VIBRATIONS

NEWSLETTER OF COLORADO SERVICES FOR CHILDREN WHO ARE DEAFBLIND Serving Children with Vision and Hearing Loss, Their Families, and Service Providers Winter 2003

Hello, we are the Miller Family: Tom, Gail and our 7 wonderful children. In July 1994 we were expecting our 7th child, but to our surprise we learned that we were expecting twins. This would not be easy considering I had high-risk pregnancies--they delivered at 25 weeks. Heather survived with a birth weight of 790 grams, her twin did not make it. Heather had intra-ventricular hemorrhage, which caused hydrocephalus and was treated with a reservoir. She was diagnosed with a hearing deficit. She had a laser procedure for retinopathy of prematurity. She also has grand mal and petite mal seizures.



We did all we could to meet Heather's physical needs. There were so many doctor appointments, we never dreamed of seeing so many physicians. As a family, we *loved* to hold her and rock her. That was so natural for all of us. Seizures increased as Heather grew, she also required several hip surgeries. Heather endured everything well, she is a real fighter.

As parents, we faced a difficult dilemma wondering how hard to push Heather so that she could reach her fullest potential. But what was her potential? With 6 other children, we knew not to compare one child to another. We always felt that each child is an original. We often tell them "there is no one else like you and you have each something special to do here". We also felt that same way with Heather, but we wondered what it was that she was to do. Her opportunities of participating more in church, school and her community came about. Getting people to not fear this beautiful child was a bit of work, but most of the time people dealt with their emotions well. At our church they have a program in place to give us and other parents with special-needs children a break. It's been a wonderful Sunday school program.

When it was time for Heather to enter school programs, play group and pre-school was no problem. When she hit kindergarten we

naturally wanted her to attend our neighborhood school. It was where all our other children and the neighbors' children went. We wanted her to be part of what we knew to be a good school, good children, and a good atmosphere. We didn't consider whether it would work, or what adjustments might be needed, or how staff would handle it. As her

parents we made those personal adjustments, we made things work, we just handled it, and we expected the community to do the same. I once heard that it takes a community to raise a child. We believe that statement to be *so* true.

As a mom, I volunteered many hours of my time to the school to pursue my personal goal, which was to watch out for Heather. I also wanted to serve as a gentle reminder of IEP (Individualized Education Plan) goals needing to be met and to give words of encouragement to those making efforts and changes for my daughter. The school has risen to the challenge. They make Heather feel welcome and show that they care. Her aide is simply wonderful and treats Heather as her own. We knew it was a good school; the staff and the children have warmly accepted Heather just as we hoped they would.

It's not always easy, but Heather makes it worthwhile, she truly completes our family. We all have something to contribute in this world and so does our sweet, gentle Heather. She teaches us and reminds us to appreciate all things, to embrace special moments, cherish time, always be patient, and to endure things with a smile.

When I look into her face I know I'm looking at a bit of heaven here on earth.

Editor's Note: This story was written by Gail Miller, Heather's mom. We would like to thank the Miller family for this wonderful story into their lives.

Parents Encouraging Parents (PEP) Conference



PEP Conferences are family centered conferences designed to offer support, information, and education to parents and professionals. PEP promotes partnerships that are essential for supporting and including children with disabilities and their families in all aspects of school and community. There is one more PEP Conference for this school year. It will be held on March 6-8, 2003 in Colorado Springs. For more information, please contact 303 866-6846.



What is new with the Colorado Deafblind Project!

This Newsletter: The topic of this edition is assessment.

Census Update: Thank you to everyone who participated in the annual registration of children and youth with combined vision and hearing loss. The census data is currently being tallied. We will have information to share about the results of the census in the next newsletter. Please be aware that a child new to the census can be registered at anytime during the calendar year. If you have a new student in your program, please call Gina Quintana at (303) 866-6605.

Colorado Student Assessment Program – Alternate (CSAPA): The CSAPA testing dates for this school year is February 3, 2003 through March 14, 2003. CSAPA is currently available in 3rd and 4th grade literacy, 5th grade math, and 7th and 10th grade literacy. Many teachers, administrators and related service providers attended administration trainings throughout the state.

Family Retreat: The Family Learning Retreat will be in Colorado Springs at the Colorado School for the Deaf and Blind on May 31-June 1, 2003. The theme of this retreat is "Hot Topics in the Summertime." If you have questions about the retreat give Gina Quintana a call at 303-866-6605. If you would like to register, please call Marybeth Herens at (719) 578-2225. See the flier in this newsletter for more information.

Technical Assistance: Gina has been out visiting schools and homes, getting to know the children on the census, parents, teachers and educational teams. She has also been involved in several IEP meetings. Technical assistance is still available throughout the summer. TA can be provided in a variety of ways, including a home visit, telephone call, or email.

Parent Networking: Several moms have been meeting monthly over breakfast, to talk about issues related to raising a child with a disability. The next breakfast for this school year is scheduled for Wednesday, March 12, 2003 at IHOP on the corner of 52nd and Wadsworth, from 9:30-11:30. We would love to have you join us. Dads are welcome too!

