



### Preparing For School



Schools are back in session and families are hoping for a successful year for their children. Families have many anxieties as the year begins Will their child adapt well to the new class and/or teacher? Will the bus schedule work well with after school care? Will the staff understand

their child's unique needs? And families' worries continue. Recently, the Special Education Advisor (July 30, 2012), a web site for families, ([www.specialeducationadvisor.com](http://www.specialeducationadvisor.com)) published a list of tips for parents whose children have IEPs.

Some of their tips are as follows:

1. "Get your child excited about going back to school by talking with them about it." This includes having your child with

vision and hearing loss get back into a routine similar to school, including preparing for school, wake up time and bed times.

2. "Go school supply shopping with your child and let them choose the school supplies that they want... within reason." For a student with vision and hearing loss, learning to make choices is an important skill to develop to increase their self-determination. Consider, too the child's unique

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

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needs when choosing supplies.

3. "Read your child's current IEP again and create a list of accommodations and services."

4. "Arrange a parent/teacher conference to

discuss your child's strengths, disabilities, accommodations, services and personality." You know your child the best. Often the new teacher is not aware of your child's unique needs to provide child a successful

school day. Your meeting is a wonderful time to share those important facts about child to build on a successful school year. Try these tips for you to help build a successful school year for your child.

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

### **Workshop on Cortical Vision Impairment (CVI): Visions of Change**

Cortical visual impairment (CVI) has been identified as the one of the leading causes of visual impairment in children. As increasing numbers of children are diagnosed with this condition, the importance of understanding CVI, its implications, and the development of effective

educational approaches have become paramount. Beth Ramella will be the presenter and is a teacher certificated in the education of students with visual impairment, a Certified Orientation and Mobility Specialist (COMS) and director of Outreach Services at the Western Pennsylvania School for Blind Children. Ms. Ramella participated in the five-year collaborative multi-state training initiative known as

the CVI Mentorship Project with Dr. Christine Roman-Lantzy. Dr. Roman-Lantzy and Ms. Ramella have worked collaboratively to develop a model for capacity building for children with CVI at the Western Pennsylvania School for Blind Children.

This free workshop will be held at Missouri School for the Blind in St. Louis on Tuesday, October 23, 2012. Registration will close: October 16, 2012. For more information contact:

*"You can teach a student a lesson for a day; but if you can teach him to learn by creating curiosity, he will continue the learning process as long as he lives. "*

Clay P. Bedford

Yvonne Ali at Outreach Services, [Yvonne.Ali@msb.dese.mo.gov](mailto:Yvonne.Ali@msb.dese.mo.gov) or 314-776-4320, ext. 3256.

### **Missouri Deafblind Technical Assistance**

**Project:** The Missouri Deafblind Technical Assistance Project is able to provide educational teams and families assistance when transitioning students into new schools, programs, and community settings. The Project is available to provide direct technical assistance to the schools and families providing them with information, resources and action steps to implement. The Project's transition specialist is available to facilitate person-centered plans and provide follow up consultation as

needed. Also, the Project spearheads interagency task forces on deafblindness that can provide resources to teams to assist students transitioning into other settings. For more information, contact the Project Coordinator, Susan Bonner at (314) 776-4320 ext 3255 or [susan.bonner@msb.dese.mo.gov](mailto:susan.bonner@msb.dese.mo.gov)



### **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 our library is available for viewing on our website at <http://msb.dese.mo.gov/documents/AnnouncedBibliography011912.pdf>.

Some acquisitions that may be of interest include:

### **Beyond Pegboards: A Guide for Teaching Adolescent Students with Multiple Disabilities.**

O'Connell, Cynthia. Perkins School for the Blind. This book provides teachers with alternative teaching methods that can be used to teach meaningful lessons for multi-disabled adolescents. In addition, it includes theme-based instruction.

*"Curiosity is the wick in the candle of learning."*

~William A. Ward

**Calendars for Students with Multiple Disabilities Including Deafblindness**

Blaha, Robbie.  
Texas School for the Blind and Visually Impaired.  
This book is written for students who need help structuring and organizing their time and activities. It includes information about: benefits of calendar systems, calendar

programming based on individual students' needs and skills, continuum of calendars available for expanding students' skills, communication and time, benefits of anticipation calendars, daily calendars, and expanded calendars for parents. It includes a section on assessing and evaluating the calendar system.

