



IN FOCUS

MISSOURI DEAFBLIND TECHNICAL ASSISTANCE PROJECT

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Helping Your Child Use Residual Vision

Helping you child maximize their use of residual vision can utilize simple modifications in the home. Sometimes technology plays an integral role in helping the student in his/her home and community. It is wise to ask the child about his/her preferences for support. If the child is unable to communicate his/her preferences, then make observations of how your child responds to his/her environment. Also, consult your child's Orientation and Mobility (O&M) Specialist, Vision Teacher, or other personnel experienced with visual and/or deafblind impairments.

Let's look around your home and discover some simple adaptations/modifications that may be used.

In This Issue...

Helping Your Child Use Residual Vision.....	Front Page
International CHARGE Conference	3
Common Syndromes Associated with Deafblindness.....	4
Update Family Needs Assessment	5
Missouri Deafblind Census.....	6
Transition	7
Calendar of Events	11

- **Play room:**

- Consider goose-neck lamps that may be moved to meet the lighting needs when performing tasks.
- Use matte finishes on counter tops rather than finishes that are glazed.
- Line shelves with dark non-glare shelf paper to contrast with objects/toys stored on shelves

- If the cabinet handles do not contrast with the cabinet, then consider wrapping handles of the cabinets with contrasting fluorescent tape
- **Dining:**
 - Adequate lighting above eating area
 - Make sure there is a contrast between table and eating utensils. Consider using contrasting placemats.
 - Avoid decorated plates, rather select solid colored plates so the food will be easily seen.
- **Bedroom:**
 - Reduce clutter of toys. Shift them around by putting some away when child is tired with some and bring out other toys, continue this cycle.
 - Check if the wattage for the light bulbs is adequate. Consider replacing with screw-in fluorescent bulbs.
- **Bathroom:**
 - Use contrasting non-skid mat for bath tub/shower
 - Clear plastic shower curtains transmit more light into the shower /tub area.
- **Living Room:**
 - Pastel colored shears on windows reduce glare coming in from outside.
 - Furniture should be contrasting color from the floor and walls. Placement of an afghan also helps the student locate furniture.
- **Halls/Walk Ways:**
 - Keep stair landings well lit, both at top of stairs and at the bottom.
 - Paint hand rails painted on stairs in a contrasting color to the wall enhance the child's ability to locate them.
 - Hallways painted a lighter color help brighten it.
 - Use a dark runner in hallway for the child to follow to get to areas in the home.
- **Outside:** Allow time for the child to adjust when going outside on a sunny day to adjust to the light. Do you have a shady area to play (But not too dark)?

Resources:

Supporting Young Adults Who Are Deaf-Blind in their Communities Jane M Everson. Paul Brookes Publishing Company, Baltimore, Maryland. 1995.

Understanding Deafblindness: Issues, Perspectives and Strategies Linda Alsop. SKI-HI Institute, HOPE Inc., North Logan, Utah. 2002.



International Charge Conference

The International CHARGE Conference was held in Costa Mesa, California, July 27–July 29, 2007. CHARGE is a genetic birth defect occurring in one in every ten-thousand births. This very complex syndrome involves extensive medical and physical difficulties. Children diagnosed with CHARGE Syndrome may have hearing loss, vision loss, balance problems, and delays in communication and other development.

The Missouri Deafblind Technical Assistance Project was able to assist three families in attending this conference. Mike and Corrie Young report that they came back from the conference with the realization that children with CHARGE Syndrome (including deafblindness) have “layer upon layer of obstacles placed in front of them, each one unique with their own set of challenges. Yet they all have one thing in common and that is tenacity. They are an amazing group of children/adults and I am proud to be a parent of two of them.”

Mike and Corrie Young attended one of the break-out sessions about *Vestibular, Function, Balance, and Development*. This session was presented by Lori Travis and James Thelin, who are conducting research at the University of Tennessee. Based on their current ongoing research they are finding correlations between gross motor development and the development of symbolic language.