The Colorado Services to Children with Deafblindness Project is part of the CO Department of Education. This project is supported by Part 307.11, Grant # H326C990030 for the U.S. Department of Education. This newsletter was produced and distributed pursuant to the grant. Points of view do not necessarily represent CDE positions or policies. Mention of trade names, commercial products, or organizations does not imply endorsement by the U.S. Government. The newsletter is published three times a year. Requests to be placed on the mailing list should be mailed to Sharron Fieber, CDE, 201 East Colfax Avenue, Denver, CO 80203. This newsletter was prepared by: Gina Quintana and Tanni Anthony.



February 21-22	Courage to Risk Conference – Colorado Springs, CO Contact: www.couragetorisk.org
March 6-8	Parents Encouraging Parents Conference - Colorado Springs, C Contact: (303) 866-6846
April 9-12	Council of Exceptional Children Conference - Seattle, WA Contact: <u>www.cec.sped.org</u>
June 2	<u>SWAAAC Conference</u> - Winter Park, CO Contact: AT Office - 303 315-1280
May 30-June 1	<u>Family Learning Retreat</u> - Colorado Springs, CO Contact: Gina Quintana for deafblind strand - 303 866-6605
July 25-27	6th International CHARGE Syndrome Conference - Ohio Contact: conference@chargesyndrome.org or DB Link at 1-800 438-9376
August 5-10	<u>World Conference on Deafblindness</u> - Ontario, Canada Contact: <u>www.dbiconferencecanada.com</u> or DB Link at 1-800-43 9376

HELEN KELLER IMAGE ON QUARTER



The State of Alabama selected Helen Keller to adorn their state quarter. Her image was selected over a moon rocket, a Cherokee Chief, and other Alabama-related symbols. This will be the first U. S. coin in circulation to include braille. The Helen Keller coin will be the 22nd quarter issued in the U. S. Mint's state quarter program, a 10-year initiative commemorating each of the 50 states.

Family Learning Retreat 2003 "Hot Topics in the Summertime"

Colorado School for the Deaf and the Blind 33 North Institute Street Colorado Springs, Colorado 80903 May 30-June 1, 2003

The Family Learning Retreat will change locations this year, returning to the Colorado



School for the Deaf and the Blind on May 30-June 1st, 2003. The weekend retreat is for any family with a child who is deaf/hard of hearing, blind/visually impaired or deafblind. This is an opportunity for families to meet other families while learning and having fun together. This year's theme is "Hot Topics in the Summertime."

Parents /adults will attend workshops during the day, while children participate in supervised recreational activities or daycare, depending on their ages. Check-in is Friday evening, May 30th starting at 5:00PM until 7:30 PM and followed by a BBQ. The retreat ends by noon on Sunday, June 1st. Lodging in the CSDB dorms is provided for both Friday and Saturday nights. All meals are included except for Saturday evening.

The cost of the Family Learning Retreat is only \$10.00 per adult and \$5.00 per child under the age of 18. Spanish and Sign language interpreters will be provided upon request. Interested or know of someone who is? Call Marybeth Herens at the Colorado School for the Deaf and the Blind at (719) 578-2225 to call in your registration. For Spanish speaking participants, contact Val Hernandez at CSDB at (719) 578-2201. For a reservation to be confirmed, a registration form must be filled out and payment received by Friday, May 2, 2003. Any registration not confirmed with a payment by that date will be released to allow others on the waiting list to take advantage of the opportunity. Please contact Marybeth Herens at (719-578-2225) or Gina Quintana at (303-866-6605) if you have any questions.

We hope to see you there!

Come and Relax. Make New Friends. Experience a valuable learning opportunity.

REGISTER TODAY!



A NEW GRANT PROPOSAL WILL SOON BE OUT THE DOOR!



We are in the fourth and final year of funding for the Colorado Services for Children with Deafblindness Project. The project is funded currently through the federal Office of Special Education Projects.

A new grant proposal will be out sometime this spring and project staff will write a new grant for the next four years. We would love to hear from you about what activities you would like to see maintained and what new activities you would like to see added to the project.

YOU CAN HELP!

Now is an exciting time to dream about how to best offer support to individuals who are deafblind (have combined vision and hearing loss), their families, and their educational team. Please share you dreams with us!



In addition, we would love to receive a letter of support from you! A letter of support would be helpful in two ways. One, your letter will provide project staff with insight on how the project has been and/or could be helpful to you. Two, it willprovide the grant proposal reviewers with information about other people's /agency's support of this project.

We are hopeful that you will take a few moments to reflect on the past work of this project and the need for its continued work in Colorado. We plan to continue with the following key projects:

- **program assistance to parents and school personnel**
- parent meetings and family support activities
- s one day training programs on specific topics
- Summer Family Retreat for families
- Summer Institute training with state and national experts
- VIBRATIONS newsletter
- Lending library
- Collaborative projects with other agencies (e.g., vision screening guidelines)
- **Regional collaboration for an early childhood / sensory disabilities conference**

If you choose to write a letter of support, please address how the project has been of assistance / support to you, how you would like to be involved with future services of the project, and any ideas that you might have for activities to be included in this proposal. Please address the letter to: Tanni Anthony, CDE, 201 East Colfax, Denver, CO 80203.

