mo.us>

**Summary:** in collaboration with other state and non-profit agencies, provides support, training and technical assistance to families and teams who work with infants, toddlers, and youth with deafblindness throughout the state. The project operates under the leadership and management of Missouri School for the Blind, Department of Elementary and Secondary Education.

Goals of the project are achieved through six major objectives:

- Assist local and state agencies in the identification, tracking and referral of infants, children and youth with deafblindness to enhance services.
- Provide an array of technical assistance activities that increase family engagement and leadership, parent education and parent networking.
- Provide an array of technical assistance and training activities to service providers that improves services and outcomes.
- Strengthen the statewide interagency collaboration model designed to build local capacity, facilitate systems change and eliminate duplication.

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- Implement a dissemination plan which ensures access and availability of information about the Project, deafblindness, research, resources and practice to its stakeholders.
- Measure and evaluate needs, outcomes and impact for children and youth with deafblindness, their families and service providers.
- Evaluate and measure impact and benefits to children with deafblindness, their families, and their service providers.

## National Center on Deaf-Blindness

### Address:

The Teaching Research Institute  
Western Oregon University  
345 North Monmouth Avenue  
Monmouth, Oregon 97361

**Fax:** (503) 838-8150

**TTY:** (800) 854-7013

**Phone:** (800) 438-9376

**Website:** <http://www.nationaldb.org/>

**Summary:** As a national technical assistance center funded by the Federal Department of Education, NCDB works to improve the quality of life for children who are deaf-blind and their families by:

- Creating visibility and direction for identified priorities through a range of practices, activities, supports and partnerships.
- Identifying and encouraging new innovations in local, state, and national practice and policy.
- Promoting opportunity for reflection, debate, and constructive dialogue around ideas and developing practice.
- Maintaining a rich repository of content, history, and knowledge, easily available and shared by all who are part of the community of deaf-blindness.

## Service and Rehabilitation Programs

### Alphapointe Association for the Blind

#### Address:

7501 Prospect  
Kansas City, Missouri 64132

**Phone:** (816) 421-5848

**Fax:** (816) 237-2019

**Contact:** Clay Berry

**Title:** Director of Education &  
Rehabilitation

**Email:** [cberry@alphapointe.org](mailto:cberry@alphapointe.org)

**Website:** [www.alphapointe.org](http://www.alphapointe.org)



**Summary:** Alphapointe's services are designed to meet the needs of youth, adults, and seniors with all types of vision loss to learn the skills needed for living and working with vision loss. It is the largest employer of blind and visually impaired individuals in Missouri and the only

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comprehensive rehabilitation and education service in the Kansas City metropolitan area as well as the state of Missouri.

### **Blindness Skills Specialists**

#### **Northeast Region**

**Address:**

Northeast Professional Development Center  
Truman State University  
Violette Hall 2200  
100 East Normal  
Kirksville, MO 63501

**Website:** <http://rpdc.truman.edu/>

**Contact:** Anthony Blades

**Phone:** (660)785-7428

**Email:** [ablades@truman.edu](mailto:ablades@truman.edu)

#### **Southwest Region**

**Address:**

Missouri State University  
Southwest Regional Professional  
Development Center  
PCOB #207  
901 S. National  
Springfield, MO 65807

**Website:**

<http://education.missouristate.edu/bss/>

**Contact:** Julie Anderson-Ituarte

**Phone:** (417) 836-5490

**Email:** [jituarte@missouristate.edu](mailto:jituarte@missouristate.edu)

**Contact:** DJ Butcher

**Phone:** (417) 836-8872

**Email:** [butcher2@missouristate.edu](mailto:butcher2@missouristate.edu)

**Summary:** Offers professional development, mentoring, demonstration of teaching strategies, agency referrals, coordination of educational programs, acts as a liaison for families and educators, and provides resource information.

#### **Children's Center for the Visually Impaired (CCVI)**

**Address:**

3101 Main  
Kansas City, MO 64111  
**Phone:** (816) 841-2284  
**Fax:** (816) 753-7836

**Contact:** Nicole Heskett

**Title:** Executive Director

**Website:** [www.ccv.org](http://www.ccv.org)

**Summary:** The mission of CCVI is to prepare children with visual impairments, including those with multiple disabilities; to reach their highest potential in the sighted world. CCVI offers a comprehensive program for visually impaired children and their families, including individualized therapy, consulting services and supportive family education. Services are provided beginning in infancy through our home-based infant program, and continue on with our preschool & Kindergarten classes, preparing children for entry into the public or private school systems.