**Guide to Designing Tactile Illustrations for Children's Books.**

American Printing House for the Blind.  
Wright, Suzette. A resource for teachers to learn about the role of illustrations, challenges of tactile illustrations, designing tactile illustrations, meaningful tactile illustrations and description of various types of tactile illustrations.

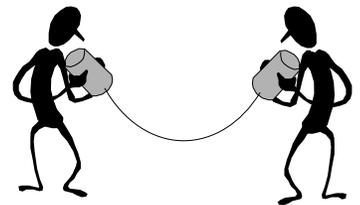
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**Hand In Hand 2012-13**

Hand In Hand is a course the Project offers each year for families and service providers. Participants come together as a team who provides support and educational services to a child identified on Missouri's Deafblind Census. Each year, the training is held in a different city in the state. For this school year, the course will be held in Columbia, Missouri at the Stoney Creek Inn.

The teams will learn:

- essential information about vision and hearing impairments and how these impairments can affect students with deafblindness;
- the interrelationship of communication and movement;
- the basic nature of communication and how students develop the



*The plain man is familiar with blindness and deafness, and knows from his everyday experience that the look of things is influenced by his senses; but it never occurs to him to regard the whole world as the creation of his senses.*

**Ernst Mach**

ability to communicate;

- how communication development is affected by deafblindness;
- the importance of assisting students with deafblindness to develop lifelong communication skills for full community participation;
- how a student's knowledge of body concepts and the environment can be affected by deafblindness; and,
- the importance of teaching students with deafblindness to become aware of their surroundings and to move or be guided purposefully and safely.

*"Touch has a  
memory."*

By John Keats

Dates for the course are:

Session 1, Tuesday through Thursday, October 2 – 4, 2012

Session 2, Tuesday & Wednesday, January 15 – 16, 2013

Session 3, Monday & Tuesday, April 8 –9, 2013

Contact Susan Bonner, Project Coordinator, for more details or registration information.

## **2012 National Family Association for Deafblindness (NFADB) Symposium in Austin, Texas, July, 2012**

**By:**

**Jamey & Amy McVicker, Parents of Aiden – 11 years old**

Sometimes things in this world are just unexplainable. We cannot tell you how blessed our family has been through the birth of our son Aiden. Amidst all the bumps & bruises, trials & tribulations, difficult decisions, trips to doctors and extra hours upon hours of raising a child with deafblindness, we have attempted to stay on course with our son's health, education and independence. It seems that we go through periods in our life where the ongoing stress of our daily tasks turns our once complex thought processor into the consistency of mashed potatoes. The symposium we attended in Austin, Texas was exactly what we needed to regain that momentum going into the next school year.



When the Missouri Deafblind Project made us aware of the symposium, the timing could not have been more appropriate. We both had our vacation days scheduled for the week after the symposium but had planned on just doing a "staycation" in our area. This opportunity afforded us a chance to be refreshed, re-energized, reconnected and motivated to

continue our journey. It also gave us the courage to venture on a 13-hour road trip with our three (3) children, allowing them a learning opportunity in a portion of the US we had not been. Therefore...we jumped on it!

Our arrival at the hotel in Austin was greeted with a warm welcome by the NFADB Board and a few connections were made early, telling of fond stories about our children. Registration was opened and we became members of the NFADB because their mission and activities align with our family. Should you have questions about their organization, it would be best to visit their website [www.nfadb.org](http://www.nfadb.org).

The Symposium was held at the Texas School for the Blind and Visually Impaired, which is going through a huge construction remodel. What a wonderful facility they will have to offer their students! We were lucky enough to be some of the first people to enter their new buildings. The opening session included two (2) parents from Texas who discussed their struggles with accessing the educational system for their children and how they lobbied their case to the State Representatives to push for better services for the deafblind population.

