

Missouri Deafblind Technical Assistance Project

Outreach Division / Missouri School for the Blind

Purpose

The purpose of the Missouri Deafblind Project is to develop partnerships, coordinate service networking and provide systematic training. Technical assistance, training and resources are available for the 170 identified students (birth through 21 years) on the Missouri Deafblind Census, their families and service providers. Leadership and support is provided by the Missouri School for the Blind Outreach Team. Services are coordinated with local education agencies, adult service providers and deafblind task forces to enhance networking and to build expertise in the community.

Services

- Assistance in the identification and tracking of children with deafblindness
- Missouri Deafblind Census
- On-site technical assistance and consultation on assessment, education and employment
- Inservice training on specific content areas
- Active state and local deafblind task forces
- Transition assistance including personal futures planning
- Parent training including a home program for children birth through 5 years (MoSPIN)
- Parent-to-Parent Networking
- Early childhood training, such as VIISA and INSITE workshops
- Deafblind coursework, such as Hand-In-Hand
- Loan library of resources on effective practices

All services are statewide.

For additional information regarding the Missouri Deafblind Project contact:

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Missouri Deafblind Technical Assistance Project
Missouri School for the Blind
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The Department of Elementary and Secondary Education does not discriminate on the basis of race, color, national origin, sex, disability or age in its programs and activities. Inquiries related to Department programs maybe directed to the Jefferson State Office, Building, Title IX Coordinator, 5th Floor, 205 Jefferson Street, Jefferson City, Missouri 65102-0480; telephone number 573-751-4212.

Missouri Deafblind Technical Assistance

Fact Sheet

The Importance of the Missouri Deafblind Census

The Missouri Deafblind Census connects families, educators, and other service providers to services and supports.

The Federal law, Individuals with Disabilities Education Act (IDEA), requires the annual conducting of a census of all individuals with deafblindness, ages birth through 21 years. The Missouri Deafblind Technical Assistance Project conducts the annual census in the state of Missouri.

One purpose of the census is to inform the United States Congress and the United States Department of Education about these infants, children, and youth with deafblindness. Another purpose is to help each state's deafblind project identify some of the services and supports needed by these individuals, their families, and the agencies that support them. By identifying individuals with deafblindness in the State of Missouri, the Missouri Deafblind Project is able to provide connections for families, educators, and other service providers to supports and other services.

The Census consists of demographic information, such as an individual's date of birth, gender, living setting, education setting and so on, along with descriptive information such as cause of deafblindness. The Missouri Deafblind Project uses this demographic and descriptive information in many ways.

When a school district, program, or agency reports an individual with deafblindness, the Project sends back to the professional reporting the individual a packet of information that summarizes not only the services and supports the Project can provide the district, program, or agency, but also information about other services and supports available on a local, state, and a national level. A similar packet is sent to families. Both packets include a simple form for the recipient to complete and return to the Project. This form is used by families and professionals to ask for specific support and services from the Project.

The Project also uses the demographic and descriptive information provided by the Census to plan specific activities such as topical workshops (past workshops included Cortical Visual Impairment and psychoeducational assessment of individuals with deafblindness). Through the Census, the Project documented a large number of transition age youth (ages 14 through 21 years) with deafblindness in Missouri and, therefore, now offers the expertise of a Transition Specialist to assist districts and families develop and implement effective transition plans that consider the unique needs of individuals who have both a visual and auditory impairment.



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How to Know If You Are Serving a Person Who Is Deafblind



What is it?

An individual is considered deafblind when that person has both a visual and auditory (hearing) impairment. If the person you serve does not have sufficient vision to compensate fully for an auditory impairment or does not have sufficient audition to compensate fully for a visual impairment, then consider the possibility of the person whom you serve as having deafblindness.

Does deafblind mean the person cannot see or hear?

Actually, no. When most people hear the term deafblindness, they tend to think of Helen Keller, who was totally blind and totally deaf. In reality, most individuals with deafblindness have some remaining audition and/or vision. So, although deafblindness does not always mean a total loss of vision and audition, the combined losses greatly impact an individual's ability to understand the world. Many individuals with deafblindness wear eyeglasses, hearing aids, or use other special devices to improve their vision, audition, and to learn more about what is happening in the world around them.

Why is the combination of visual and auditory impairments important?

