

# In Focus



## Missouri Deafblind Technical Assistance Project



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### Connecting with Families



The Missouri Deafblind Technical Assistance Project strives to keep families informed in this fast moving technology age. The internet has been a wonderful means to keep families informed of events and current news that may affect them and their child with combined vision and hearing loss.

The Project has been adding families to an email distribution list as the office acquires email addresses from families. Please mail Susan Bonner if you wish to be added to the distribution list of families. Susan will be able to keep you informed of current events and activities that may be of interest to you. You may email Susan at [susan.bonner@msb.dese.mo.gov](mailto:susan.bonner@msb.dese.mo.gov).

There is continued family interest in connecting with other Missouri

families through email groups. Several families would like to set up a listserv for parents to connect with each other and discuss common needs and supports for their children. If this interests you, please let Susan Bonner know via your email. She will pass your name onto these parents.

In the St. Louis area, several families who have been involved with Delta Gamma have started a parent group. At this time, they are addressing

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#### Missouri Deafblind Technical Assistance Project Missouri School for the Blind In Focus: Susan Bonner ....Editor

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families of children under the age of 14 in the greater St. Louis area. They plan to meet regularly and share information about their children's disabilities and

available services. For more information, families may contact Jo Russell-Brown at Delta Gamma, (314) 776-1300 ext 106



## **Educators' & Service Providers' News**

### **Resources on Deafblindness:**

The Missouri Deafblind Technical Assistance Project has a variety of free services to support service providers serving students with combined vision and hearing loss and the students' families.

First, the Project is available to provide free technical assistance to educational teams and the families. Service providers may contact Susan

Bonner at the project office and discuss their needs and identify outcomes that they wish to achieve.

The service provider secures a release of information form from the family and sends that to the project office with a letter from their administration inviting the Project to assist them.

Susan Bonner will contact the service provider and together they will identify possible outcomes that they

anticipate and identify dates for the visit. The Project will come to the program to observe the student, provide some preliminary ideas to help the team and then follow-up with a written report and phone call.

The annual Hand In Hand course encompasses lectures, practice of skills and mentoring to the educational teams serving students with combined vision and hearing loss. The course includes homework activities to be completed that relate to a student's needs and assist

*"Tell me and I forget, teach me and I may remember, involve me and I learn"*

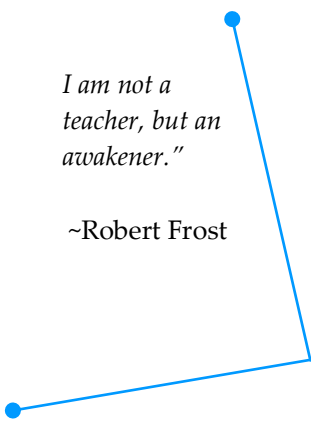
~Ben Franklin

the team in understanding the effects of combined vision and hearing loss, communication, orientation and mobility, instructional strategies and sensory needs. Participants, including parents, come as a team to the three sessions that meet for a total of seven days during the school year. A team is two or more people. It is not mandatory that the family attends. The course is free, but for a nominal tuition participants may earn two hours from Lindenwood University for their work and attendance in the class. Currently, Hand In Hand is completing the 2012-2013 School Year class in Columbia, Missouri. The Project is planning to hold the 2013-2014 course

in St. Charles County, Missouri.

A third option for service providers is SETS-DB (Supporting Educational Teams of Students with Deafblindness). SETS-DB is designed for service providers who are unable to attend Hand In Hand, but need intensive support in teaching their student with combined vision and hearing loss. In SETS-DB, the Project comes to the district to complete the activity. Day one includes project staff observing the student within their normal school routines. On that same day, late in the afternoon, the project staff provides a two-hour overview on the impact of combined vision and hearing loss as it relates to the student. During the evening, the

project staff assembles ideas and materials for the next day that are based on their observation of the student. Day two is an all day training for the staff at the school building that focuses on key instructional strategies focusing on evidence-based practices that are pertinent to student's learning needs. The team will develop an action plan and the project staff provides the team with any additional resources they may need and follow up by phone, email and/or in person. Contact Susan Bonner at (314) 776-4320 ext. 3255 if you think this may assist your program and student.