We are hoping for letters from parents, siblings, grandparents, teachers, related service providers, administrators, and individuals who are deafblind. Handwritten letters are fine – in fact, they are wonderful! The important thing is to hear from you. Please send your letter no later than **April 15, 2003** to be sure that it included the grant proposal. Thank you for your ongoing support of our state project!

What's in a Name? What Do We Mean by the Term "Deafblind?"

By Tanni Anthony



Each year as the census rolls around and it is time to register children with deafblindness, questions comes up about "who is deafblind" and "what is deafblind?" These are excellent questions. The term "deafblindness" is confusing as it implies that an individual has no hearing and no vision. Nothing could be farther from the truth. Deafblindness encompasses a variety of types of vision and hearing loss, as well as different levels of vision and hearing loss. Each person below could be described as being deafblind:

- Amy is a senior in high school. She was born with normal vision and hearing. A car accident in her junior year left her with severe head trauma. Due to a combination of brain injury, as well as physical damage to her eyes, she has both vision and hearing loss that affects her learning, communication, and mobility. She has been evaluated for her assistive technology needs and is learning to use a new communication system and an electric wheelchair.
- Matthew, now eight years old, was born two months prematurely. He has a moderate sensorinerual hearing loss with frequent ear infections. The ear infections influence his ability to hear with his hearing aids. On a good day, Matthew can hear people talk to him if they are in close range and there is not a lot of background noise. He also has vision loss due to damage to the retinas of his eyes. He can see people and objects when they are close to him. Distance vision is better when the object has good contrast with its background. He uses a magnifier during reading tasks.
- Mark was born with a profound hearing loss. When he was 10, his family noticed that he was hesitant to be outside after dark. With proper testing, he was diagnosed with a retinal disorder called Retinitis Pigmentosa at age 15. He has lost visual field and the prognosis is that his visual field will continue to diminish, as will his ability to see well in dim lighting. Mark has learned to use tactile sign in situations where he cannot visually see the signs. Mark has met people with Usher syndrome (his diagnosis) that use a long cane and read braille.
- Rosa had meningitis when she was 18 months old. Since that time, she has been diagnosed with cortical visual impairment. She failed an oto acoustic emissions test and does not respond consistently to familiar sounds. Some days, she seems to see and hear better than others, but vision and hearing are not consistent avenues of learning for her. Rosa has an object calendar and tangible communication system to assist her in both receptive and expressive communication.

All of these individuals have one thing in common. They have vision and hearing loss that interferes with some aspect of their learning, communication, and mobility. All require the educational expertise of professionals trained in sensory disabilities. What is different is the age of onset of their vision and hearing losses, the types and levels of

their vision and hearing impairments, the presence of other disabilities, and their ability to benefit from sensory enhancement aids and materials.

With that explained, it still may seem troubling to think that a person with usable vision and hearing has an educational label of "deafblindness." So what best to call it? Dual sensory impairment has been used by other states. My personal concern is that this term, just like deafblindness, needs to be explained to a person who has never heard it before. When you read this term, if you had never heard it before, did you know automatically that a person with dual sensory impairment has visual and hearing challenges? This understanding is paramount.

Colorado has students who have been identified solely as having multiple disabilities or significant support needs – when a primary or a secondary disability is really deafblindness. Without the "label" of deafblindness, this learner may not receive the educational services he or she truly deserves. Communication systems may be designed without detailed assessment information about visual abilities – how small of pictures can be used, whether the child has a full visual field to see all of a picture display, whether limited eye-movement skills will cause trouble with scanning a complicated visual display, should the child be braille reader, and so on. Without the "label" of deafblindness, a learner may not be considered a candidate for sign language, for auditory amplification systems, or other augmentative communication systems. Without the label – the educational community may not understand how the combination of both a vision and hearing loss influences the child's ability to take in information, participate in classroom activities, and explore his or her environments.

In Colorado, we use the internationally preferred term of "deafblind" – not deafblindness. The rationale is to acknowledge the vision and hearing loss up front and to indicate that it is not two additive disabilities (vision loss plus hearing loss or hearing loss plus vision loss). It is a unique situation / condition that is reflective of the combination and intertwined impact of deafness/hard of hearing and blindness/low vision. The child who is deafblind is different learner than the child who is deaf/hard of hearing and has normal vision and the child who is blind/low vision who has normal hearing. The interaction of vision and hearing impairment, no matter the type of loss or the degree of loss, places each child is an incredibly unique situation.

Personally, I would vote for a world where labels were not placed on an individual – it would be nice if we just knew what each child needed in order to learn, communicate, and be successful. Until that time, we need a word or a combination of words to describe the population of learners with combined vision and hearing loss. I would invite you to explain deafblindness as "combined vision and hearing loss."





Spring 2003

* Assessment and Interventions: Case Studies in Deafblindness

Course Description:

This on-line distance education course is designed for families, services providers, and educators working with children and youth who are deafblind. This course is taught through Case Tutorials in a Problem Based Learning approach. The Case Tutorials reflect real life issues that are of concern to families and service providers of children who are deafblind. Through these cases, participants discuss the delivery of appropriate services, alternate assessments, inclusion of students in natural settings, positive behavior supports and transition issues.