Vision and audition are our two distance senses. The world of most individuals with deafblindness is only as big as the area immediately around them and, for some, only as big as the area their fingers can reach. Unless someone is close to or is touching them, they are always alone. Proximity and intensity are essential to using the other senses such as touch and taste. With our ears, we can listen to the radio broadcast of a baseball game in another state. We can hear conversations across the room or even in the next room. With our eyes, we can look at microscopic bacteria or up at the moon. Through recordings and photos we can listen and view information frozen in time. Try doing that with touch, taste, or smell.

What do you look for to see if the person you serve is deafblind?

Although there is a lot of diversity between individuals with deafblindness, there are some characteristics that many share:

- Many use gestures, non-linguistic vocalizations, facial expressions, and/or physical behaviors as their primary mode of communication;
- Many do not use sign language, even after learning an essential vocabulary;
- More than half do not read at all, however, of those who do, many read at a 4th grade level or below; and,
- About half of the individuals with deafblindness communicate without language and may require assistance when traveling; the other half communicates using spoken or signed language.

The combined auditory and visual impairments often result in a host of challenging behaviors:

- Not being able to communicate effectively, individuals with deafblindness might use inappropriate (self-injurious, aggressive, and/or destructive) behaviors to ensure their needs are met.
- Sensory loss increases the need for sensory stimulation; therefore, many individuals with deafblindness develop unusual or repetitive habits, such as rocking or headshaking, which are occasionally mistakenly labeled as autistic. Some forms of visual and auditory impairments (particularly those that are cortical) result in behaviors often mistaken for indicators of autism.
- Since we develop our social skills through vision and audition, individuals with deafblindness may not pick up on non-verbal feedback and might develop what may be seen as socially inappropriate behaviors.

The following are some of the health conditions and events, including complications of childbirth, which may result in both a visual and auditory impairment:

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| • Congenital Rubella | • Direct eye and/or ear trauma |
| • Congenital Syphilis | • Encephalitis |
| • Congenital Toxoplasmosis | • Infections |
| • Cytomegalovirus (CMV) | • Meningitis |
| • Fetal Alcohol Syndrome | • Severe head injury |
| • Hydrocephaly | • Stroke |
| • Maternal Drug Use | • Tumors |
| • Microcephaly | • Medicines |
| • Neonatal Herpes Simplex | • Chemicals |
| • Asphyxia | |

Many syndromes have associated visual and auditory impairments. A *partial* list of these syndromes includes:

- | | |
|--|--|
| • Bardet-Biedl Syndrome (Laurence Moon-Biedl) | • Norrie Disease |
| • Batten Disease | • Prader-Willi |
| • CHARGE Syndrome | • Pierre-Robin Syndrome |
| • Cockayne Syndrome | • Treacher Collins Syndrome |
| • Cornelia de Lange | • Trisomy 13 (Trisomy 13-15, Patau Syndrome) |
| • Dandy Walker Syndrome | • Trisomy 18 (Edwards Syndrome) |
| • Down Syndrome (Trisomy 21 Syndrome) | • NF2 – Bilateral Acoustic Neurofibromatosis Turner Syndrome |
| • Goldenhar Syndrome | • Usher I Syndrome |
| • Herpes-Zoster (or Hunt) | • Waardenburg Syndrome |
| • Leber Congenital Amaurosis | • Wildervanck Syndrome |
| • Marfan Syndrome | • Wolf-Hirschorn Syndrome (Trisomy 4p) |
| • Monosomy 10p | |
| • NF1 – Neurofibromatosis (von Recklinghausen Disease) | |

For more information on deafblindness, contact one of the following individuals listed below:

Missouri Deafblind Technical Assistance Project:

Susan Bonner, Project Coordinator

(314) 776-4320 x 254

sbonner@msb.k12.mo.us

St Louis Deafblind Task Force:

Susan Bonner, Task Force Facilitator

(314) 776-4320 x 254

sbonner@msb.k12.mo.us

Kansas City Deafblind Task Force:

Dale Felder, Task Force Chairperson

(660) 584-9482

Dale.Felder@dmh.mo.gov

Central Missouri Deafblind Task Force

Katherine Schroeder, Task Force Chairperson

Katherine.C.Schroeder@dss.mo.gov

Southwest Missouri Deafblind Task Force

Ellie Widmer, Task Force SW MO Contact

ellie@gcbdd.org



MoSPIN*

*Missouri Statewide Parent Involvement Network

*A family outreach service from Missouri School for the Blind...
...Providing a statewide home-based program for families of children, Birth through 5 years old,
who are visually impaired.
A statewide home-based program for families of preschoolers with visual impairment
or visual and hearing impairment.*

Since 1987, Missouri School for the Blind has been providing a statewide home-based program to assist Missouri families with children who are visually impaired. The program is known as the Missouri Statewide Parent Involvement Network (MoSPIN).