*I am not a  
teacher, but an  
awakener."*

~Robert Frost

## **Lending Library**

The Missouri Deafblind Technical Assistance Project maintains a lending library of books, manuals and DVDs which is available to educators, service providers and families. A complete listing of the collection is available for viewing on our website at <http://msb.dese.mo.gov/documents/AnnouncedBibliography082212.pdf>. Some of our newest acquisitions that may be of interest include:

### **Informal Assessments for Transition Planning.**

Gaumer-Erickson, Amy; Clark, Gary & Patton, James. Pro-Ed. 2013. This book provides

teachers a variety of informal assessments that assists in transition planning for the students. The book includes a CD-ROM that has all the assessments in reproducible formats for use by the educational teams.

### **Design to Learn: An Environmental Inventory to Help Teachers Design Learning Opportunities for Children with Disabilities**

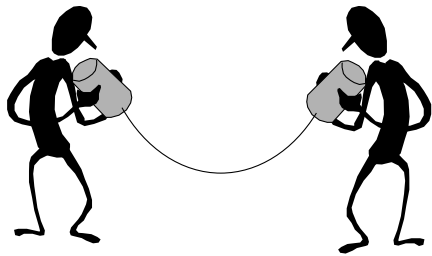
Rowland, Charity & Schweigert, Philip. Designed to Learn, Oregon Health & Science University. 2003. This inventory is used "to identify and create opportunities for active participation and learning in everyday classroom

activities." It includes a DVD which demonstrates all the concepts listed in the inventory and how to observe it if the child is demonstrating the skill. Areas addressed in the inventory include transitions in a school, the lessons, adult interactions, the student's communication, peer interactions, opportunities to communicate, opportunities to use objects and materials.

*"Imagination is more important than knowledge."*

~Albert Einstein





## Reaching Across the State

Hands and Voices is a not-for-profit parent group dedicated to supporting families with children who are Deaf or Hard of Hearing without a bias around communication modes or methodology. They provide families with the resources, networks, and information that they need to improve communication access and educational outcomes for their children. Their outreach activities, parent/professional collaboration, and advocacy efforts are focused on enabling Deaf and Hard-of-Hearing children to reach their highest potential. The Missouri chapter began formation last year. Cindy McMurtrey (Parent) [cmcmurtrey@charter.net](mailto:cmcmurtrey@charter.net) is the President of Missouri's chapter. Please contact Cindy McMurtrey for more information about the Missouri's chapter or visit their web site at <http://www.handsandvoices.org>

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## One Dad's Nuts & Bolts of Advocacy on the State Level

**By: Jamey McVicker, Parent of Aiden – 11 years old**  
**From: NCDB's "Deafblind Perspectives" with**  
**permission to print from Jamey McVicker**

*Editor's note:* During NCDB's current two-year extension, a major focus has been placed on increasing the capacity of family members to form collaborative relationships and to develop leadership and self-advocacy skills. One very practical opportunity for collaboration can be found on state special education advisory panels. IDEA [Sec. 612(a)(21)] requires that each state establish and maintain an advisory panel for the purpose of providing policy guidance with respect to special education and related services for children with disabilities in the state. As part of its overall family engagement initiative, NCDB is working to build the capacity of parents of children who are deaf-blind (as well as deaf-blind project personnel) who serve on these panels. This article highlights the perspectives and experiences of a father serving on the Missouri Special Education Advisory Panel.



In this article I aim to share my family's path and experiences, as well as my role as a dad, husband, firefighter, teacher, and activist. First, let me introduce myself and my family. My name is Jamey McVicker. My wife, Amy, and I were high school sweethearts and have been married 14 years. We have 3 children—Aiden (11), Avery (8), and Addison (5). Aiden was born with bilateral anophthalmia (the absence of eyes) and has profound bilateral hearing loss and other health and development issues. We live in Cameron, Missouri, a rural farming and bedroom community just north of Kansas City and east of St. Joseph. I am employed with the St. Joseph Fire Department as a fire captain.



*Captain Boyd Alldredge, Aiden McVicker, and Jamey McVicker.*

Like every newly married couple, we had dreams of the perfect family, the perfect life. When our son was born, we were headed down that perfect avenue. My how our lives have changed. . . and we wouldn't have it any other way. Aiden has introduced us to a world we may not have otherwise seen and passionate people we may not have met. He embodies values and characteristics that we hope to emulate. The time I have had with Aiden has helped me develop into a “Man” more than any other experience in my life. I owe it to him, and a strong faith, for making me the better person I am today.

Living in a rural town, it is difficult to acquire the necessary resources to best serve Aiden and his educational and medical needs. This past year, we as a family decided it would be best to educate Aiden at home. With the help of the Missouri Deafblind Project, we pursued a “future planning” approach. Our lesson plans are primarily life-skill based and incorporate community activities and social functions.

