



IN FOCUS

MISSOURI DEAFBLIND TECHNICAL ASSISTANCE PROJECT

Fall 2008

VOL. 6, No 1

Customized Employment

Customized Employment is an approach that looks at a “job to fit who we are, what we need and what we have to offer” (ODEP, 2005) as an employer. It individualizes the relationship between the employer and employee to meet the needs of both. In April, the Missouri Deafblind Technical Assistance Project sponsored training on “Customized Employment” utilizing the techniques developed by Michael Callahan, Executive Director of Marc Gold & Associates. Dr. Callahan developed the “Discovery Model,” a person-centered approach to get to know the person by spending time with them in order to determine their preferences and skills. According to Michael Callahan, the outcome of the process is finding “paid work, paid job experience or volunteerism.”

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Day One of the training was open to school districts and service providers serving individuals with deafblindness and multiple disabilities who are transitioning into adult roles within the next few years. Dr. Callahan provided participants with an overview of the process and how to conduct assessments. Through real life scenarios, he provided examples of how the Discovery Model

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process applied to these individuals and the outcomes of the process.

Day Two of the training was offered only to Missouri's Deafblind Task Forces. Task forces are located in St. Louis, Kansas City, Central Missouri and Southwest Missouri. Each of our four task forces developed a case study of an individual that is transitioning into adult services soon. The teams would implement the Discovery Model with their individual identified in their case study. Permissions of families and consumers were received to implement the process. Each task force presented an overview of their consumer and consulted with Dr. Callahan on beginning the Discovery Model process. Each task force then developed an action plan to begin implementation and to identify the anticipated outcomes for their consumer.



Implementing the Discovery Model may include these steps:

1. Meet with consumer and his/her family in their home
2. Drive or walk through the neighborhood to develop a picture of where the consumer lives, noting businesses
3. Compile a list of area businesses
4. Meet and interview support/teaching staff for consumer
5. Interview family members, friends and others who know consumer
6. Observe the consumer in a variety of settings
7. Accompany the consumer on a community activity
8. Review files and records
9. Compile information and develop a strategy to address what you have learned
10. Review the gathered information with the family and consumer; make needed changes

In August, a teleconference was held with Dr. Callahan and the task forces to discuss what has been done and the task forces' next steps for implementation. Dr. Callahan was impressed with the results that have been achieved to date and challenged us to go further in developing our plans. The task forces are working closely within their groups to achieve the targeted outcomes for their consumers.

Resources:

Customized Employment: Practical Solutions for Employment Success. Office of Disability Employment Policy (ODEP), US Department of Labor. June 2005.

Discovery: Charting the Course to Employment. Callahan, Michael; Shumpart, Norciva & Condon, Ellen. Marc Gold & Associates: Employment for All, Gautier, Mississippi. 2007.

Missouri Deafblind Grant

On August 28, 2008, the Missouri Deafblind Technical Assistance Project's proposed grant was approved by Office of Special Education Programs (OSEP) for funding the next five fiscal years. The new grant will begin October 1, 2008 and end September 30, 2013. In developing the grant, each state was provided guidelines, expectations and priorities. From these priorities, Missouri developed their proposed grant.

The purpose of Missouri's proposal is to sustain and scale-up services to individuals who are deafblind by strengthening partnerships, coordinating service networking and providing systematic training through interagency collaboration among service providers and families. Local capacity will be built in identification, early intervention, education, transition, employment, related services and family support. The project scope will be achieved through six major areas:

1. Assist local and state agencies in the identification and tracking of infants, toddlers and youth with deafblindness to enhance services.
2. Provide an array of technical assistance activities that increases



3. family support services, parent education and parent networking.
3. Provide an array of technical assistance and training activities to service providers that improves services and outcomes.
4. Strengthen the statewide interagency collaboration model designed to build local capacity and to facilitate systems change.
5. Implement a dissemination plan which includes information about the project, teams, effective practices and materials developed by the project.
6. Evaluate and measure impact and benefits to children with deafblindness, their families and their service providers.

Based on needs assessment and data, various activities have been identified to help Missouri achieve the anticipated outcomes of their work. To identify and track students with deafblindness, the Project will continue to maintain the Federal deafblind census. Also, the Project will

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work closely with Missouri Department of Elementary and Secondary Education to use the statewide student identification system to track student as they move within the state. The Project will continue to implement various public awareness activities through presentations, website postings, bulletins and brochures.