Travis and Thelin are also conducting research on the Vestibular-Ocular Reflex (VOR) in children with CHARGE Syndrome. The research is trying to determine how VOR affects vision and balance. Mike and Corrie Young inquired how this may impact their sons. As result, they were able to enroll their sons into this part of the ongoing research on VOR.

The next scheduled International Conference is planned for July, 2009 in Chicago, Illinois. For more information about CHARGE Syndrome view their web-site at www.chargesyndrome.org

Common Syndromes Associated with Deafblindness

Deafblindness in children is often the result of some type of syndrome occurring during the child's developmental years. There are many types of syndromes associated with deafblindness. A few of those are described below.

- **Usher Syndrome:** It is an inherited condition involving both hearing and vision loss. The vision loss is progressive due to retinitis pigmentosa (RP). Children diagnosed with Usher Syndrome are classified in three groups. The type of classification affects the type of strategies used to teach the child.
 - **Usher Syndrome Type I:** Children are born profoundly deaf and have balance problems. Vision problems appear during early childhood.
 - **Usher Syndrome Type II:** Children are born with moderate to severe hearing impairments. They have no problems with their balance. As the child gets older, night blindness develops.
 - **Usher Syndrome Type III:** Characteristics associated with Usher III do not begin to appear until adolescence. These children may have good hearing or a mild hearing loss at birth, but it progressively worsens developing into a profound hearing loss by adulthood. Night blindness appears in the adolescent years. Children with Usher III may also have a progressive balance problem.
- **Cytomegalovirus (CMV):** CMV is the result of a virus resulting in a fever, hepatitis and severe brain damage. It may occur as the result of congenital or postnatal influences. CMV may cause inflammation in the eye, resulting in scarring. Hearing loss occurs due to damage to the sensorineural areas. The virus is passed onto others through the urine. Therefore, good hand washing techniques are important.
- **CHARGE Association:** This is a rare genetic birth defect occurring one in every nine to ten thousand births. Children with CHARGE have extensive medical and physical difficulties. Deafblindness is the result of at least four (4) of the following

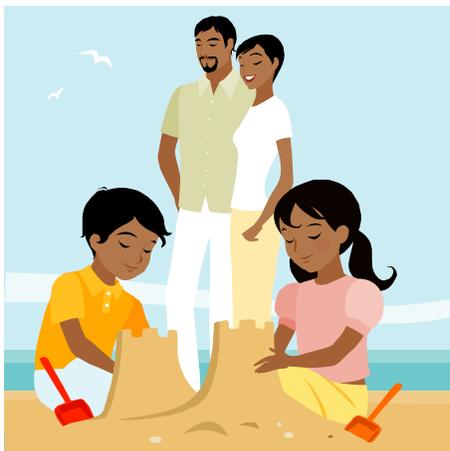


characteristics.

- **C:** Coloboma – absence of some eye tissue
 - **H:** Heart defects
 - **A:** Artesia of the choanae – absence of the opening between the nasal cavity and the back of the throat
 - **R:** Retarded growth and development of the central nervous system
 - **G:** Genital or urinary abnormalities
 - **E:** Ear abnormalities and hearing loss
- **Down Syndrome:** A genetic linked disability, usually associated with cognitive delays and often congenital heart disease. Research has shown increased visual and hearing impairment associated with this syndrome.
 - **Rubella Syndrome:** It is the result of the rubella infection passed onto the fetus from the mother when she contracts Rubella during the first trimester of pregnancy. Many children were diagnosed with deafblindness during the late 60's as a result a Rubella outbreak. In later life, some people with Rubella Syndrome may develop glaucoma and/or detached retinas. With vaccinations for prevention of Rubella, this syndrome occurs rarely now.

It is very important to understand the cause of the child's deafblindness and how it affects the child's development. Educational strategies to support the dual sensory impairment vary depending on the cause of deafblindness and what exposure to utilizing these senses the child has previously used.

