



# IN FOCUS

## MISSOURI DEAFBLIND TECHNICAL ASSISTANCE PROJECT

Spring 2009

VOL. 6, No 2

---

### Family Involvement Fund (FIF)

The Family Involvement Fund (FIF) is administered by the Missouri Deafblind Technical Assistance Project. The FIF provides limited financial assistance for family members of infants, children and youth (ages birth through 21) who are visually impaired, blind or deafblind to further their knowledge and understanding of their child's disability

and/or the programs and services that support their child. The infant, child or youth must be registered on the annual blind and/or deafblind census. The financial assistance may be provided to support attending conferences and workshops (e.g., registration fee) as well as participation in online trainings and teleconferences.

#### **In This Issue...**

Family Involvement Fund.....	Front Page
Missouri Deafblind Census.....	2
Web Connections.....	4
Family Highlight "The Youngs".....	5
Helen Keller National Center.....	6
Hand Under Hand.....	6
Resources.....	10
Calendar of Events .....	11

In general, there is a \$250 limit per person or \$500 limit per family per year. Monetary limits are subject to change depending on demand, so please inquire. The funding year runs from October 1<sup>st</sup> through September 30<sup>th</sup>. Family is defined as parents, stepparents, siblings, grandparents, legal guardians, foster parents and educational surrogate parents.

**Please note:**

- Applications must be received at least 30 days prior to an event. The applying family member will receive written notice of approval.
- If approved for the FIF, the applicant must save and submit original receipts for actual expenses and will be reimbursed up to the per person/per family approved amount. The applicant must also complete all necessary paperwork required by the State of Missouri for reimbursement.
- Prior to reimbursement, the applying family member must share the outcomes of their experience by presenting orally at a Project activity or submitting in writing an article for inclusion in a Project newsletter or report.

An application may be downloaded from the

Missouri School for the Blind website at [www.msb.k12.mo.us](http://www.msb.k12.mo.us) by selecting Missouri Deafblind Technical Assistance Project and Family Involvement Fund. For more information, contact Susan Bonner, Coordinator, 314-776-4320, extension 255, [sbonner@msb.k12.mo.us](mailto:sbonner@msb.k12.mo.us).



## Missouri Deafblind Census

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 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.

## **CHARGE Syndrome Foundation**

9<sup>th</sup> International CHARGE Conference

July 24-26, 2009

Indian Lakes Resort

Bloomington, IL 60108

Visit their website for additional information

[www.chargesyndrome.org](http://www.chargesyndrome.org)

**Missouri Deafblind Families Web  
Connections**  
*A Family Listserv Network*  
*Development Assisted by*  
*The Missouri Deafblind Technical Assistance Project*



The Missouri Deafblind Families Web Connections is a closed listserv group initiated by the Missouri Deafblind Technical Assistance Project in response to families' request and moderated by families who have children on the Missouri Deafblind Census. A listserv is a means for members of the group to discuss and/or receive information from other members on the list. Content of the listserv messages is moderated by a family moderator. Posting of questions and materials are screened by the moderator prior to posting on the listserv to reduce potential spam. Once the moderator screens the message, it is automatically emailed to all members of the listserv.

The purpose of “*Web Connections*” is to provide a way for families to network with other families who have a child with both visual and auditory losses by:

- Exchanging information about a specific disability
- Exchanging information on raising a child with a dual sensory impairment
- Interacting with other families with similar educational needs for their child
- Providing emotional support to other families with similar needs
- Posting information about special events and conferences relating to deafblindness.

“*Web Connections*” is families with a deafblind child communicating with other families to:

1. Network with other families (*f.08b*)
2. Gain knowledge of resources (*f.08c*)
3. Share knowledge of resources (*f.08d*)

To join the listserv, please send an email to Susan Bonner, [sbonner@msb.k12.mo.us](mailto:sbonner@msb.k12.mo.us), with a request to join “*Web Connections*.” Your message will be sent onto the family moderator, who will send you an invitation to join the listserv that includes the instructions for joining.

## The Youngs Meet Sarah Palin

2008 was a campaign year. Missouri hosted many political rallies for candidates from the political parties. One of Missouri's families met Sarah Palin during a campaign stop in Cape Girardeau. The following is the Young family's reactions to the visit with their son, Tate.