Family support activities will include parent education and parent networking. Parents' input of needs will be continually sought. Early intervention activities will includes Project SPARKLE (Supporting Parent Access to Resources, Knowledge, Linkage, and Education), MoSPIN (Missouri Statewide Parent Involvement Network), and transition from Part C to Part B of IDEA services. Trainings to build educational teams' capacity will be provided annually in INSITE (In-Home sensory Intervention Training and Education) , VIISA (Vision Impaired In-Service in America) and Hand in Hand coursework. The Family Involvement Fund will be implemented providing stipends to families to participate in trainings and conferences.

Direct technical assistance is available to service providers if the legal guardian provides the necessary releases of information. Technical assistance may be provided via direct classroom observation,

person-centered planning and provision of resources to the service providers that impact an individual student. The Project will provide training and resources to service providers on topics and resources related to deafblindness.

Interagency collaboration is facilitated through collaboration with Part C and Part B programs. The Project will work closely with the state and local deafblind task forces that support interagency collaboration for individuals with deafblindness to build local capacity and services. The Project will collaborate with other federal, state and local agencies to address the needs of individuals with deafblindness. The Project will increase their use of technology to improve the website and use online resources to provide information and training.

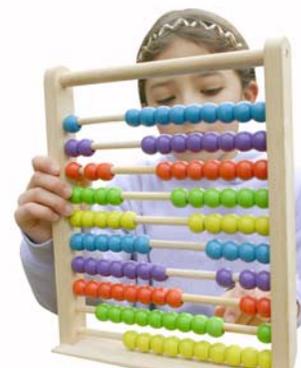
The Project will continuously evaluate the impact services have on the community and consult with others to measure success and identify any current and future needs.

For more information or to request services, contact:

Susan Bonner, Coordinator
314-776-4320 ext. 255
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 forth, along with descriptive information such as the cause of deafblindness. The Missouri Deafblind Project uses this demographic and descriptive information in many ways. It was a key element in identifying Missouri's needs for the development of our Grant. This past school year, we were able to locate many individuals thought to be lost that we could restore to our census count.

When a school district, program or agency reports a new 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.

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.



Family Involvement Fund

The Missouri Deafblind Technical Assistance Project strives to support families in addressing their needs to assist them increase their knowledge and understanding of their child's disability and/or programs and services that support their child. Historically, the Project has provided stipends to families to attend certain workshops, conventions and trainings related to their child's disability. To meet the Project's needs with the next grant cycle,

some revisions have been made in the process.

1. The family's child, aged birth through 21, must be registered on the annual blind and/or deafblind census.
2. The financial assistance may be used to support attending conferences, workshops, online trainings and/or teleconferences.
3. \$250 per person or \$500 per family fiscal year (October 1 – September 30) maximum allowance.
4. Family is defined as parents, stepparents, siblings, grandparents, legal guardians, foster parents or educational surrogate.

Approval is based on available funds and limits may change due to budgetary constraints. An application must be completed and submitted to Susan Bonner, sbonner@msb.k12.mo.us, or Jennie Mascheck, jmascheck@msb.k12.mo.us. These applications may be downloaded from the Missouri School for the Blind website following the links to the Missouri Deafblind Technical Assistance Project, Family Resources. The applications need to be submitted at least thirty (30) days in advance to give the Project adequate time to review the request and the family adequate time to make the necessary arrangements. If approved, original receipts for actual expenses to be reimbursed must be returned to the Project's office within 30 days of the event. Also, the family will need a plan as to

how they will share the information learned at the event with other Missouri families via a presentation or an article for the newsletter. It is our hope that we may help more families' needs with this revised process as well as keep other families informed who are unable to attend such events.



Professional Organizations for Families and Educators

The following is a listing of some common organizations that are involved with individuals with deafblindness and their families. This information will be maintained on our website as well as other groups. This information will be updated as needed. These organizations disseminate many resources on various topics to assist educational teams and the families of individuals with deafblindness. Future "In Focus" newsletters will highlight some of these groups.