Course Objectives:

Students will:

- 1. Describe various diagnoses and syndromes that effect or result in vision and hearing loss.
- 2. Describe the effect that vision and hearing loss has on the development of the child.
- 3. Develop strategies for successful Transdisciplinary teamwork.
- 4. Demonstrate the skills / strategies necessary for the successful collaboration between families and school professionals.
- 5. Develop and implement ongoing assessment and intervention strategies for working with children and youth with deafblindness.
- 6. Become familiar with the intent of IDEA relative to public policy.

⇒ Deafblindness: Impact on Learning with Emphasis on Communication Issues

<u>Course Description</u>: This online course provides an insight into the world of deafblindness. The definitions, causes, and learning consequences of deafblindness are defined and explored. Simulations are included to facilitate experiences similar or closely related to deafblindness. Virtual Conference center discussions are maintained throughout the duration of the course to facilitate learning, sharing, and constructive brainstorming. The course is designed for families, individuals, or educational teams working with an individual who is deafblind.

Course Objectives:

Following completion of this course, the learner will have:

- □ Participated and interacted online using Internet and web tools.
- □ Learned the definition and scope of deafblindness
- □ Learned to read an audiogram
- □ Experienced a visual impairment
- □ Completed a functional analysis of communicative intent
- □ Completed a communication profile

<u>Cost</u>: There is no charge unless you apply for credit through UNM (University of New Mexico). A certificate of completion will be provided to all participants. Resource materials will be provided.

For information and to register, please contact: Project for NM Children and Youth Who are Deaf-blind Center for Developmental Disability University of New Mexico 2300 Menaul NE Albuquerque, NM 87107 (505) 272-0321 (v/TTY) – (505) 272-5280 (fax) Or visit their website at cdd.unm.edu and follow the link to The Project for NM Children and Youth who are Deaf-blind.



Corry can be contacted at (801) 968-2816 or corrynfadb@attbi.com.



The Mom's Support Group will begin meeting again in March. We will meet at the International House of Pancakes, 52nd and Wadsworth, from 9:30-11:30. The meeting dates are as follows:

- * March 12
- 🗮 April 2
- 🗮 May 14

This is a time for mom's to visit with one another and talk about the trials and tribulations of raising a child with deafblindness.



CSAP and **CSAPA**

Adapted from the Colorado Student Assessment Program – Alternate Brochure Available on the CDE website <www.cde.state.co.us>

The Colorado Student Assessment Program (**CSAP**) is designed to provide a picture of how students in the state of Colorado are progressing toward meeting academic standards, and how schools are doing to ensure learning success of students There are a few students with an Individual Education Program (IEP) who will not be able to take the general CSAP because of the nature and intensity of their disability. These students need a different way to show what they know and can do. The Colorado Student Assessment Program-Alternate, (**CSAPA**), was developed to measure progress for students who are beginning to demonstrate foundational skills of content standards.

The **CSAP-A** is not a paper and pencil test. Student performance is observed and documented during literacy based activities. The activities include attending to a story and answering questions for understanding, going to the library, reading with a teacher or peer, and creating/writing a story. The assessment measures how **independently** the student performs tasks (indicators) within the activity. The information is intended to be helpful to educators and families to evaluate the student's current progress toward expanded reading and writing benchmarks. In addition, the information will assist educators and families in planning curriculum to meet standards.

The Individual Education Program (IEP) team makes decisions about whether a student should take the CSAP or the CSAPA. Decisions are based on a student's individual needs, not a disability category, expected performance, or where the student receives services. Remember, the CSAPA assesses **emerging** literacy skills.

The CSAPA is a test that is Criterion-referenced assessment and is a demonstration of the student's performance while being scored on the level of support need for the student to complete each indicator. ANY adaptation necessary for the student to perform the task is allowed. It is scored on 5 performance levels.

The performance levels are:

- \Rightarrow Novice
- \Rightarrow Developing
- \Rightarrow Emerging
- \Rightarrow Exploring
- \Rightarrow Inconclusive

The CSAPA is administered in the Spring each year and this year the window of administration is from February 4 – March 14, 2003. The CSAPA should be used by the IEP team to guide instruction for the student's program. It provides information about where the student is performing and what some next steps might be. If you have any questions about the CSAPA, you can find information on the CDE website www.cde.state.co.us or give Gina or Tanni a call.

Training Opportunity with Phil Schweigert!

Over 40 people took advantage of the 2002 Summer Institute on Deafblindness. Phil Schweigert presented for two and a half days on the important topic of Tangible Communication Systems. Phil is coming back to Colorado and will be offering an evening training again on this topic - though in a much more abbreviated format. The training will be held from 6:00-8:00 p.m. on Tuesday, February 25th at the Best Western Hotel on Quebec Street off of 1-70. Light refreshments will be served. We need an accurate count of people who would like to attend this session. Please call Gina Quintana at (303) 866-6605 or Tanni Anthony (303) 866-6681, if you want to join us. If you get our voice mail, PLEASE leave your name and contact phone number so we can confirm your participant. Attendance is space limited - so be sure to call soon!