"Yes, we got to meet Sarah and Todd Palin this morning at her rally here in Cape!!! She came up and I shook her hand and told her that we had two children with special needs and what an inspiration she was to us. She touched my cheek and said, "bless you" and then she asked about the boys. I told her that they had CHARGE Syndrome and she asked what that was. I gave her a brief description about CHARGE and then gave her an envelope that I had for her. Inside was a brochure on CHARGE Syndrome along with two adorable pics of Peyton and Tate and letter about being a mom to special needs children. It's the "Mom Sorority" for any special needs moms reading this. One of Tate's therapists had sent it to me a couple of days ago and I thought to myself "perfect, I'll give it to Sarah" not knowing if I would even be able to get near her!



Then she asked how old Tate was and rubbed his little head and I told her "two". She and Todd both commented on how big he was for two. Then I told her how we loved Trig and how cute we thought

he was. I told her how I was always watching for him on TV. Then she moved on to Peyton and I introduced her to his two teachers that were with us (Mandy Smith and Nancy Robertson) and told her they were wonderful. Todd shook both our hands (Mike didn't get to shake Sarah's, he was too busy taking pictures, what a husband!) and I think Mike even shook Todd's twice. It was all so surreal. I can't tell you how genuine and down to earth she was throughout our little conversation. It was such an amazing experience that I'll never forget. I feel like Marcia Brady, I don't want to wash my cheek or Tate's head again! Ha!

We never dreamed we'd even be able to be that close to her let alone meet her and talk with her and Todd! Yeah!!!"

### National Family Association for Deaf-Blind

#### ***Families Connecting with Families***

July 17 – 19, 2009

Hilton Orange County, 3050 Bristol

Costa Mesa, California

[www.NFADB.org](http://www.NFADB.org) or [www.napvi.org](http://www.napvi.org)

Interactive sessions & panel discussions to address parents' needs

Networking with other families & professionals

Free Daycare

Activities designed for teens

Fun for whole family with special reception & events

Preview new assessment guide for children who are deaf-blind

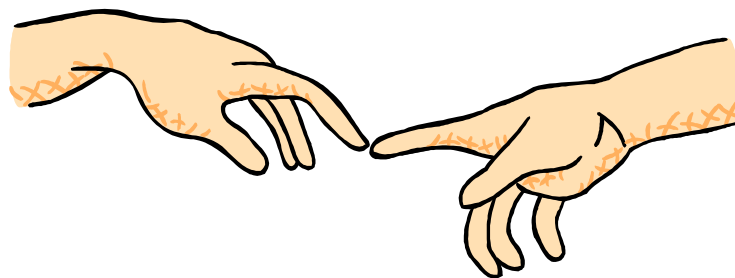
Communication issues for children who are deaf-blind

## Helen Keller National Center



The **Helen Keller National Center** (HKNC) maintains a National Registry of people who have both hearing and vision loss. Although your child is on the MO Deafblind Project census, we need your permission to share the information with HKNC. There are many benefits of adding your child to the National Registry. HKNC can serve as a lifelong point of contact for information and resources. This is especially important as your child exits the school system and enters the adult service world.

Beth Jordan is the HKNC regional representative who serves Missouri families and youth. She is based in the Kansas City area. You can contact Beth by calling 913-677-4562 voice or TTY. You can also email her at [HKNC7BJ@aol.com](mailto:HKNC7BJ@aol.com). Beth can take the National Registry information over the phone or you can enter the information on the HKNC website at [www.HKNC.org](http://www.HKNC.org). Click on “National Registry form” to complete the form on-line.



### Hand Under Hand

*From Oregon Deafblind Project  
“Building Effective Programs” Spring  
2008*

*Reprinted permission from Lyn Ayer, Project Coordinator*

#### **Purpose of Hand-Under-Hand**

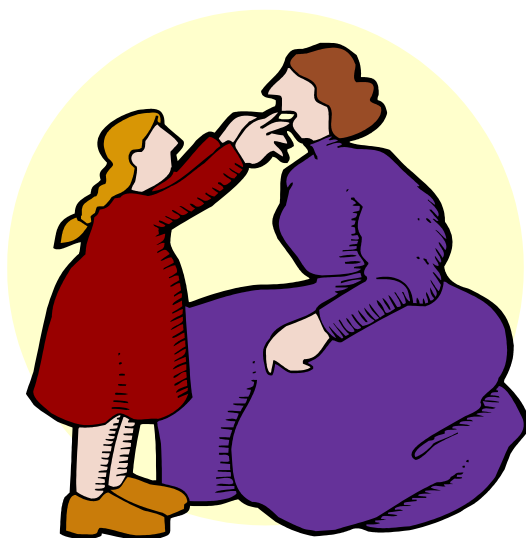
Children who cannot see very well do not really know how other people use their hands. They are often not aware of all that their own hands can do! They may not know:

1. How their hands relate to one another – i.e., how many movements need BOTH their hands
2. That there are times when one hand can be used – while the other one “rests.” For example – one hand

writes, while the other one rests on the piece of paper to keep it from moving..

