IN FOCUS

MISSOURI DEAFBLIND TECHNICAL ASSISTANCE PROJECT
Fall 2009 VOL. 7, No 1

Family Highlights: International CHARGE Conference

With Highlights from the Jacobs Family of Independence, the Sorkin Family of St. Louis and the Young Family of Cape Girardeau

The International CHARGE Conference was held in July 2009, in the suburbs of Chicago, Illinois. Via the Family Involvement Fund, the Missouri Deafblind Technical Assistance Project supported participation of three families. The families learned much about CHARGE Syndrome, deafblindness and teaching strategies as well as networking with other families and professionals in the field of deafblindness. These families' perspectives about the conference follow.

In This Issue...

The following is Stephanie Jacobs' experience at the conference: "I am a mother of a 5-year old son who was diagnosed with CHARGE Syndrome at 1 month old. Thanks to the financial help from the Missouri Deafblind Technical Assistance Project, our family has been able to attend the last two CHARGE Syndrome Conferences.

In Focus Fall 2009

I am a mother who has read every article I can find about CHARGE Syndrome, with the hope that I can try to understand what the challenges are that my son is facing and how I may be able to help him with those challenges. Yet, with all of that information I soon realized how unique and complicated this syndrome is. In addition, all of this knowledge brought new hope for my son, but is also brought with it more fears.

Having the opportunity to be in a place where families and professionals meet to discuss only CHARGE was a gift. I was not only able to listen to these people talk, but was given the ability to ask questions that had been weighing so heavily on my mind. In addition I was given the opportunity to be introduced to many parents and professionals who were happy to share any information they had that could help me with my need to understand my son's condition and help him.

In the real world, having a child with special needs creates a distance from friends and family who were in your life before you had your child. It's not something that is intentional or because those friends and family want to leave your life, it's simply because many of them can't relate to or understand your life anymore. At home we are also battling professionals everyday for our children, and trying to help others around us understand our challenges, but it is almost impossible for them to step into our shoes without actually living in them.

Meeting other families, who are facing many of the same challenges we are, is an amazing feeling. For those three days we felt as if we belonged somewhere again. We were all "a family" who understood many of each other's worries and fears. Nobody stares at your child, everyone understands how exhausted you are, and everyone is looking for any information available that may help our children with the challenges they are facing.

Everyone at the conference realizes the miracles that they have been given and love to brag about them, we understand the incredible amount of hard work it takes to move those mountains to reach those milestones.

I really enjoyed listening to parents sharing their stories, and experiences, and learned so much information from the professionals' who shared their research. I returned home with a new list of to-do's and a renewed hope for my son, and a much needed feeling that some people do understand what my family is going through, and are battling everyday just like us. The feeling of belonging to this new family is amazing and I am looking forward to attending the next conference and rejoining our newly discovered family and friends."

Corrie Young attended the CHARGE Conference with her family including two sons with CHARGE Syndrome. She reports; "The 2009 CHARGE Syndrome conference was very fulfilling and rewarding one for us. This was our sixth conference to attend and we continued to get a great deal out of it. We came away with some questions and ideas for our sons' therapists. One was the use of orthotics. This came from the presentation of a physical therapist who works at Perkins School for the Blind.

Another idea was the importance of slant boards to prevent poor posture. Many older children with CHARGE have curvature of their spines from poor posture due to poor vision and balance. To prevent this as much as possible, proper positioning needs to always be addressed. One way is through the use of a slant board.

Most important to us was the chance to get together with other parents and children with CHARGE. It's very refreshing, with CHARGE being so rare, to meet and talk with others who face the same struggles that we do. We even met another family who also had two sons with CHARGE like us. They were from Texas.

This year, our sons' vision teacher and intervener were able to attend so that was an added bonus. They both learned quite a bit and enjoyed meeting others as well. All in all, the conference was wonderful and a great learning experience for my husband, myself and all of our children."