MoSPIN provides direct, in-home services to families throughout the state through specially trained “parent advisors.” The program is designed for parents of children who are visually impaired and who may also have other disabilities (developmental delay, hearing impairment, motor impairment, etc.).

Eligibility is based on a visual diagnosis by a certified ophthalmologist.

MoSPIN includes the following components:

- Regularly scheduled home visits by parent advisors
- Focus on parents as their child’s first and most important teacher
- Information to help parents understand their child’s visual diagnosis and learning characteristics
- Parent lessons on communication techniques, sensory stimulation and basic developmental skills from the INSITE curriculum
- Ongoing support and provision of resources to families

In addition to home-based services, Missouri School for the Blind Outreach Staff are available to provide technical assistance, resources and support to school personnel, early childhood providers and parents.

For more information, contact:

Ginny Williams
Lead Parent Advisor
Missouri School for the Blind
3653 County Road 4008
Holts Summit, MO 65043
573-295-4808
573-295-4669 (fax)
800-622-5672 (leave message only)
ginwilliams@aol.com



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Frequently Asked Questions About MoSPIN “Missouri Statewide Parent Involvement Network”

An outreach service from the Missouri School for the Blind for families of children who are visually impaired, birth through 5 years old.

What is MoSPIN?

What is included in MoSPIN services?

Who is eligible?

What do MoSPIN families say about the program?

Are services available statewide?

Who do I contact for more information or to make a referral?

What is MoSPIN?

Since 1987, Missouri School for the Blind has been providing parent education via a statewide home-based program to assist Missouri families with young children who are visually impaired. The program is known as MoSPIN (Missouri Statewide Parent Involvement Network).

What is included in MoSPIN services?

MoSPIN provides direct, in-home services to families throughout the state through specially trained “Parent Advisors”. This program of parent education is designed for families of children who are visually impaired and who may have other disabilities (developmental delay, hearing impairment, motor delays, etc.). What makes MoSPIN unique is its focus on the family rather than direct service to the child.

MoSPIN includes the following components:

- Home visits by Parent Advisors (Parents select one or two hour visits, not to exceed 4 hours per month.)
- Focus on parents as their child’s first and most important teacher
- Information to help parents understand their child’s visual diagnosis and learning characteristics
- Parent lessons on vision, communication, motor, hearing , or cognition from the INSITE curriculum
- Ongoing support and provision of resources to families

Who is eligible?

Families of children birth through 5 years old are eligible. Eligibility is based on a current eye report (within one year) with a visual diagnosis by an ophthalmologist. Parents agree to be the active learners in this home-based program.

Are services available statewide?

MoSPIN services are available to all eligible Missouri families.

What do MoSPIN families say about the program?

*Everything I do in and out of my home has been sharply influenced by information received through MoSPIN.

*MoSPIN has been an amazing program for us. We received emotional support, knowledge to use for our son, and skills to help him in being a happy, healthy, independent child.

*MoSPIN gave me tools to better understand and help my child.

*The program gave us confidence and knowledge to move forward as a family.

*I was scared and in shock when my daughter was diagnosed. My Parent Advisor was really there for me – she not only provided education, but empowered me and gave me courage to be the parent my daughter needs me to be for her to develop and learn.

Who do I contact for more information or to make a referral?

Parents are encouraged to contact:

Ginny Williams
Lead Parent Advisor
Missouri School for the Blind
3653 County Road 4008
Holts Summit, MO 65043
573-295-4808
573-295-4669 (fax)
800-622-5672 (to leave message only)
ginwilliams@aol.com

Missouri Instructional Resource Center f/t Visually Impaired

Yvonne Ali, Supervisor
Missouri School for the Blind
3815 Magnolia Avenue
St. Louis, MO 63110

314-776-4320 ext. 256
800-622-5672 (Only for leaving messages)
yali@msb.k12.mo.us

Fax: 314-773-3762
Email:

Services

- Registers, on an annual basis, Missouri students who are legally blind for Federal Quota Funds.
- Purchases braille and large print textbooks and instructional aids from APH (American Printing House for the Blind, Louisville, KY) to lend to schools for use by registered students.
- Maintains a library of textbooks and a storeroom of instructional aids, consisting of APH materials and materials donated by school districts.
- Lends textbooks and aids primarily to registered students, but also to visually-impaired students who do not qualify for registration.
- Provides lender or vendor sources for books unavailable from the Center.