Long story short, they were the innovators to push the limit and break the ground to get trained Deafblind Interveners in Texas. That session also included two (2) adults with deafblindness who gave their personal stories and advocacy for a change in legislation. The first has a child with deafblindness who, with the use of her Support Service Provider (SSP), just piloted an airplane. Very impressive and evidence to never give up on your dreams! The second was Kim Powers-Smith. Kim is a role model for the DB community and her advocacy on the State and Federal levels are endless. One of her endeavors that particularly caught my attention was that she used to host a television show in Tulsa, OK called "Kim's World" this is where she would go out in the world with her SSP and, being deafblind, access and experience the world around her. Adventures, such as SCUBA diving, visiting the zoo up close and personal with some dangerous animals, cooking, etc., allowed viewers to



**Figure 1: Aiden, Dad and Sisters**

*The love of family and the admiration of friends is much more important than wealth and privilege.*

**Charles Kuralt**

*"You've got to be very careful if you don't know where you're going, because you might not get there."*

Yogi Berra

see/experience the world "through her eyes." That show was canceled but a station in California has acquired her to do the show on the West Coast and perhaps on YouTube!!! These individuals are awe-inspiring people and are to be commended for their perseverance against all odds. Very interesting and motivating to listen to!

The keynote speaker for the weekend was Dr. Beth Mount of New York City. She does a lot of Person-Centered Planning for youth in the area and assists with the transitioning into the workforce and independence. She is adamant that Person-Centered Planning provides clarity to sort through the details of paperwork and daily tasks to reach the imaginative future for that person. She believes that this should be the new force that drives a person's educational curriculum. "You find the gifts of a person and fit it to who/what/where needs that gift. Look and approach those immediately around you. They are happy to help but shy to approach. You need to be on the approach. When a person finds their place...their value...that is when a person COMES TO LIFE!"

Dr. Mount went on to state that Washington state has set the precedent for the nation in achieving the equalization of unemployment between the disabled workforce and the non-disabled. Their slogan is "If you can believe it...you can see it!" She also broke down "customized employment vs. supported employment." Customized is when the person goes to an employer, sees the tasks needed and fits the task to a person. This creates a dependency on that person. Supported is opening the 'Want Ads' and fitting a person to a task. Dr. Mount was quick to add that statistics show supported employment, where an employee is supported in

a particular job, there has been a 20-30% layoff rate since the economic downturn. In contrast, not one (1) person has lost their job in the same time frame if the task was fitted for the employee (customized).



Linda Alsop of Utah State University and Sally Prouty of the Minnesota DB Project gave a presentation on Interveners. They have recently released a new

handbook called 'A Family's Guide to Interveners.' I believe she stated that all State DB projects were going to receive it and that it can be found on [www.intervener.org](http://www.intervener.org). This, my friends, is a must-have resource for your family. We truly wish we had this book five (5) years ago. It is a wonderful guide to assist you in accessing your child's needs.

“Deafblindness is an information flow problem of one’s distant senses. The compensatory senses of touch, taste and smell are too close to make up for the loss. Deafblindness is truly a disability of access to visual and auditory information.” I found this as a great definition the two used to assist those in understanding our children’s disability. One concept I found very informational is the Learning Pyramid and how this model is reversed for our kiddos. Incidental learning is ineffective, whereas direct (hands-on) learning is the best. This style learning is the difficulty we face as it is not conducive in the typical classroom setting. The way an individual learns is a 7-step process but DB students’ learning stops at Step 1 = Receiving. This is where the Intervener steps in and allows for the DB individual access to communication and his or her environment. Some other key concepts/ideas/notes from these presenters are as follows:

*“As I entered this world, I would leave behind the nurturing of my family and my home, but in another sense I would take their protection with me. The lessons I had learned, the feelings of groundedness and belonging that have been woven into my character there, would be my companions on the journey.”*

[Sidney Poitier](#)

- Interveners serve three (3) key purposes for the DB individual:
  - Gets information to child in a way he or she can understand
  - Makes individual aware of his or her environment and the people in it
  - Conceptual development and direct learning experiences
- The Intervener is the piece to the puzzle that has to be there for an effective and consistent delivery system.
- The Intervener is the communication link, which in turn reduces the link to isolation and the effects isolation has on the brain.
- Trained Interveners are so much more “connected” than trained paraprofessionals. They are there to connect the DB individual to the world!
- There cannot be a least restrictive environment (LRE) in any setting without a trained and educated Intervener because of the isolation.
- The state of Minnesota is the only state in the union that recognizes Interveners as a related service and employs between 30-40 trained Interveners for adults. That number does not include Interveners in the school setting.
- The National Intervener Task Force provides support for states, families and individuals. You may request the blue packet on Interveners from your state DB Project given to them by this organization.
- There is a large push now for the National Deafblind Intervener Initiative to lobby for the Reauthorization of IDEA on the federal level to recognize Interveners as a related service. This includes an educational curriculum and credentialing.
- The Office of Special Education Programs (OSEP) has taken note of the value Interveners provide and requested State Projects to include Intervener training. They are also compiling statistics to support this.