National Consortium on Deaf-Blindness - Area 2

Address:

4330 Shawnee Mission Parkway
Suite 108
Shawnee Mission KS 66205
Fax: (913) 677-1544
TTY: (913) 677-4562

Contact: Barbara Purvis

Title: Technical Assistance Specialist

Email: babara.purvis@hknc.org

Phone: (913) 677-4562 (voice mail # 12)

Website: <http://www.nationaldb.org/>

Summary: This project combines the resources and expertise of three organizations, Teaching Research Institute at Western Oregon University, Hilton/Perkins Program, Perkins School for the Blind and the Helen Keller National Center. The Consortium (NCDB) provides technical assistance on a national level, makes information relevant to deafblindness easily available and promotes

personnel training efforts to improve the skills and knowledge of those working with children who are deafblind. Activities include workshops, national conferences, Webinars, consultation, maintenance of a special library of information, dissemination and product development. NCDB staff work with families, service providers, state deafblind projects, educational service personnel and federal agencies to ensure that children who are deaf-blind receive the assistance they need to achieve educational results consistent with the promises of NCLB and IDEA.



Helen Keller National Center Great Plains Regional Office

Address:

4330 Shawnee Mission Parkway
Suite 108
Shawnee Mission KS 66205-2522
Fax: (913) 677-1544
TTY: (913) 677-4562

Contact: Beth Jordan

Title: Regional Representative

Email: hknc7bj@aol.com

Phone: (913) 677-4562 (voice mail # 11)

Summary: HKNC regional representatives provide consultation and technical assistance to individuals with deaf-blindness and their families, and to public and private education and adult service agencies in their region. They locate, assist and refer individuals to the most appropriate programs for services, if needed. States covered by this regional office: IA, KS, MO, NE.

AFB

American Foundation for the Blind

American Foundation for the Blind

Address:

11 Penn Plaza, Suite 3400
New York, New York 10001
Phone: (212) 502-7600
(800)-AFB-LINE (232-5463)

Email: afbinfo@afb.net

Website: www.afb.org

Summary: An organization aimed at assisting the blind in the United States. Their mission is to expand the possibilities for people with vision losses. Priorities include broadening access to

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technology, raising the quality of information and tools for professionals serving individuals with vision loss. It also includes promoting healthy independent living.

Missouri Deaf-Blind Association

Address:

353 E. Caddo Street
Fair Grove MO 65648
TTY: (417) 759-1334

Contact: Carolyn Sue Alflen
Email: csuejw@cs.com

Summary: Missouri Deaf-Blind Association (MDBA) mission is to empower people who are deaf-blind, visually disabled, and hearing impaired: to live a more independent life, to share their feelings and experiences with others, and to learn and use tactile sign language, tracking, and other methods of communication. MDBA also educates and provides awareness of deaf-blind community. MDBA meets odd month for socials, meetings, activities, and field trips. MDBA has membership which is renewed yearly and publishes four newsletters per year. MDBA is an affiliate of American Association of the Deaf-Blind (AADB).



Address:

8301 State Line Rd
Suite 204
Kansas City MO 64114
Fax: (816) 531-4777
TTY: 800-743-7634

Contact: Mary Kay Savage
Title: Executive Director
Email: msavage@ptimpact.com
Phone: (816) 531-7070

Summary: This organization is a state-wide non-profit parent training and information center for families with a child with any kind of disability. It was established in January 1988 and has regional coordinators. Services include training, information and fact sheets and support on Special Education Law with a resource library, and teaching parents to advocate for their children's educational rights. A brochure is available and a newsletter is published quarterly. Several resources are available in Spanish. MPACT's mission is to ensure that all children with special needs receive an education, which allows them to achieve their personal goals.



National Family Association for Deaf-Blind

Address:

141 Middle Neck Road
Sands Point, New York 1105
(800) 255-0411

Contact: Linda Syler

Title: President

E-mail: nfadb@aol.com

Website: <http://www.nfadb.org>

Summary: The National Family Association for Deaf-Blind (NFADB) is a national organization that advocates for all persons who are deaf-blind, supports national policy to benefit people who are deaf-blind, encourages the founding and strengthening of family organizations in each state and collaborates with professionals in each state and collaborates with professionals who work with persons who are deaf-blind. NFADB Board Members can be contacted to share information and provide resources and referrals. The states in NFADB Region 7 include: IA KS MO NE.

American Association of the Deaf-Blind (AADB)

8630 Fenton, Street, Suite 121
Silver Spring, MD 20910
TTY: (301) 495-4402
Voice: (301) 495-4403

Fax: (301) 588-8705

<http://www.aadb.org>

The American Association of the Deaf-Blind (AADB) is a national adult consumer advocacy organization for people who have combined hearing and vision impairments. AADB is open to all persons who are deaf-blind and individuals directly concerned with their well being, including spouses, children, friends, and health care professionals



Helen Keller National Center For Deaf-Blind Youth and Adults (HKNC)

111 Middle Neck Road
Sands Point, NY 11050-1299
(516) 944-8900

Fax: 516-944-7302,

TTY: 516/944-8637

<http://www.hknc.org/>

HKNC is a national program that provides evaluation, short-term comprehensive vocational rehabilitation training, work experience training and assistance to deaf-blind clients for job and residential placements.