### **The Delta Gamma Center for Children with Visual Impairments**

**Address:**

1750 South Big Bend  
Saint Louis, MO 63117  
**Phone:** (314) 776-1300

**Contact:** Deborah Naucke  
**Title:** Executive Director  
**Email:** [danaucke@dgckids.org](mailto:danaucke@dgckids.org)  
**Website:** [www.dgckids.org](http://www.dgckids.org)

**Summary:** The Delta Gamma Center for Children with Visual Impairments is committed to helping children who are blind or visually impaired reach their full potential through individualized education and therapy services for infants (birth to three years) and their parents and through support services for children of all ages, their families and the community.

### **Helen Keller National Center Great Plains Regional Office**

**Address:**

450 E. Park Street  
Olathe KS 66061  
**Fax:** (913) 677-1544  
**TTY:** (913) 677-4562

**Contact:** Beth Jordan  
**Title:** Regional Representative  
**Email:** [beth.jordan@hknc.org](mailto:beth.jordan@hknc.org)  
**Phone:** (913) 677-4562  
**Phone:** (913) 277-4282

**Contact:** Dianna Meier  
**Title:** Administrative Assistant  
**Email:** [dianna.meier@hknc.org](mailto:dianna.meier@hknc.org)  
**Phone:** (913) 677-4562

**Summary:** The mission of the Helen Keller National Center for Deaf-Blind Youths and Adults is to enable each person who is deaf-blind to live and work in his or her community of choice. HKNC Regional Representatives provide consultation and technical assistance to individuals with deaf-blindness and their families, and to public and private education and adult service agencies in their region. The Regional Representatives are responsible for assessing the needs of individuals, communities and states within their regions; developing strategies of collaboration, coordination and cooperation to help meet those needs; advocating for those who are deaf-blind in local, state, national and international forums.

### **Midwestern Braille Volunteers**

**Address:**

104 W. Adams St.  
St. Louis, MO 63122  
**Phone:** (314) 966-5828  
**Fax:** (314) 966-0388

**Email:** [mbvol@sbcglobal.net](mailto:mbvol@sbcglobal.net)  
**Website:** <http://www.mbvoll.org>

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**Summary:** This organization provides transcribing services (textbooks) for blind students, and transcription services for businesses, churches and community organizations.

### **Rehabilitation Services for the Blind**

**Address:** Central Office:  
615 Howerton Court  
Jefferson City, MO 65102-2320  
**Phone:** (573) 751-4249  
**Toll free:** (800)-592-6004  
**Fax:** (573)751-4984

**Contact:** Kevin Faust, Director  
**Email:** [Kevin.r.faust@dss.mo.gov](mailto:Kevin.r.faust@dss.mo.gov)  
**Website:** [www.dss.mo.gov/fsd/rsb/](http://www.dss.mo.gov/fsd/rsb/)

**Summary:** Provides advocacy, referrals, parent education and recommendations for services to legally blind individuals in Missouri, including assistance and support for educational and employment opportunities. Assists students and parents in developing transition programs at age 14. RSB is the point of contact for the Center for Braille and Narration Production

### **St. Louis Society for the Blind**

**Address:**  
8770 Manchester Rd.  
St. Louis, MO 63144  
**Phone:** (314) 968-9000

**Contact:** David Ekin  
**Email:** [socserv@sldbvi.org](mailto:socserv@sldbvi.org)  
**Website:** [www.sldbvi.org](http://www.sldbvi.org)

**Summary:** St Louis for the Blind and Visually Impaired provides the full range of vision rehabilitation and education services to children and adults. Although the majority of individuals served are experiencing age-related vision loss, programs and services are offered to students attending public schools through contractual agreements with local special education entities and summer programs. Other services are provided to individuals of all ages.