Steve Sorkin and his seventeen-year old son with CHARGE Syndrome were also able to attend the conference. Mr. Sorkin summarized the conference for us:

"The Ninth International CHARGE Syndrome Conference, held in suburban Chicago in July, was a wonderful gathering of people from around the world with CHARGE; their parents, family members, and caregivers; and education, healthcare, and medical professionals. Over 750 people from six continents attended the enlightening and uplifting get-together, making it the largest CHARGE conference ever.

BACKGROUND

CHARGE Syndrome is one of the most common causes of deaf-blindness. The term “CHARGE” is an acronym for many of the disabilities and abnormalities seen in people with CHARGE. In addition to hearing and vision impairment, common features seen in the syndrome include problems with the heart, breathing, swallowing, and feeding, which are frequently life-threatening, especially at birth and in the early years. Other frequently seen problems include motor and balance difficulties, cleft lip and palate, facial palsy, genital and urinary problems, and developmental delays. There is an extremely wide range of physical and developmental disabilities among people with CHARGE, but often the physical appearance—unusually shaped and low-set ears, and wide face—can be used to identify “CHARGERS,” much like similar appearance can be used with Down Syndrome.

The CHARGE Syndrome brochure states that CHARGE “is a genetic condition most often caused by a new change or mutation in a [certain] gene on chromosome number eight.” Most children with CHARGE are extremely multi-sensory impaired, “having difficulties not just with vision and hearing, but also with the senses that perceive balance, touch, temperature, pain, pressure, and smell.”

The CHARGE Syndrome Foundation is a parent-led organization that started in Missouri and until recently was headquartered in Columbia. The office is now at Helen Keller Services for the Blind in New York. The International Conference is held every other year. The first one was in St. Louis in 1993.

THIS YEAR’S CONFERENCE

The Conference opened and closed with inspirational talks. The first speaker was Dr. Bryan Hall, the pioneer pediatrician who was the first doctor to notice a pattern of disabilities in some of his infant patients. His extensive research led to his publication of an article noting this pattern— mainly choanal atresia (closed airways), developmental delays, and ear abnormalities—in the late 1970s. Just three years later, Dr. Roberta Pagon and her associates coined the term “CHARGE” to identify the syndrome.

The final two speakers were both parents of CHARGE Syndrome children. Michelle Westmass from Pittsfield, Illinois presented an often humorous look at the trials and tribulations of raising a family, in which a child with CHARGE can keep a parent's hands even more full than usual!

The award for "Unique Speaker" goes to Cynthia Antaya of Virginia, the other closing speaker. Cynthia and her husband have a two year old with CHARGE. While enduring the endless number of operations and medical procedures a typical CHARGE baby goes through, she noticed a lot of similarities to health problems she had as a child, including deafness. (Cynthia is oral.) After discussions with doctors, she was told at age 27 that she has CHARGE Syndrome, too! While many people active in the CHARGE Syndrome Foundation wear two hats—CHARGE parent and medical or educational professional—Cynthia is the first to wear the third hat of also being a person with CHARGE.

There were over thirty panels and discussion groups offered during the two and a half-day conference. One track of workshops was exclusively for young adults with CHARGE, and another for siblings. Having attended many previous CHARGE Conferences, and with my son Aaron about to turn 17, I did not attend the many sessions available for parents of young CHARGERS and those attending their first conference. I focused on those that promised information for parents of CHARGE teens, and I was not disappointed.

For example, one continuing concern of parents is how to deal with the small stature and delayed growth of most children with CHARGE. This includes not just height but many issues related to puberty for both girls and boys. A question and answer session with Dr. Jeremy Kirk, an endocrinologist, addressed several of these concerns. Dr. Kirk discussed the differences between growth hormones and sex hormones, and when it is appropriate to consider administering either or both to a child. Growth hormone can help but can also affect muscle tone and sleep patterns, and scoliosis can be a side effect. Sex hormone replacement therapy can also bring some side effects but can help guard against osteoporosis, which is common in youth with delayed puberty.