Update Family Needs Assessment



Recently, a Family Needs Assessment was sent to all families whose child is on Missouri's Deafblind Census. This survey was contained in our follow-up packets sent to families of students registered on the annual census report. This information is being used to plan what information is important to families of children with deafblindness and how they would like to best receive this

information. Also, this information is beneficial as the Missouri Deafblind Technical Assistance Project prepare for the next federal grant cycle. Our current grant will end in 2008 and the Project staff is busy preparing the Missouri’s proposal to the federal government, Office of Special Education Programs (OSEP).

The majority of families responding to the survey were interested in these activities as they pertain to current activities of the Project:

- ✓ Onsite consultation to your child’s school/program: 63%
- ✓ Assistance in planning assessments (vision, hearing, communication etc.): 58%
- ✓ Stipends to attend workshops and seminars related to deafblindness 58%



Even though families showed a lower priority on some topics about deafblindness, these families still were interested in learning about these topics. When a topic had a lower priority of interest, families still wanted to receive information about the topic via the internet or materials sent to them. This newsletter plans to be used to provide families with this information. These topics were the following:

Low Interest Topics

Topic	Delivery			
	Workshop	School In-service	Materials sent	Internet
Information on specific etiology/cause of deafblindness 57%	13%	13%	56%	38%
Overview of hearing and hearing impairments 53%	12%	12%	59%	35%
Information on a specific type of hearing impairment 56%	13%	19%	56%	31%

High interest topics showed that families wanted information in a variety of forms, but those topics of highest interest strongly showed families’ interests to have information delivered

through workshops or school in-services.

High Interest Topics

Topic	Delivery			
	Workshop	School In-service	Materials sent	Internet
How deafblindness affects communication, cognition, motor development, socialization, etc. 81%	52%	31%	17%	6%
Orientation and mobility for children with deafblindness 94%	53%	24%	29%	6%
Assessing orientation and mobility of a child with deafblindness 94%	25%	38%	31%	0%
Communication systems used by children with deafblindness 76%	38%	25%	13%	6%
Assessing the communication of a child with deafblindness 82%	25%	44%	25%	0%
Teaching communication skills 88%	47%	29%	12%	6%
Assessing the cognition of a child with deafblindness 80%	53%	20%	13%	7%
Education assessments of students with deafblindness 77%	35%	29%	24%	6%
Behavioral issues of infants, children and youth with deafblindness 80%	53%	13%	13%	7%
Increasing social connections for infants, children and youth with deafblindness 67%	33%	7%	33%	20%
Transitioning youth with deafblindness from school to adult living 69%	13%	19%	25%	6%
Accessing services and supports in the community for infants, children and youth with deafblindness as well as their families 94%	25%	13%	44%	6%

The Missouri Deafblind Technical Assistance wishes to thank all the families that responded to the survey. We will be using this information to plan activities to provide you with your identified needs. We hope that this newsletter will also serve as a means to deliver information to families.

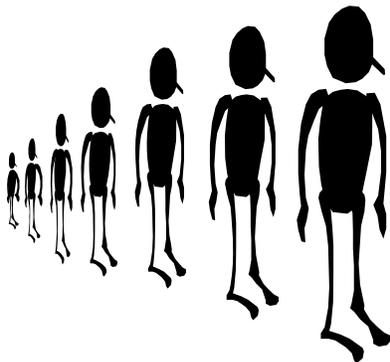
Missouri Deafblind Census Connects Families, Educators, and Other Service Providers to Services and Supports

The Federal law, Individuals with Disabilities Education Act (IDEA), requires the annual conducting of a census of all individuals with deafblindness, ages birth through 21 years. The Missouri Deafblind Technical Assistance Project conducts the annual census in the state of Missouri.

One purpose of the census is to inform the United States Congress and the United States Department of Education about these infants, children, and youth with deafblindness. Another purpose is to help each state's deafblind project identify some of the services and supports needed by these individuals, their families, and the agencies that support them. By identifying individuals with deafblindness in the State of Missouri, the Missouri Deafblind Project is able to provide connections for families, educators, and other service providers to supports and other services.