## **Missouri State Resources**

**State Department of Education: Special Education**  
Dr. Stephen Barr, Assistant Commissioner  
Division of Special Education  
Department of Elementary and Secondary Education  
P.O. Box 480  
Jefferson City, MO 65102  
(573) 751-4404  
E-mail: [stephen.barr@msb.dese.mo.gov](mailto:stephen.barr@msb.dese.mo.gov)  
Web: <http://dese.mo.gov/special-education>



**Councils on Developmental Disabilities**

Vicky Davidson, Executive Director  
Missouri Planning Council Developmental Disabilities  
1706 E. Elm  
P.O. Box 687  
Jefferson City, MO 65102  
(573) 751-8206; (800) 500-7878 (In MO)  
Web: [www.moddcouncil.org](http://www.moddcouncil.org)

**First Steps: Ages Birth through 2**

Special Education Services  
Department of Elementary and Secondary Education  
Pam Thomas, Coordinator  
Special Education Services  
P.O. Box 480  
Jefferson City, MO 65102  
(573) 522-8762  
(800 ) 583-2392  
E-mail: [pam.thomas@dese.mo.gov](mailto:pam.thomas@dese.mo.gov)  
Web: <http://dese.mo.gov/special-education/first-steps>

**Missouri School for the Blind**

Geoffrey Barney, Superintendent  
3815 Magnolia Avenue  
St. Louis, MO 63110  
(314) 776-4320; (800) 622-5672  
Web: [www.msb.dese.mo.gov](http://www.msb.dese.mo.gov)

**Missouri School for the Deaf**

Ernest Garrett III, Superintendent  
505 E. 5th Street  
Fulton, MO 65251-1799  
(573) 592-4000  
Web: [www.msd.dese.mo.gov](http://www.msd.dese.mo.gov)

**Programs for Children and Youth who are Blind or Visually Impaired or Deaf-Blind**

Kevin Faust, Deputy Director  
Rehabilitation Services for the Blind  
Family Support Division  
615 Howerton Court

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P.O. Box 2320

Jefferson City, MO 65102-2320

(573) 751-4249; (800) 592-6004

E-mail: [kevin.r.faust@dss.mo.gov](mailto:kevin.r.faust@dss.mo.gov)

Web: [www.dss.mo.gov/fsd/rsb/index.htm](http://www.dss.mo.gov/fsd/rsb/index.htm)

### **Programs for Children and Youth who are Deaf or Hard of Hearing**

Opeoluwa Sotonwa, Executive Director

Missouri Commission for the Deaf and Hard of Hearing

1500 Southridge Dr., Suite 201

Jefferson City, MO 65109

(573) 526-5205

(573) 415-0083 (Videophone)

Web: [www.mcdhh.mo.gov](http://www.mcdhh.mo.gov)

### **Programs for Children with Disabilities: Ages 3 through 21**

Special Education Compliance Section

Department of Elementary and Secondary Education

P.O. Box 480

Jefferson City, MO 65102

(573) 751-0699

E-mail: [secompliances@dese.mo.gov](mailto:secompliances@dese.mo.gov)

Web: [www.dese.mo.gov/divspeced/](http://www.dese.mo.gov/divspeced/)

### **Programs for Children with Special Health Care Needs**

Special Health Care Needs

Department of Health and Senior Services

P.O. Box 570

Jefferson City, MO 65102

(573) 751-6246; (800) 451-0669

Web: <http://health.mo.gov/living/families/shcn/cyshcn.php>

### **Programs for People with Developmental Disabilities**

Valerie Huhn, Division Director

Division of Mental Retardation and Developmental Disabilities

1706 E. Elm

P.O. Box 687

Jefferson City, MO 65102

(573) 751-8676; (800) 207-9329

Web: [www.dmh.mo.gov](http://www.dmh.mo.gov)

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**Protection and Advocacy Agency**

Missouri Protection and Advocacy Services

925 S. Country Club Drive

Jefferson City, MO 65109

(573) 893-3333; (866) 777-7199

Web: [www.moadvocacy.org](http://www.moadvocacy.org)

**Regional ADA & IT Technical Assistance Center**

Great Plains Disability and Business Technical Assistance Center

University of Missouri/Columbia

100 Corporate Lake Drive

Columbia, MO 65203

(573) 882-3600 (V/TTY)

Web: <http://www.gpadacenter.org/>

E-mail: [adacenter@missouri.edu](mailto:adacenter@missouri.edu)

**RelayMO: Telecommunications Relay Services for Individuals who are Deaf, Hard of Hearing, or with Speech Impairments**

(800) 735-2466 (V)

(800) 735-2966 (TTY); 711 (TTY)

(877) 242-2823 (CapTel)

(877) 735-7877 (Speech to Speech)

Web: <http://www.relaymissouri.com/>

**Special Format Library**

Donna Riegel, Division Director

Wolfner Library for the Blind and Physically Handicapped

P.O. Box 387

Jefferson City, MO 65102-0387

(573) 751-8720; (800) 392-2614 (in MO)