Children with disabilities who are self-aware and high-functioning enough to ask about their disabilities often pose tough questions for their parents. A workshop led by two educators with CHARGE Syndrome expertise was very helpful to parents with related quandaries. Interviews and surveys of older CHARGERS and their families show that it is not usually helpful to emphasize CHARGE and the syndrome itself. These families recommended that the focus be on specific functional disabilities and how they might affect the child. Discussing CHARGE can be saved for when older or for when it is appropriate to an individual situation.

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Although most people with CHARGE do not drive because of visual impairments, reaching driving age is a common trigger for discussing CHARGE. Another “teachable moment” comes when the possibility of having babies comes up.

In what is probably good advice for all families affected by disability, it was strongly recommended that the parents discuss these feelings just between them first, and if other children are involved, also analyze their feelings, before having a whole-family discussion with the child with disabilities.

The biennial conference has proven to be a great opportunity for families and medical and educational professionals to learn from each other. Several educators and doctors have been given ideas for research through discussions with parents at the conference. For example, several years ago parents brought up a previously little-known impairment in CHARGE children: many do not have a sense of smell. As a result of that discovery, doctors began researching the problem. At this year’s conference, the results of one study were released that shows a definitive link between a lack of a sense of smell and no onset of puberty. Testing for smell early in childhood can help parents plan for the possible need for age-appropriate induction of puberty.

As great as the workshops and presentations were, the best part of the CHARGE conference is always spending time with other CHARGE families. The fantastic childcare provided at the conference makes it easy for parents to attend worry-free and also provides the child with a wonderful experience. Seeing people even only once every two years can bring on real friendships when you have CHARGE children in common! Sharing life's challenges and successes is invigorating and great for the soul.

NEXT CONFERENCE AND MORE INFORMATION

The next CHARGE conference will be in July 2011, in Orlando, Florida. More information can be found on the Foundation's website, www.chargesyndrome.org. The website also has a wealth of information about CHARGE, access to great resources, and a link to the CHARGE listserv.

Financial support from the Missouri Deafblind Project made it possible for Aaron and me to attend the conference. I thank them for allowing me to participate in an extremely worthwhile conference."

Family Involvement Fund

The Family Involvement Fund is a means for families to attend conferences, workshops and network with other families concerning their child with a dual sensory loss. It was with the support of the Family Involvement Fund that families were able to attend to CHARGE International Conference.

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 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 1st through September 30th. 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 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 .

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.

Membership is by invitation only. 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.

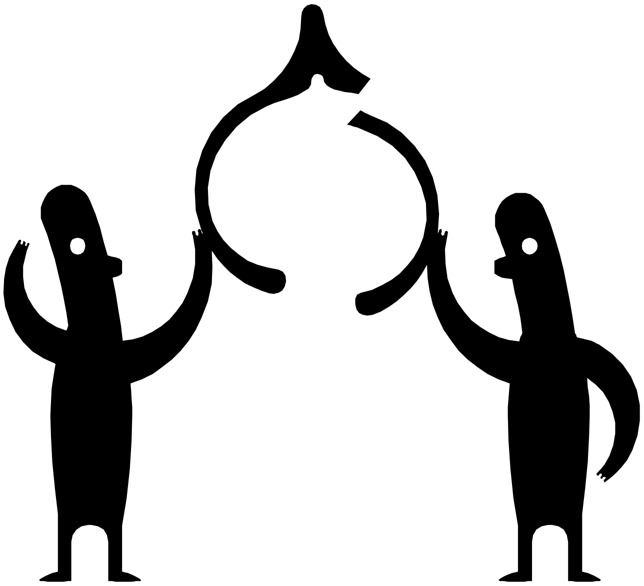
The purpose of "*Web Connections*" is to provide a way for families to network with other families who have a child with both visual and auditory losses by:

- 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
- Provide 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, 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.