The Census consists of demographic information, such as an individual's date of birth, gender, living setting, education setting and so on, along with descriptive information such as cause of deafblindness. The Missouri Deafblind Project uses this demographic and descriptive information in many ways.

When a school district, program, or agency reports an individual with deafblindness, the Project sends back to the professional reporting the individual a packet of information that summarizes not only the services and supports the Project can provide the district, program, or agency, but also information about other services and



supports available on a local, state, and a national level. A similar packet is sent to families. Both packets include a simple form for the recipient to complete and return to the Project. This form is used by families and professionals to ask for specific support and services from the Project.

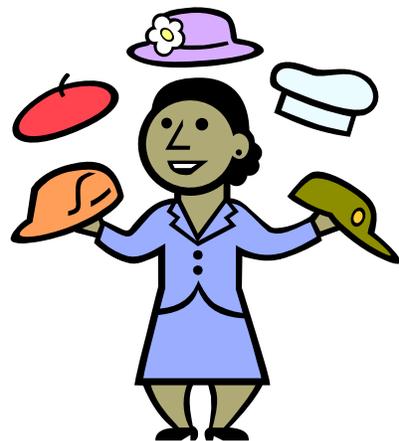
The Project also uses the demographic and descriptive information provided by the Census to plan specific activities such as topical workshops (past workshops included Cortical Visual Impairment and assessment of individuals with deafblindness). Through the Census, the Project documented a large number of transition age youth (ages 14 through 21 years) with deafblindness in Missouri and, therefore, now offers the expertise of a Transition Specialist to assist districts and families develop and implement effective transition plans that consider the unique needs of individuals who have both a visual and auditory impairment.

Transition

IEP Definition

According to IDEA (Individuals with Disabilities Education Act), transition planning is a coordinated set of learning experiences and activities with long-range outcomes. Through the IEP (individual Education Plan), the transition plan addresses linkages to community resources for post-school outcomes that is based on individual student needs, interests, and preferences. Transition planning is required for all students with an IEP beginning at age 16, but IEP teams may address it as early as age 14. Annually the IEP team will review the Plan.

Long-range planning should address the student's preferences for living arrangements, employment, community participation, leisure and any other important life areas. The IEP team will address what skills the student needs to achieve these goals and linkages to make facilitate the process. As the IEP team formulates the plan, they must identify the skills needed to learn within the associated curricular areas. The team identifies what other linkages are needed for the student to achieve outcomes, how they will be achieved, and who will assist the student and



family.

How does transition affect students with deafblindness?

Developing and implementing transition plans for youth with deafblindness provides unique challenges to families and educators. Youth with deafblindness often need a greater level support than youth with only a visual, auditory, or cognitive impairment. Effective transition plans not only require thorough documentation of how to appropriately support each individual youth with deafblindness, the plans also need to identify and provide linkages to adult and community agencies that can provide these needed supports. Students with deafblindness often begin transition planning earlier than age 16. It is an IEP team's decision to address it an age earlier than 16. The IEP team may wish to begin addressing a student's transition needs as early as age 14.

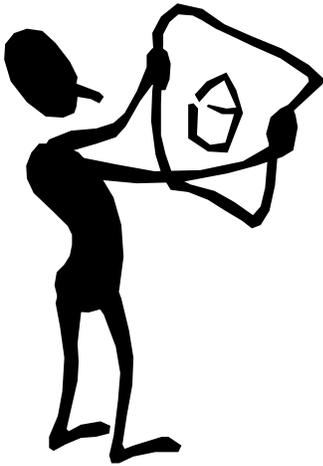
Reasons an IEP team chooses to address transition needs at an earlier age may be one or more of the following:

- The student's unique needs require extensive planning and time to achieve desired outcomes
- The post-school service providers need to understand deafblindness and student's unique needs
- The student requires extensive time to apply skills to new environments concerning
 - Auditory needs
 - Visual needs
 - Communication needs
 - Orientation and mobility
 - Social skills regarding routines and interactions with others
- The service providers may need training and/or consultation to serve the student
- Waiting lists for funding of adult services may be long
- There may be adult service gaps, that require advocacy of funding sources to facilitate in new service development