(800) 347-1379 (TDD/ in MO)

E-mail: [wolfner@sos.mo.gov](mailto:wolfner@sos.mo.gov)

Web: [www.sos.mo.gov/wolfner/](http://www.sos.mo.gov/wolfner/)

**State CHIP Program**

**Children's Health Insurance Program**

*(health care for low-income uninsured children)*

MC+ for Children

Missouri Department of Social Services

(888) 275-5908

Web: [www.dss.mo.gov/mhk/index.htm](http://www.dss.mo.gov/mhk/index.htm)

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**State Mental Health Agency**

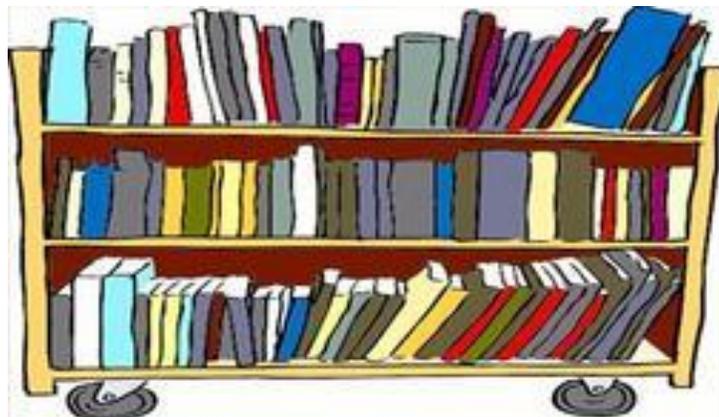
Mark Stringer, Director  
Department of Mental Health  
1706 East Elm  
P.O. Box 687  
Jefferson City, MO 65102  
(573) 751-4122 (800) 364-9687  
Web: [www.dmh.mo.gov](http://www.dmh.mo.gov)

**State Vocational Rehabilitation Agency**

C. Jeanne Loyd, Assistant Commissioner  
Division of Vocational Rehabilitation  
Department of Education  
3024 Dupont Circle  
Jefferson City, MO 65109-0525  
(573) 751-3251  
Web: <http://dese.mo.gov/adult-learning-rehabilitation-services/vocational-rehabilitation/>

**University Centers for Excellence in Developmental Disabilities**

Carl F. Calkins, Director  
UMKC Institute for Human Development  
215 W. Pershing Road, 6<sup>th</sup> floor  
Kansas City, MO 64108  
(816) 235-1770  
(800) 452-1185 (TTY)  
Web: [www.ihd.umkc.edu](http://www.ihd.umkc.edu)



## Missouri Assistive Technology



C. Marty Exline, Director

**Address:** 1501 NW Jefferson Blue Springs, MO 64015

**Phone:** (816) 655-6706; (816) 655-6700; (800) 647-8557, (816) 655-6711 TTY

**Main E-mail:** [moat1501@att.net](mailto:moat1501@att.net)

**Web:** [www.at.mo.gov](http://www.at.mo.gov)

### Programs:

#### Equipment Technology Consortium (ETC)

ETC is a short-term assistive device loan program for Missouri schools and agencies. A school or agency can borrow from a pool of over 900 devices including augmentative communication, computer access, environmental controls, hearing devices, telecommunications, visual aids, and learning aids. The program can be utilized free of charge. Equipment can be borrowed for up to six weeks for trial before making a purchasing decision, for use while equipment is in for repair, or for other short-term needs. For more information, please call (816) 655-6708 or review information at <http://at.mo.gov/device-loan/>

**Telecommunications Access Program (TAP):** <http://at.mo.gov/telecom-access-program/> For more info, contact (800) 647-8557 (voice) or (800) 647-8558 (tty).

**Telephone:** TAP for Telephone provides adaptive telephone equipment for Missourians with disabilities who have telephone service and who have difficulty using standard telephone equipment for voice calling. TAP-T provides adaptive equipment for all disabilities including text telephones and amplified telephones for hearing disabilities, hands free and remote controlled phones for mobility disabilities, voice dialing and Braille dial pads for vision disabilities, and photo phones for cognitive disabilities.