3. How much force to use – when they need to push or pull hard, or when to be gentle.
4. Whether an action needs to be done fast or slow.
5. What the “shape” of the movement looks like (e.g.’ the twisting motion of opening a jar)
6. About the “space” between their hands – and why it is important to know about this\About hands and how their hands relate to direction.

We want children to learn about all of the above-mentioned points to that they can then begin to understand what they need to do with their hands to perform routine tasks, and to learn to do these independently of the hands of others.



They need to understand that they do not need the hands of others to do most of the routine

tasks that are required of them. But they also need to know that the hands of others can be involved in some tasks that need joint action (such as lifting and carrying a heavy piece of furniture), or that have some “social” meaning (e.g., holding hands).

In encouraging hand-under-hand, we hope to

- Stimulate their curiosity rather than make them feel that they are being “controlled.”
- Encourage the desire to be independent in the use of their hands.
- Reduce – even eliminate – the need for prompting for the various steps of a task.

### **How to Use Hand-Under-Hand**

The best way to give student an experience of what THEIR hands can do will be to position yourself in such a way that they can feel the natural movements from their point of view. This will not occur if you sit opposite a child. Instead, you need to sit behind a child (if the child is small enough physically – and your arms are long enough) OR sit beside a child (on the side of his/her “preferred” hand makes most sense). A very young child, especially a child who needs additional physical support could even sit on your lap. Things to consider:

- Make sure you are at the child’s level.
- Place your hands under the child’s hands – your right hand under his/her right hand, left hand under his/her left hand.
- For children who are “touch sensitive”

and tend to withdraw their hands, you may initially have to gently “anchor” their hands with your thumbs – or allow your fingers to interlock with theirs. You will be surprised at how soon children will learn to relax once they know they are just being asked to “followed” and not to “do.”

- For children who are REALLY resistant, you may begin just with physical contact – e.g., arm to arm, hands beside rather than under or over a child’s hands. Play some movement games, or tap on the table. Make it evident they you are NOT going to force them to do something until they are ready.
- Initially find a task that is gentle and repetitive – such as stirring something in a bowl. Make sure there is some “resistance” to what you are stirring – so the child can really feel the movement of the spoon “stirring” the mixture – and how to hold on to the bowl, too.
- When the child starts to show “curiosity” about the spoon, the bowl, or the contents, allow his/her hands to slide down - or to feel “between” your finger; at some point, gently encourage “joint” holding of the spoon, bowl.
- Examples of other activities to try:
  - Cutting food, scooping food, using utensils
  - Reading a Braille book
  - Zipping up a jacket; also snaps.



- Velcro fasteners on shoes, garments
- Using a three-hole punch, paperclips

### **Key Concepts of Hand-Under-Hand**

The hands of a child who is Deafblind are not just “tools,” or sensory organs deriving information from around them, but they are also the child’s “voice.” So, in Barbara Miles’ words, “it is crucial for educators, parents, and friends of people who are Deafblind to become especially sensitive to hands. Just as they would never poke or control the sensitive eyes of a child who can see, they must learn not to control the equally sensitive hands of a child who is Deafblind, whose hands must function as eyes.” <http://eee.dblink.org/pdf/hands.pdf>

So, what follows is that we think of hands in the same terms as eyes. The child needs TWO hands:

- To gather maximum information
- To know how to use them together – perhaps to do two different movements that is part of one total action.
- To understand the “space” that is involved.



- To understand that the world is three-dimensional: to acquire depth perception.

Keep in mind, especially if touch is the main learning mode for a child:

- That too much touch may become confusing to the child's brain. For example, touching the back of a child's hand (as in hand-over-hand guidance) may distract attention from what is under the hand. The child may pay more attention to your hand than what is under his/her own hand.
- Deep pressure massage to fingers and palm will help when a child continues to be resistant to touch. In most cases you will actually FEEL a child's hand become more and more relaxed.
- Talking constantly as one works with a child tactilely is also distracting to the brain. Use short precise words or phrases that describe the action or the concept – IF you need to talk. Sometimes, just working silently is best!
- Words are more often than not, abstract and difficult – for some children, impossible – to understand. SO create contextual clues that have more meaning. Pairing these with words might ultimately give the words some "meaning."
- As always, repetition is very important.
- Slow down! Do this especially as you start out – so as not to alarm the child, or to make a child feel he/she is under

pressure to feel something before it disappears.