New Books in the Lending Library

<u>The Transition Process: Early Intervention to Preschool</u>, SKI-HI Institute, 2001. This invaluable resource is for service providers and intervention teams who are involved with transitioning children with special needs from early intervention to preschool settings. (Order #89)

<u>Understanding Deafblindness:</u> Issues, Perspectives, and Strategies, Volumes 1 and 2. "This manual is for parents, interveners and service providers. It covers all aspects of deafblind programming such as communication, concept development, vision, hearing, family issues, touch, sensory integration, intervention, physical education, additional disabilities, orientation and mobility, community support and evaluation. It contains clear and informative presentations with helpful summaries and many visuals." This set of modules was published by the Ski Hi Institute, 2002. (Order $\# 90_1$ and 90_2).

<u>Deaf Mentor Curriculum, A Resource Manual for Home-based, Bilingual-Bicultural</u> <u>Programming for Young Children who are Deaf</u>, by Paul Pittman, SKI HI Institute, 2001. This curriculum is the first one of its kind ever developed for use by deaf mentors who are working with young children who are deaf and their families. (Order # H11).

<u>Grandparents Caring for Young Children with Disabilities: A Labor of Love,</u> by Barbara B. Glover, SKI HI Institute, 2001. In this monograph, the special challenge of grandparents, who are caring for grandchildren with special needs, are discussed. Highly practical, sound advice is offered to persons working with grandparents, including parent advisors who have worked with grandparents. (Order #E25).



New Videos in the Library

<u>Move and Discover: The Active Learning Approach for Children with Disabilities</u>, by the North Dakota Deafblind Services Project, University of North Dakota TV Center, 2002. The video is based on Lilli Nielsen's active learning philosophy. Through movement children can discover texture, shape, weight, quantity, temperature, and spatial relationship. You will learn how to create a fun environment for a child and then be able to quietly watch the child play, learn, and grow. (Order #96)

Interdisciplinary Strategies: Infants with Multiple Disabilities, October 21, 2002, Teleconference featuring Deb Chen. (Video #97).

<u>Full of HOPE</u> – Visually Impaired Preschool Services – "Full of Hope will be especially helpful to families of newly diagnosed infants and preschoolers with visual and multiple impairments. By sharing the experiences of diverse children and a young adult with visual impairments, this videotape offers hope and encouragement to families and the professionals who work with them." (Order #98)

National Resource Center for Deafblindness Expanding Options in Deafblindness

About Us....

The National Resource Center for Deafblindness is a non-profit corporation. NRCDB focuses on the needs of families and individuals with deafblindness by supporting the development and improvement of materials and practices in the deafblind field. NRCDB uses a combination of public, private, business and foundation funds to support its efforts.

Our Objectives....

At the present time, there are many gaps in supports, services and knowledge for individuals with deafblindness, their parents and service providers. With the influx of funds and support from the NRCDB, along with what is already in place, it is hoped that these gaps will soon be filled.

Funding from the NRCDB will be used to promote efforts and activities such as:

- * The development of materials that will help IEP teams better understand deafblindness.
- The development of materials that will help adult individuals with deafblindness be successful at the work place.
- ✤ Research in the field of deafblindness.
- Training for parents to help them better understand and be able to advocate for their children.
- The development of an intervener service model and training in that model.
- * The development of a national training program for interveners.
- * National advocacy efforts for individuals who are deafblind.
- * Support for new ideas and innovative practices.

The Mission of the National Resources Center For Deafblindness is to support the advancement of knowledge and improvement of practices serving children and adults with Deafblindness

For More Information Contact:

Ralph Warner National Resource Center for Deafblindness 1052 Mill Hill Road East Greenville, PA 18041

Phone: 215-541-4477 Fax: 215-679-3639

e-mail: rwadvocate@aol.com

Literacy Modality / Communication Plan Form

Colorado law stipulates that all school age children with a visual impairment must have a Literacy Modality Plan on file with his or her Individual Education Plan (IEP). Colorado law also stipulates that all school age children who are deaf/hard of hearing have a Communication plan on file with his or her IEP. This means that a student who has combined vision and hearing loss must have both plans on file with his or her IEP. To simplify the process Judy Mumford and Carol Clark from District 20 have drafted one form that can be used for both purposes. See the next page for this form. Thanks Judy and Carol!