**Internet:** The Telecommunication Access Program for Internet (TAP-I) provides to Missourians with disabilities the adaptive computer equipment needed for basic access to the internet and email. TAP-I provides a range of adaptive equipment including screen reading, enlarging systems, refreshable Braille displays, adaptive software, alternative keyboards and pointing devices. Consumer support is provided throughout the state to assist applicants in determining the adaptive equipment they need and to provide training for consumers after equipment delivery.

**Wireless Port:** The new Telecommunications Access Program (TAP) Wireless Project will provide wireless equipment for participants with disabilities who may not traditionally have access to this equipment. The world of telecommunications is changing drastically and new improvements in accessibility are being introduced for persons with disabilities. The project covers equipment from a very simple large button cell phone to an iPhone® or iPad®, with accessibility apps pre-installed.

**Deaf-Blind Equipment Distribution Program (iCanConnect):** <http://at.mo.gov/deaf-blind-equipment-distribution/>

The goal of the deaf-Blind Equipment Fund is to ensure that every person with combined hearing and vision loss has access to modern telecommunication tools and the training necessary to use them. Missouri Assistive Technology (MoAT) is certified by the FCC to administer the project in the state of Missouri. The program covers a variety of equipment based on the individual participant's distance communication needs. Individuals apply for technology such as an iPhone or iPad or computer with magnification software or a screen-reader. Other equipment may include a neckloop, Braille display, or large-print keyboard. Contact Brenda with questions about the program, [brenda.whitlock@att.net](mailto:brenda.whitlock@att.net) or 816-655-6700.

**Missouri AT Regional Demonstration Centers:** <http://at.mo.gov/information-resources-publications/demonstration.html>

With locations throughout Missouri, these centers are charged with providing hands-on demonstrations of a range of assistive technology. For more info and exact locations, contact (816) 655-6703 or email [David.bkr@att.net](mailto:David.bkr@att.net).

**Missouri AT Recycling Program:** <http://at.mo.gov/recycle-reuse/>

The Statewide Recycling network offers recycled and refurbished durable medical equipment such as manual and power wheelchairs, walkers, hydraulic lifts, feeder seats, bathroom equipment and other similar devices. Included are other technology devices such as computers

**AT Reimbursement Program**

The Division of Special Education provides funding for districts to obtain assistive technology required in student IEPs. Missouri Assistive Technology is administering the program through an application process. Eligible assistive technology includes adaptive devices and systems necessary for delivering an appropriate educational program for students with disabilities. The assistive technology must be identified in a student's IEP. For more info call (816) 655-6709, (800) 647-8557, or email [john.effinger@att.net](mailto:john.effinger@att.net) .

**Show-Me Loans**

Show-Me Loans is a low-interest loan program for individuals with disabilities and their families to borrow money for the purchase of assistive technology. Assistive technology eligible for loans includes but is not limited to braille equipment, hearing aids, environmental controls, housing access modifications and motor vehicle access modifications. For more information, contact (816) 655-6702, (800) 647-8557, or email [Eileen.belton@att.net](mailto:Eileen.belton@att.net) .

**Kids Assistive Technology**

Kids Assistive Technology (KAT) can be a resource for families of low to moderate income when needed for purchase of assistive technology (AT) for children through age 20. The purpose is to provide help when no other funding source is available, or when other funding sources are not adequate to cover the costs of the needed item. KAT can help with costs of minor home access modifications, vehicle access such as wheelchair lifts, and for AT such as Braille or low-vision devices, augmentative communication devices, wheeled mobility, hearing devices, etc. For more information, contact (816) 655-6702 or email [eileen.belton@att.net](mailto:eileen.belton@att.net) .

### **Power Up Conference and Expo-Training**

The annual Assistive Technology Conference and Expo draws participants, presenters, and vendors from Missouri and throughout the nation. Power Up is scheduled for March or April in mid Missouri. Check their website for updates. Missouri Assistive Technology also provides training on assistive technology topics at statewide and regional conferences and events. For more info on training contact <http://at.mo.gov/power-up-conference/>

## **Individual and Family Support Organizations**



### **Missouri Deaf-Blind Association**

**Address:**

353 E. Caddo Street  
Fair Grove MO 65648

**TTY:** (417) 759-1334

**Contact:** Carolyn Sue Alflen

**Email:** [modba4@att.net](mailto:modba4@att.net)

**Summary:** Missouri Deaf-Blind Association (MDBA) mission is to empower people who are deaf-blind, visually disabled, and hearing impaired: to live a more independent life, to share their feelings and experiences with others, and to learn and use tactile sign language, tracking, and other methods of communication. MDBA also educates and provides awareness of deaf-blind community. MDBA meets odd month for socials, meetings, activities, and field trips. MDBA has membership which is renewed yearly and publishes four newsletters per year. MDBA is an affiliate of American Association of the Deaf-Blind (AADB).