I Wish I Had ….
WISDOM FROM PARENTS OF CHILDREN WHO ARE DEAFBLIND



The National Consortium on Deaf-blindness (NCDB) is a national technical assistance and dissemination center for children and youth who are deaf-blind that is funded by the U.S. Department of Education's Office of Special Education Programs (OSEP). NCDB works closely with the various state deafblind projects. NCDB's newest publication is ***"I Wish I Had…Wisdom from Parents of Children Who Are Deaf-Blind."*** In this publication, parents from across the country share their thoughts and experiences with regard to their family and their child who is deafblind. Two parents from Missouri were cited in this July 2009 publication.

Jamey and Amy McVicker spoke about their wish that they could communicate with their son. Their thoughts are: "***I wish I had*** a machine that was able to tell us what was happening in our son's thoughts. This would help us communicate with him by having immediate access to what is going on in his mind. This would allow for better two-way communication, as we think he is constantly giving us clues about what he is trying to say. It's just that we are not picking up on the clues. I wonder how much progress we could make in educating or son if we had an inside track into what is on his mind."

Stephanie Jacobs wrote about the impact of her son's disabilities was on her. She said; "***I wish I had*** not been so surprised with each new diagnosis and its implications for my son. The most devastating thing to learn is that there is something wrong with your child, but even more devastating is discovering that it should have been found earlier, or handled differently, or that it was completely "missed" by all of the professionals that you entrusted with the care of your child. It is so important to research and to understand your child's diagnosis and its implication yourself because who your child needs to understand them, is you. Professionals can be great supports, but you are your child's best advocate."

To read more about others' perspectives, go to the NCDB link that follows and read the entire booklet.
http://nationaldb.org/documents/Family/Iwish.pdf

Sign up for the family listserv, ***Web Connections***, if you wish to correspond with other families.

Hand In Hand

The **Missouri Deafblind Technical Assistance Project** sponsors a variety of training, workshops and courses to help support families, educators and service providers. One of these courses is **Hand In Hand: Understanding Deafblindness for Education Teams of Students Who Are Deafblind**. This course, totaling seven days throughout the academic year, provides instruction on the theory and practice for the education of students with deafblindness.

The course is intended for the educational teams of students with deafblindness (including parents/family members). The course combines self-studies, homework assignments and action planning with onsite mentoring and three face-to-face sessions (totaling seven days) with course instructors. Participants apply acquired knowledge regarding visual impairment, auditory impairment, communication and movement to the programming of the students that they serve with dual sensory losses.

The course lasts one academic year. This school year, the dates are October 28 - 30, 2009; January 27 – 28, 2010 and April 21 – 22, 2010. This year's Hand In Hand course will be held in the Springfield, Missouri area.

The course is offered free of charge and all training materials (including text) are provided by the Missouri Deafblind Technical Assistance Project. Optional two-hour graduate credit is available from Lindenwood University for the course. Family members may be provided financial support to attend (mileage, housing and meals).

Contact Susan Bonner for more information at 314-776-4320 ext 255 or sbonner@msb.k12.mo.us. You may also go to Missouri School for the Blind's website to download the information and registration forms: http://www.msb.k12.mo.us/msb_opportunities.html.

Successful Transitions Between Programs

by Maurice Belote, California Deaf-Blind Services, Project Coordinator

For educators, transitions that students make from program to program happen so frequently that we can forget the significance of these events to children and their families. For families, transitions can be a time of uncertainty, fear, and doubt about new programs; this is particularly true of transitions from home-based early intervention programs to center-based preschools and from pre-school to elementary school. The following represents some strategies that might help students, their families and educational teams during transitions between educational programs.