	Date of Meeting					
Le	gal Name of Child/Student	Child/Stude	ent ID	Date of Birth		
Literacy & Communication Learning Plan						
For Students with Combined Vision and Hearing Loss						
1.	 Please indicate the selected mode(s) for this student to achieve literacy. Literacy modes: (a) auditory, (b) tactual, (c) visual mode with optical enhancement, and/or (d) visual mode <i>(Literacy Modes must be determined by a teacher certified in the area of visual impairment)</i> Communication modes: (a) aural/oral speech based, (b) sign based, (c) auditory/sign combined based, (d) gestural, (e) bio-behavioral, (f) assistive technology. Communication modes must be determined by a teacher certified in the area of visual impairment by a teacher certified in the area of deafness. 					
	Current Literacy Mode:	Primary:	Secondary	/:		
	Recommended Literacy Mode:	Primary:	Secondary	/:		
	Current Communication Mode:	Primary:	Secondary	/:		
	Recommended Communication Mode:	Primary:	Secondary	/:		
2.	 2. Justification of learning mode selections: summarize evaluation data and how the learning modes were selected. ¥ Vision: 					
	* Hearing:					
3.	. How will learning modes be supported?					
	✤ Environment:					
	* Adaptations/Modifications:					
4.	. Is the student's learning style & mode integrated into IEP goals and educational activities?YesNo Action Plan, if any:					
5.	Was parent input gathered as a part of the literacy and communication mode selection process:YesNo					
6.	If Braille is a selected literacy mode, has the teacher delivering Braille instruction demonstrated competency in Braille reading and writing according to established guidelines from the Colorado Department of Education?					
	YesNoN	lot Applicable				
7.	If sign language is a selected communication mode, has the teacher or interpreter delivering the communication plan demonstrated competency in sign language according to the State Competency Standards?					
	YesNoNo	t Applicable				

Thoughts on the Assessment of the Student with the Most Profound Disabilities

By Robbie Blaha, Education Specialist, TSBVI Deafblind Outreach with help from Stacy Shafer, Millie Smith and Kate Moss, TSBVI Outreach

Since it's inception of laws providing for the free and appropriate education for all students in this country our schools have seen a steady increase in the population of students who are considered to have the most profound disabilities. Although our willingness to serve these children is evident, our understanding of these students' educational needs, assessment and programming is still very much in its infancy. It is easy to feel we do not know what to do with these students. Developmental checklists and assessment tools used with other populations are not often sensitive enough to provide usable information to those charged with the instruction of this type of student.

The purpose of this article is to: (1) present basic user friendly assessment questions and background information which relates to this particular population, (2) acknowledge the individuality of each of these children by building a personal picture of how they learn, and (3) provide useful information with which to develop programming. This is not intended to be a comprehensive assessment process but rather some questions and background information to consider when planning for this particular population.

WHAT CAN BE DONE TO GAIN AND HOLD THIS CHILD'S ATTENTION?

ATTENDING AND BIOBEHAVIORAL STATES

A typical nervous system exhibits a range of levels of arousal. In all of us there is a structure in the brain stem that controls levels of arousal (biobehavioral states). Some examples of these levels of arousal states are deep sleep, drowsiness, alertness, anxiousness, and agitation. (Guess, 1988). If our nervous systems are n the normal range, we spend our day shifting across the states in a typical manner. We sleep at night, are alert and absorbed in a good book and drowsy after a big noon meal We may become very agitated when paying our bills or it a stray dog digs up the garden.

We are able to consciously control some of these arousal states. For example, if we find we are getting sleepy behind the wheel of a car, we stop to get a cup of coffee. We are calmer in a stressful situation if we bring along a friend or wear a favorite outfit. If something agitates or makes us anxious, we may engage in "self talk" as a form of state management. For example, to calm down we might think to ourselves, "I'm not going to worry about it. It's not that big of a deal. If worse comes to worse I'll just..."

For all of us, the only time we can learn new information is when we are able to achieve and maintain an alert state. This is why, after something traumatic throws you into an extremely agitated state, it is sometimes impossible to remember things that were said or to reconstruct a particular sequence of events. You may also find that, after a big lunch in a warm room, you become incredibly sleepy and have trouble reading a long memo from your boss. The ability to attain and maintain an alert state is essential for understanding and learning.

Children with profound disabilities may not exhibit the typical range of states. This is a characteristic of a number of students with profound disabilities. One student may always seem to be sleeping or drowsy. Another is chronically irritable or anxious,

leaving adults fearful of interacting with her lest they "set the child off." Many of these children may have brief cyclical periods of alertness, but seem unable to maintain this state long enough for typical instructional activities. Slightly over-stimulating this child can cause him / her to "shut down" to a sleep state.

Often these children have difficulty achieving and / or maintaining alert states. They may experience health setbacks that bring incredible drains on their energies and effectively prevent them from being able to respond to any environmental demands outside their bodies. In some students with deafblindness the lack of normal stimulation due to an extensive sensory loss causes them to spend much of their time in other than alert states. The key to instructing these children is to understand the internal influences on the child's ability to attend to instruction.

There is a growing interest in the possibility that external factors can have impact on biobehavioral states in these children. During the assessments, we want to learn things about children that might help them develop better control of their states and maintain alert states for longer periods of time. The more adept they become to attending, the more opportunity they have for learning. Therefore assessment should help determine the child's current profile of states and what adaptations to the environment may assist the child in achieving and maintaining an alert state.

The questions related to biobehavioral states that should be answered during assessments are:

- \Rightarrow What are the range of states the child exhibits across the day or week?
- \Rightarrow What are the child's most common states?
- \Rightarrow Is this child able to reach the quiet alert or active alert state?
- \Rightarrow Can he maintain it?
- \Rightarrow What problems does the child have in shifting and maintaining states?
- \Rightarrow What variables appear to effect state in the child (especially attending)?