### **Missouri Parents Act (MPACT)**

**Address:**

7421 Mexico Rd.  
Suite 200  
St. Peters, MO 63376  
**Phone:** 800-743-7634

**Web:** <http://ptimpact.org/>

**Email:** [info@ptimpact.org](mailto:info@ptimpact.org)

**Summary:** This organization is a state-wide non-profit parent training and information center for families with a child with any kind of disability. It was established in January 1988 and has regional coordinators. Services include training, information and fact sheets and support on Special Education Law with a resource library, and teaching parents to advocate for their children's educational rights. A brochure is available and a newsletter is published quarterly. Several resources are available in Spanish. MPACT's mission is to ensure that all children with special needs receive an education, which allows them to achieve their personal goals.

### **National Family Association for Deaf-Blind**

**Address:**

141 Middle Neck Road  
Sands Point, New York 11050  
(800) 255-0411

**Contact:** Clara Berg

**Title:** President

**E-mail:** [NFADBinfo@gmail.com](mailto:NFADBinfo@gmail.com)

**Website:** <http://nfadb.org/>

**Summary:** The National Family Association for Deaf-Blind (NFADB) is a national organization that advocates for all persons who are deaf-blind, supports national policy to benefit people who are deaf-blind, encourages the founding and strengthening of family organizations in each state and collaborates with professionals in each state and collaborates with professionals who work with persons who are deaf-blind. NFADB Board Members can be contacted to share information and provide resources and referrals. The states in NFADB Region 7 include: IA KS MO NE.

### **American Association of the Deaf-Blind (AADB)**

**President:** Mark Gasaway

**Email:** [mark.gasaway@comcast.net](mailto:mark.gasaway@comcast.net).

**Video Phone:** (866) 957-6153

**Phone:** (770) 492-8646. (TTY)

**Web:** <http://www.aadb.org/index.html>

The American Association of the Deaf-Blind (AADB) is a national adult consumer advocacy organization for people who have combined hearing and vision impairments. AADB is open to all persons who are deaf-blind and individuals directly concerned with their well being, including spouses, children, friends, and health care professionals.

### **Helen Keller National Center for Deaf-Blind Youth and Adults (HKNC)**

111 Middle Neck Road  
Sands Point, NY 11050-1299  
(516) 944-8900

**Fax:** (516)-944-7302,

**TTY:** (516) 944-8637

<http://www.hknc.org/>

HKNC is a national program that provides evaluation, short-term comprehensive vocational rehabilitation training, work experience training and assistance to deaf-blind clients for job and residential placements.

## Perkins School for the Blind

175 N. Beacon Street  
Watertown, MA 02172  
(617) 972-7220

Fax: (617) 923-8076  
<http://www.perkins.org/>

Hilton/Perkins program provides consultation, training and technical assistance to programs throughout the nation and in developing countries. Emphasis is on program development for multi-handicapped blind and deaf-blind infants, toddlers and school-aged children.

## Informational Websites



**A to Z DeafBlindness:** This web site has been developed by James Gallagher, who is himself deafblind. It has links to many other sites and includes such interesting sections as poetry page and videos for training.

<http://www.deafblind.com/>

**A Deafblindness Web Resource:** This web site is an extensive listing of internet resources related to deafblindness.

<http://www.deafblind.co.uk/>

**Boys Town Hospital:** National Center for the Treatment and Study of Ushers Syndrome

<https://www.boystownhospital.org/>

**CHARGE: CHARGE Syndrome Foundation:** Family web site for information about CHARGE Syndrome and related resources

<http://www.chargesyndrome.org>

**The National Center on Deaf-Blindness:** “Information to nurture, empower, and instruct children who are deaf-blind”

<https://nationaldb.org/>

**National Organization for Rare Disorders (NORD):** For information about rare syndromes and disabilities

<http://www.rarediseases.org/>

**Texas School for the Blind and Visually Impaired:** A comprehensive site, with information about a wide variety of topics relating to blindness, visual impairment, deafblindness, and children with multiple disabilities.

<http://www.tsbvi.edu/>