The second portion discussed the roles of an interpreter for the DB population. The New York State DB Project coordinator shared with us the contrast of an Intervener and an Interpreter. Interpreters are not responsible for the “instruction of a student” or for “teaching language.” They communicate the message to the individual. They maintain a professional distance and an impartial, neutral perspective. Many interpreters find this very difficult when working with a DB individual. DB

skills-set interpreting responsibilities include:

- Environmental information into the interpretation
- Facilitate introductions & make connections with people
- Describe layout and mood of room
- Include non-manual markers/non-verbal information
- Utilize specific techniques that will assist with information flow and comprehension



The third portion topic was on Support Service Providers (SSP). These trained individuals provide visual information, facilitate communication, offer human guiding, and assist with transportation. One comment the presenter gave that made an immediate impact on me was “Isolation is considered one of the greatest obstacles for the DB as most individuals have a limited number and variety of experiences. SSP’s allow for the facilitation of getting an individual out into the world for those opportunities.” SSP’s do not provide for personal care, housekeeping or run errands without the DB individual...a common misconception. The SSP is the link between “community access” and the DB individual. American Disabilities Act covers an SSP for community settings, not home. In other words, it is not community access for a taxi driver to drop off the individual at the grocery store doors. The access is linking the individual and the environmental surroundings in and around the store.

Saturday evening included a social gathering to network with other families and professionals. We made several connections and had a wonderful evening sharing experiences with those that have walked our walk and those getting ready to make that journey as well. Joe McNulty of the Helen Keller Center announced that the FCC has grants worth \$10 million dollars per year for the states, divided evenly, for their DB population to receive communicative equipment. This is for the assessment, purchase and training on the equipment.



Aiden McVicker

Sunday morning we had a small group session where we were able to choose a category of interest. Prior to the Symposium, Mr. John Reiman from the National Consortium for Deafblindness contacted me to participate as a panel member in his session. The session was “State Advocacy in School-Age Services” where he asked a 3-person panel about our experiences with serving on the State Special Education Advisory Panel. I, Jamey, am starting my 3<sup>rd</sup> year on this panel and have enjoyed this experience. The questions Mr. Reiman asked ranged from “how did I come to learn about this panel” and “what was the application process”, to “what time commitments does this entail”, and “what have been some benefits to my child and other children due to my service on this panel”. The goal of the session was to create a strong advocate on the State Panel for the DB population. Our shared vision is to have at least one representative in each state. I have volunteered to serve on a national committee to start recruiting efforts to advocate for the DB community. If you or anyone you know would be interested in learning more, please contact me so that we may align and cooperate to have a stronger advocacy effort. I am proud to say that I want Missouri to lead by example in this charge!

In conclusion, it seems we have several exciting things in our horizon. We hope to build stronger families by starting a family group for support, resource & information sharing, and advocacy. The DB Community is on the verge of some ground-breaking events!!! We need everyone to get involved as the time is now. We each need to step out of our comfort zone for our children and believe in our efforts. We wish to thank the Missouri Deafblind Project for their efforts in making this symposium a reality for us!

“Sorrow looks back...Doubt looks down...Worry looks around...Faith looks up.”  
-Unknown

“The highest result of education is tolerance.”  
-Helen Keller

Courage, Love & Vision,  
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## Learning about Interveners

*From Interveners and Children Who Are Deafblind*  
Website on interveners: <http://intervener.org/>

“An Intervener is a person who:

- Works consistently one-to-one with an individual who is deafblind
- Has training and specialized skills in deafblindness

An intervener provides a bridge to the world for the student who is deafblind. The intervener helps the student gather information, learn concepts and skills, develop communication and language, and establish relationships that lead to greater independence. The intervener is a support person who does with, not for the student. Specialized training is needed to become an effective intervener. Training should address a wide range of topics necessary to understanding the nature and impact of deafblindness, the role of the intervener, and appropriate educational strategies to work with students with combined vision and hearing loss (Alsop, Killoran, Robinson, Durkel, & Prouty, 2004; McGinnes, 1986; Robinson et al., 2000).”

The intervener’s role includes:

- Facilitating access to the environment that is usually gained through vision and hearing
- Facilitating development and use of receptive and expressive communication
- Promoting social and emotional well-being for the child with deafblindness.