Federal Quota Registration

Each year in January, school districts and educational agencies nationwide register legally blind students under "An Act to Promote the Education of the Blind" (1879). Federal Quota Funds are then allocated based on registrations. Eligibility for Registration

"...central visual acuity of 20/200 or less in the better eye with best correction; a peripheral field so contracted that the widest diameter of such field subtends an angular distance no greater than 20 degrees; or visual performance reduced by a brain injury or dysfunction when visual function meets the definition of blindness as determined by an eye care specialist or neurologist."

The student must have been enrolled the first Monday in January in a formally organized public, private, or parochial, non-profit educational program of less than college level.

Late Enrollment or Change of School

The Center accepts responsibility for students who move into Missouri or who become legally blind between annual registrations.

Documents to be Maintained at the Local School in The Event of a Federal Audit

A current (within 3 years) eye report by an ophthalmologist, optometrist or neurologist if the student is classified as "Functions at the Definition of Blindness" that provides the visual acuity of both eyes (required). Exemption from the current eye report regulation: students with proven non-changing eye conditions, such as bilateral enucleations, anophthalmos, or other conditions determined immutable.

A written education plan for each student registered (required).

Recommended: Any available assessment reports, such as the Functional Vision Assessment (FVA) offered by Missouri School for the Blind, Outreach Services Division (not required)

Federal Quota Funds

Congress provides funds each year. APH allocates funds to each state. Each registered student brings Missouri approximately \$255 for purchase of APH materials only. The Center manages the Missouri quota as a lump sum. Students may get more than \$255 allocated depending on availability of requested items. Even if your student(s) will not be using quota funds, other Missouri students can use the funds, so it is vital to register all eligible students each year. Quota funds supplement local funds; they rarely supply all the materials needed by a student.

Textbook & Instructional Aids Request Procedures

Send a list of items needed to the Missouri Instructional Resources Center. Telephone requests are discouraged, except in emergencies, because of the extra time it takes to write down telephone requests and the possibility of transcription errors. Include the following information:

Student:	Name, Grade, School Year, Format (Braille, large print, tape or e-file)
Educator:	Name, Title, District, Shipping Address, Phone, Fax, E-mail Address
Textbooks:	Title, Author, Publisher, Copyright Date, ISBN from the student edition of text
Aids:	Name of the Instructional Aid, APH Catalog Number, and Quantity Needed

We ship in-stock items to you, and order APH items from Louisville, if quota funds are available. For items we cannot provide, we identify agencies that will lend or sell the items to you. You then contact them for more information. (The Center has no budget other than Federal Quota Funds to supply materials to districts.) Finally, we send you a summary of our actions and recommended sources.

Ownership of Materials

The Missouri Instructional Resource Center at the Missouri School for the Blind is the official repository for APH materials. All materials including equipment purchased from APH with Federal Quota Funds are the property of the Missouri Department of Elementary and Secondary Education. Textbooks must be returned to the Center at the end of the school year; contact us if you wish to renew them or transfer them to another student.

Some instructional aids, such as writing paper, are consumable. All other aids are on loan to you until no longer needed. Return all non-consumable aids to the Center when they are not being used anymore. Please do not return any textbooks or aids to APH in Louisville, because they will not accept them back.

Limits on Requests

We reserve the right to limit textbook orders to copyrights within the past five years. For expensive requests, we sometimes suggest substituting tapes from Recording for the Blind and Dyslexic or similar agencies. We do not order workbooks, tests (other than standardized tests), or recreational reading. **If the Missouri Instructional Resource Center cannot supply a book or instructional aid, it is the responsibility of your school to obtain the item using your school's state special education funds, Outstanding Schools Act funds, or other local funds.**

For More Information

Please review our web pages on the Missouri School for the Blind (MSB) website. Just go to www.msb.k12.mo.us, scroll down, and click on the link "Missouri Instructional Resource Center". It contains additional information about the Federal Quota Program, our services, instructions on how to request materials, request and equipment forms, and an extensive list of links to websites frequently used for accessible materials, and more.



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