Hilton/Perkins Program - Perkins School for the Blind

175 N. Beacon Street
Watertown, MA 02172
(617) 972-7220

Fax: (617) 923-8076
<http://www.perkins.org>
collinsm@perkins.org

Hilton/Perkins program provides consultation, training and technical assistance to programs throughout the nation and in developing countries. Emphasis is on program development for multi-handicapped blind and deaf-blind infants, toddlers and school-aged children.

Informational Websites



Boys Town Hospital: National Center for the Treatment and Study of Ushers Syndrome

<http://www.boystownhospital.org/Usher/index.asp>



CHARGE: CHARGE Syndrome Foundation: Family web site for information about CHARGE Syndrome and related resources

<http://www.chargesyndrome.org>



DB-LINK - The National Consortium on Deaf-Blindness: “Information to nurture, empower, and instruct

children who are deaf-blind”

<http://www.tr.wou.edu/dblink/>



National Organization for Rare Disorders (NORD): For information about rare syndromes and disabilities

<http://www.rarediseases.org/>

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T S B V I Texas School for the Blind and Visually Impaired: A comprehensive site, with information about a wide variety of topics relating to blindness, visual impairment, deafblindness, and children with multiple disabilities.

<http://www.tsbvi.edu/>

VI Guide: A guide to internet resources about visual impairments for parents and teachers.

<http://www.viguide.com/>

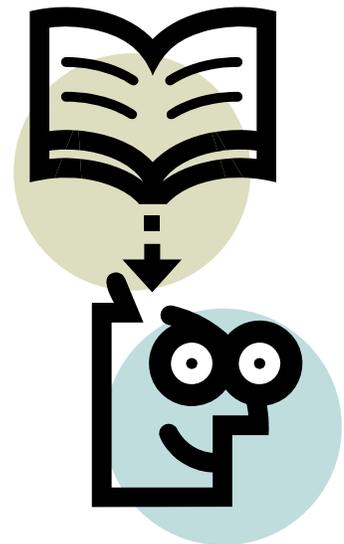
Literacy for Students with Deafblindness

When we think of literacy for children with deafblindness, we must look at in a different manner. Literacy is not just about reading and writing. According to United Nations Educational, Scientific and Cultural Organization (UNESCO), “literacy is the ability to identify, understand, interpret, create, communicate, compute and use printed and written materials associated with varying contexts.” With this definition, we can look at varying degrees of literacy for individuals with deafblindness.

Children with deafblindness may not be able to access literacy-based curriculum in the traditional methods. Some traditional methods and adaptations for students, with visual impairments only, include:

- Read newspapers, books, notes, calendars, signs, menus, etc.
- Opportunities to read, write and interpret Braille
- Expressing emotions
- Opportunities to communicate to develop relationships
- Listen to dialogue read to them
- Touch and use Braille and other forms of communication

(Adapted from Miles, January, 2005)



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A child who is deafblind may not have opportunities to see and hear people writing and reading. Research has shown this practice promotes literacy. Let's look at some ideas to promote this skill.

1) Meaningful conversations also promote literacy. Ideas for promoting meaningful conversations with children with deafblindness may include:

- ✓ Make a teachable moment, when a child notices a label or written materials. Say; "yes that is _____, here is another one." Pause and wait to see if the child responds by touching that item. Validate response. If no response after 10 seconds, provide additional dialogue and/or cues.
- ✓ Develop a story book using real or small pieces of objects to tell a story. Place them in book format using a binder to hold the pages of the story that have objects adhered to each page. "We have a dog (piece of fur) his name is Max; we play tug-of-war together (piece of knotted nylon used to play tug-of-war); I help feed Max (piece of dog biscuit); when Max is tired he sleeps in his crate on a rug (piece of plastic similar to make-up of crate or piece of rug Max uses as a bed). As the family reads the story, each item is touched. Add descriptions to the touched item as the story is read, "The fur is soft, the dog biscuit is hard, the dog bed is warm."
- ✓ Respond to any written or drawn items made by the child.