The topic of interveners has grown in recent years. Research is showing that interveners may have a major impact for students with deafblindness to access the general curriculum, increase communication and increase interactions with peers and adults.

Gloria Rodriguez-Gill of the California Deafblind Project has listed some guidelines for intervener, “*The Intervener’s Motto: Do With, Not For*,” California Deaf-Blind Newsletter May 2011:

- “Provide clear information so that the individual who is deafblind understands what is happening.
- Provide just enough support so the individual who is deafblind learns that he or she is the person who is in charge.
- Provide enough time so that it is possible for the individual who is deafblind to respond accordingly

“Many small people, in many small places, do many small things, that can alter the face of the world.”

Anonymous

- Provide a partnership so that the relationship with the individual who is deafblind is not only about the support you provide, but also the things you do together. “

*“Teamwork divides the task and multiplies the success. “*

Author Unknown

The role of an intervener is clearly different than an interpreter, who provides only communication of what is being said and relays the interpretation of what the individual is communicating. An intervener does this, plus relays information to the individual with deafblindness incidental learning concepts that are normally gained through a person’s vision and hearing. For more information on interveners visit their website.

## The Project at Work

During the summer, the Project staff met for planning of our activities for the coming year. It is not often that we are all together. Our frequent means of communication is our email system and the telephone. At our meeting we took a few minutes to pose for a picture. Starting on the left is the Project’s Secretary, Margaret Winston, a valuable resource in helping us in keeping our records in order. Next, is our Transition Specialist, Janus Hinson. An important person for the Project is our former director and now a consultant to the Project, Linda Van Eck-Niedringhaus. Mike Grady, is our evaluator, who assists with our data collection which is critical to keep. In front, of Mike is Ginny Williams, our Family Specialist and Lead Parent Advisor for MoSPIN. Jennie Mascheck our Project Director is next to Ginny. Andrea Harrington is the Project’s Education Specialist. Last shown is Susan Bonner, Project Coordinator.



## Families' Corner:

### Pallister-Killian Syndrome (PKS) Conference

By Cammie Gray & Kate Hettiger, Parents of Children on the Deafblind Census



Kelsey and Luke both struggle with deafblindness as a result of their extremely rare chromosomal disorder, Pallister-Killian Syndrome. Currently, there are only three (3) known families in the State of Missouri with a child with PKS. In addition to developmental disabilities, physical delays, seizure disorders and structural abnormalities, PKS almost always includes visual and hearing impairments. The dual sensory impairment on top of health and developmental concerns cause special challenges for children with PKS. Often children with PKS have Cortical Visual Impairment, small retinas and/or hypo-pigmented retinas. Also, a bilateral hearing loss of mild to profound is usually present in those with PKS. Therefore, many to most children with PKS are also qualified to be on their state's Deafblind Registries.

Kelsey and Luke, two (2) of the three (3) known children in Missouri and their families were fortunate enough to attend the 3<sup>rd</sup> PKS Kids Biannual Face to Face Medical Conference in the Washington, DC area in June. In addition to medical presentations by genetics, neurology, nutrition, audiology and coping with children with disabilities, the PKS Kids Conference had Sally Prouty of the Minnesota Deafblind Project and Julie Durando of the Virginia Deafblind Project present to the families. They co-presented an excellent talk about the nature of dual sensory impairments and the beneficial role of interveners as in working with children with dual sensory losses. Three (3) interveners supported attendees' children with PKS in the childcare room while the parents attended the conference. The interveners reported to each parent at the end of the day about how their visit with the children went. Parents left the conference with a new perspective about helping their children with deafblindness and a new motivation to contact, if they have not already, their state's Deafblind Projects. Well done Minnesota and Virginia Projects!

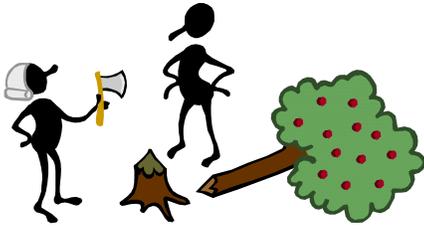
For more information about Pallister-Killian Syndrome, go to their website: [www.pkskids.net](http://www.pkskids.net) .

### 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. Watch their website for more information: [www.chargesyndrome.com](http://www.chargesyndrome.com) .



## Missouri Going 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. 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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