- Work up to a normal rate of speed for that specific activity – because this is where you want the child to be. This might happen during the very first session, or it may take several sessions.
- Keep BOTH the child's hand engaged in the task. You will find that, initially one hand (usually the non-dominant one) will tend to "wander" or not participate. The child may even need a tactile – or verbal – reminder of what each hand is doing. An example: holding a bowl while stirring something in it.
- You can use hand-under-hand activities to emphasize what parts of a hand are needed to do a task – arm, wrist, finger, palms. You can even teach the child more about what each of these parts are capable of doing.

You will KNOW you are making progress when:



- A child's hands feel increasingly relaxed while they "watch" what to do.

- The child begins to show curiosity about what is beneath your hands – and gradually begins to do more of the activity (e.g., joint holding of a spoon while stirring).
- A child becomes excited when you place your hands under his/hers – or when the child places his/hers over yours indicating they are ready to “GO” – to learn something new.

- There is a “comfortable” feeling involved in joint tactile activities.
- A child actually does the activity independent of your hands.

*Lyn Ayer thanks Barbara Miles and Geraldine G. Larrington for their “guiding ideas” on this topic.*

*Missouri Deafblind Project thanks Lyn Ayer for permission to reprint this article.*



## Resources

*The following is a listing of some informational items that may interest families and service providers.*

**Winter '09 Free Media for Deaf & Blind Students Features “Barack Obama: The Power of Change:”** Free online video available through the website of **Described and Captioned Media Program (DCMP)**, administered by the **National Association of the Deaf (NAD)** and funded by **U.S. Department of Education**. With messages from Michelle Obama, Stevie Wonder, Oprah Winfrey and Caroline Kennedy,

visit [www.dcmp.org/powerofchange](http://www.dcmp.org/powerofchange) for more information.

**Sight & Sound Impaired of St. Louis:** A new social group for adults and young adults with deafblindness. They meet monthly at 8764 Manchester, Suite 201, St. Louis, Missouri. They continue to look for new members and volunteers, who may assist as interpreters, with transportation or with other functions of the group. For more information, contact Mary Hale at [sasistl@sbcglobal.net](mailto:sasistl@sbcglobal.net)

**DeafMD.org:** This group maintains a website, [www.DeafMD.org](http://www.DeafMD.org). This website offers information about health topics in American Sign Language (ASL). Their search is available to look up

information on diseases, illnesses, medical tests, and current news, with translation in sign language.

**National Family Association for Deaf-Blind (NFADB):** A non-profit volunteer-based family association networking families focusing on issues surrounding deaf-blindness. For more information: [www.NFADB.org](http://www.NFADB.org) or 1-800-255-0411. Family membership in \$15.00 a year. Mail membership application to 111 Middle Neck Road, Sands Pont, New York 11050-1129.

**The White House Agenda on Disabilities:** “We must build a world free of unnecessary barriers, stereotypes and discrimination ... policies must be developed, attitudes must be shaped, and buildings and organizations must be designed to ensure that everyone has a chance to get the education they need and live independently as full citizens in their community.” *Barrack Obama, April 11, 2008.* Visit [www.whitehouse.gov/agenda/disabilities](http://www.whitehouse.gov/agenda/disabilities). Key points of the agenda include: 1) supporting IDEA, early intervention, and improving college opportunities for high school graduates; 2) ending discrimination and providing equal opportunities by restoring the Americans with Disabilities Act; 3) increasing employment rate of workers with disabilities; 4) supporting community-based living.