Choose a specific date for the transition and stick to it. This may seem like a minor point, but consider the following example. A student is slated to move to a new program on a specific date, but two weeks before the date, a vacancy opens in the new program so the student is unexpectedly moved two weeks early. This sudden and unexpected move might get in the way of all of the planned transition activities on the part of both the school staff and the student's family. In addition, the student might not have the opportunity for the farewells with teachers and classmates. We must remember that without a well-planned transition to a new program—such as the case in which a student's bus simply drops him or her off at a new school one morning—the lack of access to information and the lack of control are sure to create a level of passivity in the student that will hinder his or her success in the future.

Collect all personal materials—including communication systems—and make sure they move with the student. Some equipment the student uses may not be able to be moved to a new program; there may be issues of ownership among educational agencies. But materials such as a communication system specifically developed for a student must move with the student if we are to give the student every chance to succeed in her or his new setting. It's surprising how often personal belongings of students get left behind during moves—pictures, books, puzzles, CDs, etc.

Provide the new program with as much useful documentation as possible. The new staff is sure to appreciate any documentation that might assist them to better meet the needs of the student who is new to their program. This might include a personal communication dictionary, a Personal Passport (visit the Call Center at http://callcentre.education.ed.ac.uk for information), videotape footage of the student in various settings, etc. This information is likely to be much more useful than written reports taken from the child's school records.

Familiarize the student with the new setting. If possible, allow the student a few opportunities to visit the new program prior to the transition. Of course, these opportunities are essential when a student needs support and time to orient to the new environment, learn new routes, etc., often under the direction of an Orientation and Mobility Specialist. All students, however, are likely to benefit from these early visits; the visits are sure to take away much of the mystery and fear of the pending move.

Establish time for the sending and receiving teams to meet. Whenever possible, it makes sense to provide two opportunities for the two teams to meet. The first meeting should occur prior to the move so that the sending program can provide as much information about the student to the receiving team, especially information that might not be in the child's file, e.g., personal communication dictionary, home-to-school log, etc. The second opportunity to meet should occur after the student has been in the new program for a short period of time. This is when the most questions arise—once new program staff has a chance to get to know the student and his or her idiosyncrasies.

Consistency of DIS staff and/or one-on-one assistant. Whether a student is moving to a new school or merely changing rooms within a school, it might be beneficial if the student's DIS staff, e.g., vision specialist, physical therapist, orientation and mobility specialist, etc. can follow the child to her or his new program. This will lessen the magnitude of the change; the location and classroom teacher might be new, for example, but at least some of the other familiar staff remains constant and this may make for a much smoother transition. We want to capitalize on the variables we have some control over, such as itinerants and one-on-one aides, since we have much less control over other variables such as buildings and teachers' classroom assignments.

Set clear and high expectations from the start. Resist the temptation to wait a few days to get to know new students before clear and high expectations are identified and set. Days turn into weeks and weeks into months, and suddenly the realization hits that time truly is fleeting.

Change is stressful. A child may exhibit many reactions to a change as monumental as a transition to a new program, especially if the child had been in the former program for a long time. Some students may be on their best behavior and provide staff with what's been called a honeymoon period, while others might be at their most obstinate and grumpiest worst. Whether a child exhibits some of these reactions or seems to show no reaction at all to the move, we have to remember that the stress of change will manifest itself one way or another—that's for sure.

Change is good. Change, as stressful and disruptive as it can be, can also be a positive force in many ways. It is said that when one door closes, another opens, and this open door can be the pathway to new experiences, relationships, and possibilities. The student who has been in a comfortable special day class preschool for three years might discover a world rich with new activities and language models in an inclusive kindergarten. The student who has been in a comfortable high school class might discover the excitement of job training and community recreation found in a transition program.