There are a number of tools that can help in obtaining this information. These include:

- Assessment of Biobehavioral States and Analysis of Related Influences (see pages 40-45)
- Appetite / Aversion Form (see page 38)
- * Assessment of Voluntary Movement Component (see page 40-41)
- Carolina Record of Individual Behavior (CRIB)
- Analyzing Behavior State and Learning Environments Profile (ABLE). The Key to Attending: The Orienting Reflex

People have a subconscious monitoring system that is working at all times. If this system detects something that needs our immediate attention, it pulls us to attention with the powerful orienting reflex. The orienting reflex is just that: a reflexive alerting to: significant things. It tells us when to pay strict attention so that we may make a decision whether or not to defend ourselves or to get more information. It alerts the senses to the fact that they need to pay attention, so that survival matters and novel things can be handled. (Silverrain, 1991)

All of us have orienting reflexes throughout the day. As an example, say that you are driving along listening to the afternoon news. The words roll by you until suddenly you

hear your street address being said over the air. You snap to attention, lean forward, and turn up the dial to take in every word. You reflexively oriented to something that is important to you. The orienting reflex is powerful because it is the prerequisite to the alert state in the array of biobehavioral states. (Rainforth, 1982) It pulls you to an alert state from another state. Parents use this reflex all the time. If you have a fussy (agitated state) child in the grocery store, you try to distract her so she will calm down. ("Do you see that man with the funny hat? What do you think his name is?"). What you are actually doing is trying to trigger the orienting reflex in the child so she will shift from an agitated state to a calm state.

In the area of attending, a critical component in both assessment and instruction is the orienting reflex. (van Dijk, 1985) It is important to consider because the orienting reflex can potentially be used to help the child who is usually in "other than alert states" shift into attending. The hope is that you can capture their attention on a reflexive level; then provide instruction. (See "associative learning" discussion.)

If the child shows an orienting reflex in response to a change in position, a particular scent, or colored lights, these materials or strategies can be embedded in the lessons to try to gain the child's attention and help him shift to an alert state. Once he makes that shift, you have a brief window of opportunity to provide further information and to attempt to extend the amount of time that he attends.

An important thing to note: There is a difference between the orienting reflex and a defensive startle. Overhearing your name in a conversation produces an orienting reflex. "The orienting reflex readies the nervous system for further learning." (Silverrain, 1991) The blare of a fire alarm typically produces a defensive startle. A startle indicates an overload of the nervous system, which is aversive rather than appealing. The result is not "attending," but rather physical agitation and / or disorientation and / or withdrawal. The child who experiences a defensive startle during an interaction with his instructors or his environment feels under assault rather than invited to participate.

If the stimulus is perceived as aversive, you are less likely to attend and more likely to spend your energies trying to get away from the stimulus. Children who cannot physically get away from an aversive stimulus may literally shut down into sleep to escape. That is why it is critical to determine what the child tolerates or is attracted to (appetite) versus what repels the child (aversion). (van Dijk, 1985)

Families as well as other members of the child's team often have valuable pieces of information related to the things that seem to catch his attention or deeply bothers him. In the assessment process you need to identify things that elicit an orienting reflex so that you can embed those in your lesson to help the child maintain attending. You also need to assess what things are aversive to the child so you do NOT inadvertently include these things in lessons or social interactions with him and take away his ability to attend.

The questions related to orienting reflex that must be answered during assessment are:

- What does the orienting reflex look like in this child?
- What elicits an orienting reflex in this child?
- What does the defensive startle look like in this child?
- What elicits a defensive startle in this child?

There are a number of tools that can help in obtaining this information. These include:

- * Assessment of Biobehavioral States and Analysis of Related Influences,
- * Appetite / Aversion Form,
- * Assessment of Voluntary Movement Component

HOW DOES THE CHILD TAKE IN INFORMATION?

PREFERRED SENSORY MODALITIES

We all use our senses to gather information from our environment. These senses include: visual, auditory, vestibular (related to movement and spatial orientation sensed through muscles, tendons, joints, and the inner ear) kinesthetic (related to bodily position, weight, or movement sensed through the muscles, tendons, and joints, olfactory (smell), and gustatory (taste).

We also have preferred senses for taking in information which impacts how we best learn. Some of us learn new material best by listening, others prefer to read the information, and others may need to write new information down. It is important to determine which sensory channel (s) the child with profound disabilities prefers to use and then provide instructional activities and information through those preferred channels. For example, a child may alert to a change in lighting. She may attend longer if there is some music involved in the lesson. She will accept certain types of tactual input in the palm of the hands but never on her mouth. Looking at the self-stimulatory behaviors (i.e. rocking, flicking, etc.) can also give you some information about which sensory systems have value to the child. (Moss & Blaha, 1993)

It is helpful to systematically test across all sensory channels with tools like *Every Move Counts* and to compile and analyze anecdotal information from families and staff who have daily interactions with the child. These observations contain clues about sensory things involving water. You observe that the one sound that seems to "tune him up" (bring him to attending) is the sound of water running from a faucet. That piece of information tells you that the child recognizes a consistent and a distinct auditory cue and associates it with something that he really enjoys.