The staff with the Missouri Deafblind Project witnessed our passion for the deaf-blind community and encouraged us to participate at the state level, advocating for this population. Thoughts and prayers were given to the idea of serving on the Missouri Special Education Advisory Panel, which advises and recommends policies, procedures, and practices for the Missouri Department of Education, concerning special education. It is comprised of individuals with a disability, parents of individuals with a disability, educators, and administrators. I concluded that it would behoove our family, and others, to fill this need. I applied for a position on the panel and was appointed by the Commissioner of Education the next month.

*"Any man  
can be a  
father but it  
takes  
someone  
special to be  
a dad."*

~Anne  
Geddes

This position was outside of my comfort zone, but I was willing to step out for my child. I have never been one to put myself in the public spotlight. I do not have a master's degree in education, but I do have a passion for my child. The time requirements were minimal. The panel meets quarterly, and the meetings run approximately 5 hours. Transportation and meals are provided. Going into the first meeting, my stomach was in my throat because of anxiety and nerves. What can a firefighter bring to the table? Firefighters, and dads, fix things. It's just what we do (with a manly grunt). We use our practicality, experience, innovation and our hands. Our family had been thrust into something I couldn't fix. But I felt I could play a role. I could help "fix" the way people think about disabilities and help policymakers better meet the needs of children with disabilities. Much to my surprise, I found my niche quickly and took a leadership role on the panel. I do have a lot to offer, and it is experience-based. No one knows what families need better than the families themselves.

My experience serving on Missouri's Special Education Advisory Panel has been highly enlightening. I've learned about educational techniques, state and nationwide trends, and new, innovative adaptive equipment and technology. I'm now learning about new legislation coming down the pike. It is very rewarding to receive this knowledge and be able to provide a credible influence for children in our state—all because I was able to step out of my comfort zone. I would encourage anyone who has an interest to pursue a position on their state's panel, and to do so wholeheartedly. Deaf-blind awareness-raising and legislation to benefit children who are deaf-blind need all the advocates they can get because of the low incidence of dual sensory loss. It is a very exciting time for deaf-blind education, particularly involving the development and recognition of interveners—individuals with special training in deaf-blindness who work with children who are deaf-blind and provide access to the environment, communication, and other people. We owe this progress to all the activists who travelled this road before us. Now it is our turn to take the torch and run.

If I had one wish for Aiden's education, it would be for him to have had intervener services at an early age and continuing into adulthood. My hope for all individuals who are deaf-blind is to mimic Minnesota's intervener programming inside the schools and within the community. The intervener role is on the verge of breaking out nationwide, and I hope we all share the same values as the Minnesota deaf-blind community leaders. Should you have questions, concerns, or anxiety about playing a role on your State Special Education Advisory Panel, please do not hesitate to contact me. Wouldn't it be amazing to have at least one representative for the deaf-blind community on every State Special Education Advisory



Panel? Together, we can collaborate; share our experiences, successes and failures; and make great strides forward for future generations.

Thank you for taking the time to read about my family and our experiences. I know we all have many trials and tribulations, but I wish to share our successes and smiles as well. Too many tears have been shed through the years. Many of them could have been prevented if only we had opportunities to collaborate on effective strategies, as well as to learn from each others' failures. I would also like to thank NCDB for allowing me this opportunity to share and hopefully motivate others. I have failed many times and in many different capacities in my life. I hope that I have learned from these times and that they have made me grow to know what it takes to be a better dad, husband, firefighter, teacher, activist, student, and son. I would like to share with you a thought of mine that I feel is very true to all life experiences, whether they be academics, athletics, or any other endeavor:

*“Only failure can leave the motivation to fuel the hard work that produces success. To have had success means to have known and understood failure.”*

Jamey McVicker may be contacted at [jmcvicker@centurytel.net](mailto:jmcvicker@centurytel.net)



## Understanding Hearing Loss

***From Missouri School for the Deaf “Deaf Educator News,” Nov. 2012***

1. Even minimal hearing loss (16-25 dB) can affect academic achievement, and thus there are likely to be many students who need extra educational services but are not receiving them. (Spencer, 2010)
2. At least 35% and perhaps over 50% of deaf and hard-of-hearing students in the US have an additional, educationally significant condition or disability. (Spencer, 2010)
3. In general education classrooms, it is quite unlikely that the deaf and hard-of-hearing students understand language as well as their hearing peers. The teacher must check with them frequently to ensure they understand (Spencer, 2010)
4. Hearing aids, cochlear implants, FM systems and other technologies help children gain access to sounds in their environment, including speech, but none of them provide access equal to that of normal hearing. (Marschark, 2012)



"If I hadn't lost my hearing, I wouldn't be where I am now. It forced me to maximize my own potential. I have to be better than the average person to succeed."