Schedule visits to the former program. Whenever possible, it is a great idea to have the student visit his or her former program. Among students in general education, think about how often they come back to visit former programs and teachers to relish in their own growth and maturation and to re-live the memories and good feelings of days gone by. For students who are deaf-blind, they may not have any idea what happens to former teachers, staff members and classmates when they transition to a new program. It may seem, to the child who is deaf-blind, that these former friends and teachers just vanished off of the end of the earth. In addition, the student who is deaf-blind has probably developed closer relationships with program staff than other students might, and it will help the student deal with feelings of loss if he or she can visit occasionally and keep these special relationships alive.

Fact sheets from California Deaf-Blind Services are to be used by both families and professionals serving individuals who are deaf-blind. The information applies to students 0–22 years of age. The purpose of the fact sheet is to give general information on a specific topic. More specific information for an individual student can be provided through individualized technical assistance available from CDBS. The fact sheet is a starting point for further information.

Missouri Deafblind Project thanks Maurice Belote for permission to reprint this article.

Calendar of Events

Fall, 2009

Date:	Monday, October 5, 2009
Topic:	Cortical Vision Workshop
Location:	#7 London Hall, University of Missouri - Columbia
Audience:	Classroom teachers, teachers of the visually Impaired, O&M Specialist and other interested parties.
Cost:	$65.00
Contact:	www.heartofmissourirpdc.org

Date: Monday & Tuesday, October 5 & 6, 2009
Topic: 2009 Children's Vision Summit
Location: Truman Hotel, Jefferson City
Audience: Parents, classroom teachers, teachers of the visually impaired, students and other interested parties
Contact: Mike Merrick 573-751-4989, michael.l.merrick@dss.mo.gov

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

Date: October 20-21, 2009
Topic: Assessment of Functional Vision/Learning Media & Assessment of Functional Hearing
Location: Missouri School for the Blind
Audience: Teachers of the visually impaired, Teachers of the Deaf and Hard of Hearing, Certified Orientation & Mobility Specialists, Speech Language Pathologists
Contact: sbonner@msb.k12.mo.us or yali@msb.k12.mo.us

Date: Wednesday, October 21, 2009
Topic: Early Intervention from A - Z
Location: Central Institute for the Deaf, 825 S. Taylor, St. Louis
Audience: Special instructors, service coordinators, speech-language pathologists working with children who are deaf or hard of hearing and their families
Contact: Dianne Gushleff, 314-977-0133, dgushleff@cid.edu

Date: Wednesday, October 28, 2009
Topic: What's New at the American Printing House for the Blind?
Location: #7 London Hall, University of Missouri - Columbia
Audience: Classroom teachers, teachers of the visually Impaired, O&M Specialist and other interested parties.
Cost: $65.00
Contact: www.heartofmissourirpdc.org

Date: October 28-30, 2009, January 27 – 28, 2010, & April 21 – 22, 2010
Topic: Hand In Hand Course

Location: Springfield, Missouri

Audience: Parents, educators and related services supporting students with deafblindness

Contact: Susan Bonner, 314-776-4320 ext 255, sbonner@msb.k12.mo.us

Date: November 13–15, 2009

Topic: AER Regional Conference

Location: Crowne Plaza Cleveland City Centre, Ohio

Content: Trainings in the blind & visually impaired

Contact: www.aerbvi.org/regionalconf

Winter, 2010

Date: Thursday, January 14, 2010

Topic: Welcoming a Student with a Visual Impairment to Your School

Location: Missouri School for the Blind

Audience: Teachers and paraprofessionals providing services to students with visual impairments

Contact: Jennie Mascheck, 314-776-4320 ext 250, jmascheck@msb.k12.mo.us

Date: Thursday & Friday, March 4 & 5, 2010

Topic: Early Intervention: Beyond the Basics

Location: Central Institute for the Deaf, 825 S. Taylor, St. Louis

Audience: Special instructors, service coordinators, speech-language pathologists working with children who are deaf or hard of hearing and their families

Contact: Dianne Gushleff, 314-977-0133, dgushleff@cid.edu

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

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.

IDEAs that Work
Office of Special Education Programs

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

In Focus