Person-Centered Planning

Person-centered planning refers to a variety of methods utilized by teams supporting individuals with disabilities to organize and plan for the individual's participation in the community and attainment of long-range life goals. There are a variety of person-centered planning approaches utilized. These approaches have some common threads:



- The individual with disabilities is the focus of the planning
 - Who is this person
 - What positive community connections has the individual had
 - What skills does the individual have
- The purpose of meeting is make plans into actions
- Promote community inclusion
- Collaborative planning among agencies
- Respect the dignity of the individual with disabilities and seek their capabilities
- Assist the person with disabilities achieve life goals

The Missouri Deafblind Project offers the expertise of the Project's Deafblind Transition Specialist, Janus Hinson, to education teams and families planning the transition of youth with deafblindness from school to adult living. Some specific supports the Transition Specialist can provide to education teams include: facilitation of Personal Futures Plans (PFPs) and Essential Lifestyles Plans (ELPs), assistance in developing transition plans that reflect effective practices, information regarding resources (local, state, and national), as well as facilitation of linkages between education teams and other organizations that provide services and supports critical for successful transitioning. For more information regarding the Transition Specialist and/or to request assistance from the Transition Specialist, please contact the Deafblind Project at (314) 776-4320 x 255 or e-mail your request to: sbonner@msb.k12.mo.us.

Calendar of Events

November, 2007

Date: November 15- 17 2007
Topic: Working with Students with Deafblindness
Location: Orlando, Florida
Abstract: Dr. June Downing will speak on her years of experience and research in the field of deafblindness.
Audience: Teachers, service providers and administrators
Contact: Shelly Voelker, Florida Outreach Project for Children & Young Adults with Deaf-Blindness, 800-667-4052 or shelly.voelker@mbi.ufl.edu

December, 2007

Date: December 5 - 7, 2007
Topic: Annual TASH (The Association for Persons with Severe Handicaps) Conference
Location: Seattle, Washington
Audience: Teachers, service providers, paraprofessionals, and administrators
Contact: www.tash.org



Date: December 6 - 8, 2007
Topic: Discovery 2007: The Low Vision Conference
Location: Chicago, Illinois
Audience: Teachers, service providers, paraprofessionals, and administrators
Contact: www.deicke.org

March, 2008

Date: March 7 – 9, 2008
Topic: Missouri Council for Exceptional Children Conference: Connections The Heart of Education
Location: The Lodge of the Four Seasons, Lake of the Ozarks, Missouri
Audience: Teachers and administrators
Contact: Pam Widener, 16125 County Road 4220, Rolla, Missouri 65401, 573-265-9211, pamwidener@wildblue.net

April, 2008

Date: April 2, 2008 – April 5, 2008
Topic: Council for Exceptional Children Convention & Expo
Location: Boston, Massachusetts
Audience: Teachers, service providers, and administrators
Contact: www.cec.sped.org

Date: April 27, 2008 – May 2, 2008
Topic: Association for Research in Vision and Ophthalmology Annual Meeting
Location: Fort Lauderdale, Florida
Audience: Teachers, service providers, and administrators
Contact: www.arvo.org

July, 2008

Date: July 7 -10, 2008
Topic: Vision 2008: Ninth International Conference on Low Vision
Location: Montreal, Quebec, Canada
Audience: Teachers, service providers, and administrators
Contact: www.vision2008.ca

Date: July 22- 27, 2008
Topic: Association for Education and Rehabilitation of the Blind and Visually Impaired (AER) Biennial International Conference
Location: Chicago, Illinois
Audience: Teachers, service providers, and administrators
Contact: www.aerbvi.org

Missouri Deafblind Technical Assistance Project
Missouri School for the Blind

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

In Focus

Susan Bonner Editor

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In Focus