2) Typical instructional materials and books may not meet the needs of students with deafblindness. Ideas to make materials accessible include:

- ✓ Books on tape
- ✓ Braille books
- ✓ Children's books with textures and/or touch and smell
- ✓ Use dolls as characters or toys to relate to the story to use when reading to the child
- ✓ Pair dialogue with sign language
- ✓ Enlarged print
- ✓ Adapt the story to meet the comprehension needs of the student. Communicate key points of story.
- ✓ Program an augmentative communication device to tell a story. Each grid on the device or each hit of the switch has the next page of the story recorded.

3) Other related activities to promote literacy for the student with deafblindness include:

- ✓ Use textured materials as an ink blot to make an art project (stamp, rolling pin,

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pasta shells, woodblock)

- ✓ Opportunities to play and explore a slate and stylus and Braillewriter
- ✓ Use of drawing programs on a computer
- ✓ Time to use and explore unaided materials such as crayons, markers or paints
- ✓ Use of clay or play dough
- ✓ Develop and use a daily schedule using objects to associate the day's activities, what happened yesterday and what will happen tomorrow.

(Adapted from Miles, January 2005)

Once we connect to the child with deafblindness, many doors of growth and development evolve. Seek help, talk to teachers, parents and related professionals to assist you develop a strategy to meet your child's needs. Once that first initial learning step is achieved then the next learning steps will come easier.

Resources:

Erickson, Karen; Musselwhite, Caroline Ramsey & Ziolkowski, Ruth. *The Beginning Literacy Framework*. Don Johnston, Inc. 2002.

Hanser, Gretchen. *Promoting Literacy and Communication for Students with Multiple Disabilities Including Visual Impairments, Blindness and/lr Deaf-Blindness*. NCDB Literacy Topical Workshop. Orlando, Florida. May, 2008.

Miles, Barbara. *The Importance of Literacy for One Who is Deaf-Blind*. National Consortium on Deaf-Blindness (NCDB). www.nationaldb.org/NCDBProducts.php?prodID=37 January 2005.

National Consortium on Deaf-Blindness. *The Path to Symbolism*. Practice Perspectives-Highlighting Information on Deaf-Blindness, No. 3, August 2008.

Calendar of Events

October, 2008

Date: October 22-26, 2008
Topic: 2008 Southeastern Regional
Institute on Deafness and Touch



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the Future – Transition conference

Location: Atlanta, Georgia
Audience: Teachers, service providers, and administrators
Contact: Valencia.Thomas@dol.state.ga.us

Date: October 24, 2008, 10 AM - 3 PM
Topic: When You Have a Student with a Visual Impairment

Location: Alphapointe, Kansas City, MO
Cost: Free
Audience: Teachers, service providers, and administrators
Contact: Anthony Blades, Blind Skills Specialist, ablades@truman.edu or (660) 785-7428

November, 2008

Date: November 6 -7, 2008
Topic: Sensory Learning Kit
Location: Missouri School for the Blind, St. Louis, Missouri
Cost: \$25.00
Abstract: Millie Smith will present a 2-day training on strategies to use when using the APH Sensory Learning Kits and how to design activities to the specific skills identified on IEPs
Audience: Teachers and administrators
Contact: Yvonne Ali, 314-776-4320 ext 256 or yali@msb.k12.mo.us

Date: November 20-22, 2008
Topic: Addressing the Needs of Students Labeled Deaf and Low Functioning
Location: 5th Year Conference of Addressing the Needs of Deaf and Deafblind
Cost: \$50.00
Abstract: This conference will address strategies to address the needs of students with deafness and deafblindness and the implementation of these strategies.
Audience: Teachers, administrators and parents
Contact: tjohnson@esc4.net

Missouri Deafblind Technical Assistance Project
Missouri School for the Blind
Project Staff
Jennie Mascheck ...Project Director
Susan BonnerProject Coordinator
Andrea Harrington...Education Specialist
Janus HinsonTransition Specialist
Virginia WilliamsFamily Specialist
Michael GradyProject Evaluator
Margaret Anthony.....Project Secretary

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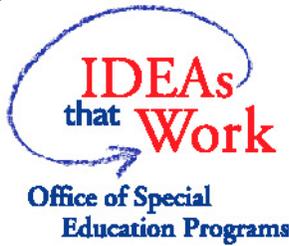
**Missouri Deafblind Technical Assistance Project
Missouri School for the Blind**

In Focus

Susan Bonner Editor

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