## Calendar of Events

### *Online /Distance Education*

**Date:** April 28, 2009, 1 PM – 2:30 PM

**Topic:** Webcast: Lifelong Learning in Career Education

**Location:** Fee webcast. Register at: [www.afb.org/careerconnect](http://www.afb.org/careerconnect)

**Audience:** Professionals working with children and adults with visual impairments.

**Contact:** American Federation for the Blind (888) 824-2184

**Date:** April 29, 2009, 1 PM – 2:30 PM



**Topic:** Webcast: Determining Current & Future AT Needs

**Location:** Free webcast. Register at: [www.afb.org/careerconnect](http://www.afb.org/careerconnect)

**Audience:** Professionals working with children and adults with visual impairments.

**Contact:** American Federation for the Blind (888) 824-2184

In Focus Fall 2008

**Topic:** Graduate Certification in Deafblindness

**Location:** Department of Curriculum and Instruction, East Carolina University

**Audience:** Distance education certification with e-supervision of practice

**Contact:** Alana Zambone, (252) 328-5746 or [zambonea@ecu.edu](mailto:zambonea@ecu.edu)

*Summer, 2009*

**Date:** Sunday, June 7 – Friday, June 26, 2009

**Topic:** Project STEP

**Location:** Webster University, St. Louis, Missouri

**Audience:** This program is specifically for students who intend to attend college, a vocational training program, or seek competitive employment upon graduation from secondary school. Maximum of 12 students in this residential program.

**Contact:** [kjhollinger@gmail.com](mailto:kjhollinger@gmail.com) or [ayorke@lhbindustries.com](mailto:ayorke@lhbindustries.com)

**Date:** June 28 –July 2, 2009

**Topic:** 2009 Annual Chromosome 18 Conference

**Location:** Red Rock Casino, Resort & Spa, Las Vegas, Nevada

**Audience:** Families and service providers

**Contact:** [www.chromosome18.org/Service/annualconference./2009annualconference](http://www.chromosome18.org/Service/annualconference./2009annualconference)

**Date:** July 5-10, 2009

**Topic:** Emerging Literacy for Children with Multiple Disabilities Including Deafblindness

**Location:** Tennessee Deafblind Project

**Audience:** Teachers, service providers, and administrators

**Contact:** Jennifer Vick (615) 936-2862 or [Jennifer.Vick@vanderbilt.edu](mailto:Jennifer.Vick@vanderbilt.edu)

**Date:** July 17-19, 2009

**Topic:** National Family Association on Deaf-Blindness: Families Connecting with Families Conference

**Location:** Costa Mesa, California

**Audience:** Families

**Contact:** [www.NFADB.org](http://www.NFADB.org)

In Focus Fall 2008

**Date:** July 24-26, 2009  
**Topic:** 9<sup>th</sup> International CHARGE Conference

**Location:** Indian Lakes Resort, Bloomingdale, Illinois

**Audience:** Families and teachers

**Contact:** [www.chargesyndrome.org](http://www.chargesyndrome.org)

**Date:** August 13 – August 16, 2009  
**Topic:** Norrie Disease Association International Conference

**Location:** Holiday Inn Boston at Beacon Hill, Boston, Massachusetts

**Audience:** Families and interested service providers

**Contact:** [joinNDA@gmail.com](mailto:joinNDA@gmail.com)

*Fall, 2009*

**Date:** October 9-10, 2009

**Topic:** Symposium on Research advances in Hearing Loss

**Location:** Houser Hearing Institute, Louisville, Kentucky

**Audience:** Audiologists, Early Childhood Interventionists, Newborn hearing screeners

**Contact:** [dmarr@thehearinginstitute.org](mailto:dmarr@thehearinginstitute.org)



Missouri Deafblind Technical Assistance Project  
Missouri School for the Blind

Project Staff

Jennie Mascheck ...Project Director  
Susan Bonner .....Project Coordinator  
Andrea Harrington...Education Specialist  
Janus Hinson .....Transition Specialist  
Virginia Williams ....Family Specialist  
Michael Grady .....Project Evaluator  
Linda Van Eck .....Project Consultant  
Margaret Anthony.....Project Secretary

3815 Magnolia Avenue  
St. Louis, MO 63110  
(314) 776-4320 x 255  
[www.msb.k12.mo.us](http://www.msb.k12.mo.us)

**Missouri Deafblind Technical Assistance Project  
Missouri School for the Blind**

***In Focus***

Susan Bonner ..... Editor

This newsletter is supported in part by the U.S. Department of Education, Office of Special Education Programs. However, the opinions expressed herein do not necessarily reflect the policy or position of the U.S. Department of Education, Office of Special Education Programs, and no official endorsement by the Department should be inferred.

*NOTE: There are no copyright restrictions on this document; however, please credit the source and support of federal funds when copying all or part of this material.*



This newsletter is supported in part by the Missouri School for the Blind, Missouri Department of Elementary and Secondary Education. The Department of Elementary and Secondary Education does not discriminate on the basis of race,

**Missouri School for the Blind  
3815 Magnolia Ave  
St Louis, MO 63110**



**In Focus**