~Lou Ferrigno

5. Parents and Teachers often overlook the overwhelming amount of learning that takes place in informal interactions and activities both in and out of school. Often this type of learning is not accessible to deaf and hard-of-hearing children. (Marschark, 2012)

6. Sign language does not interfere with the development of spoken language. The benefits of knowing two languages over one are well documented. (Marschark, 2012)

7. It is essential that deaf children acquire both language fluency and skill in visual learning strategies. (Marschark, 2012)

8. Adults and students (either deaf or hearing) that are fluent in ASL tend to have better visual spatial memory than hearing students, while oral deaf and hearing students tend to have better sequential memory. (Marschark, 2012)

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Marschark, M. &. (2012). *How Deaf Children Learn*. Oxford University Press.

Spencer, P. &. (2010). *Evidence-Based Practice in Educating Deaf and Hard-of-Hearing Students*. Oxford University e.

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## The Project at Work: Education Specialist



Andrea Harrington, BS, is the Project's Deafblind Education Specialist. Andy is a graduate from the University of Nebraska with a degree in Speech Pathology and Audiology. For 25 years, prior to joining the Project staff, Andy was a teacher of infants, children, and youth with deafblindness and multiple impairments in Kansas City, MO.

In addition to bringing 25 years of educational experience to the Project, she brings experience as a speech pathologist and audiologist. Andrea works closely with Susan Bonner providing technical assistance to service providers and schools as well as serving as a lead instructor for our Hand In Hand course.

## Families' Corner:

### Transition Assistance

When students turn sixteen (16), the students' individual educational plan (IEP) team must begin discussing transitioning for post-secondary services. If the IEP team views that transitioning needs to be addressed sooner, then they may begin discussing those goals as early as age fourteen (14). Many times families and the students may not have any ideas of what potential opportunities are available to the student. The IEP team addresses potential goals and strategies to reach those post-secondary goals. The Missouri Deafblind Project has several activities that the team may consider. The Project's transition specialist, Janus Hinson, is available to facilitate a person-centered plan to identify the skills and talents of the child and then identify future environments that the family and student desire to attend. Also, Project staff is available to develop a Discovery Profile for the team to use in planning the postsecondary outcomes. Discovery addresses the skills and talents of the student and then describes how they may translate into work skills. Discovery is a positive approach to address job development. Michael Callahan of Marc Gold & Associates developed the Discovery process. Contact Susan Bonner if this interests you and the IEP team.



### ICAN: International Children's Anophthalmia and Microphthalmia Network

The ICAN International Conference is scheduled for July 12<sup>th</sup> – 14<sup>th</sup> in Chicago, Illinois at the DoubleTree Magnificent Mile Hotel. Topics to include: Treatment updates, genetics update, panel discussion including individuals with A/M and parents, question and answer forums to answer questions from parents, issues related to the trials and tribulations of raising children with special needs. There will also be a licensed psychologist to facilitate group sessions for the kids (both those with A/M and their siblings). Watch their website <http://www.anophthalmia.org/conference.shtml> for more information. Interested parents may access the Family Involvement Fund from Missouri Deafblind Technical Assistance Project. Contact Susan Bonner at (314) 776-4320 ext. 3255.

### Save the Date: CHARGE Syndrome Foundation

The 11<sup>th</sup> *International CHARGE Syndrome Conference* is scheduled for July 25-28, 2013, at the Fairmont Scottsdale Princess, in Scottsdale, Arizona. Are you interested in attending, but need assistance? The Missouri Deafblind Technical Assistance Project is able to assist families with some of the costs to attend this conference. For assistance contact Susan Bonner at (314) 776-4320 ex. 3255. For more information about the conference go to [www.chargesyndrome.org](http://www.chargesyndrome.org).



## Help Missouri Go Green



The Missouri Deafblind Assistance Project wants to go green. Please email our Project Coordinator if you would like your future issues of “*In Focus*” to come by email. You will continue to receive hard copies by mail if you wish. Also, Susan Bonner maintains the families’ email addresses as a distribution list. As information is received that may be of interest to families, Susan emails immediately the information received. Those interested in going green contact: [susan.bonner@msb.dese.mo.gov](mailto:susan.bonner@msb.dese.mo.gov). Thank you.

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