The strategy of "multi-sensory approach" is sometimes recommended for this population. There seem to be different working definitions for this term. This approach is sometimes perceived as stimulating all the child's senses at the same time with the same level of intensity. This version of multi-sensory approach assumes a couple of things:

(1) All senses are triggered in pleasant ways. This may not be true for these children. A child may orient to music through the auditory channel but find tactile information through his hands frightening. Combining these with equal intensity in a lesson may throw the child for a loop.

(2) The child can combine completely different sensory input into a meaningful whole. This may not be possible for all children. For example, some students may need to focus on one channel at a time to understand what is happening. It may be better to pace the lesson so the child can have a longer time to look at or touch something before you start talking about it. You can relate to this need if you think of the times you have turned off your radio when you were looking for a freeway exit in a large unfamiliar city.

The questions that should be considered in assessment related to sensory channels are:

- What sensory channels are most effective for gaining the child's attention?
- What sensory channels are important for conveying reliable information to the child?
- What degree of sensory information or pacing of presentation of information helps the child shift his state to attending?
- What channels are associated with orienting reflexes?

Assessment tools that help to provide this information include:

- Learning Media Assessment (LMA),
- *Every Move Counts,*
- * Appetite / Aversion Form,
- Inventory of Self-Stimulatory Behaviors (see page 39).

DOES THE CHILD REMEMBER AND LEARN?

Any type of learning has to do with memory. The following are indicators that a child is remembering specific sensory information.

HABITUATION AS AN INDICATOR OF MEMORY

When I first moved to Austin I rented a home near the airport. It was a great house but unfortunately stood under the flight path. Incoming flights woke me up at night and interrupted phone conversations for the first few days. After a time, however, I tuned it out and stopped noticing the noise. When my sister came for a visit she asked me, "How can you stand it?" I honestly had no idea what she was talking about. I had gotten used to the sounds and had stopped hearing them. This is an example of habituation. Our minds unconsciously sort through incoming information. Habituation is an indication of memory because you only get used to things that your system is able to remember. Habituation decides what we should ignore or notice and is characterized by a lack of response. This is very important as it allows the nervous system to focus on relevant events and not be overwhelmed by all the trivial types of stimulation occurring around us all the time.

Watching for signs of habituation in a child is important because it tells you he is remembering. Many times you hear comments like, "He used to really jump when the intercom came on, but now he doesn't seem to notice it. I don't know if he can still hear it." Or "This used to be her favorite tape, but now she doesn't seem to respond to it." These could be indicators of habituation which signifies that the child views the information as "old news."

BUILDING ASSOCIATIONS AS AN INDICATOR OF MEMORY

Building associations between two events is a type of learning and remembering. Linking a new fact with a familiar one (associative learning) is one way we grow to understand the things around us. Before we talk about ourselves, however, let's talk about less complex life forms and what they have shown us about associative learning. "Snails, believe it or not, demonstrate simple associative learning. Recent studies show the effects of learning on the nervous systems of snails. Large groups of sea snails are given a fast spin (simulating the roll of a wave) which makes them contract. Each spin is preceded by a burst of bright light. Bursts of bright light alone have no effect on snails. After a while, the snails will contract when the light is shone on them, as if a spin were imminent. Researchers have shown that during this learning, new nerve connections have grown that did not exist before. The snails began to react or anticipate the spin simply by association with the burst of light."

"You might find it interesting to know that new born human infants have also shown the ability to associate a preceding event with one that follows. A hungry, crying baby will become quiet when she hears her parent's footsteps approaching in the night because she anticipates the bottle. We know that the human nervous system is capable of making associations between two events when the final event in the chain relates to basic survival or pleasure needs." (Silverrain, 1991)

A child who dearly loves the taste of pudding initially shows no recognition of a spoon. However, over time, you may see him develop the same level of enthusiasm for a spoon as the pudding because you the repeatedly paired the spoon with the pleasure of eating pudding. The ability to make an association between the spoon and the pudding is an example of associative learning. (Note: We have learned from early studies that present the spoon immediately before he tastes the pudding is the way to help the child make the connection.) By building these meaningful pairs in a child's life you are expanding his understanding of the world. Noting any associations that child may have already is important assessment information.

ANTICIPATION AS AN INDICATOR OF MEMORY

Anticipation should be considered an indication of learning and memory. When a child feels his bib go about his neck and begins to open and close his mouth, he is anticipating the next step. He is showing us that he remembers. Unlike habituation that is characterized by a lack of response, anticipation is characterized by a "tuning up" of the system and some action on the part of the child that says "Oh yeah, I remember this!" Anticipation tells you that you have been successful in developing associative learning. You have built an association between bib and eating.

Anticipation of an upcoming event can "rev you up" to maintain an attending state. For example, a person is on a road trip and knows that the exit he must take will be a few miles past a factory on the left. This guy may drive along lost in his own thoughts for thirty minutes or so until suddenly, the factory appears on the left and triggers an orienting reflex. He shifs into the alert state and begins to anticipated the exit. Because he anticipates the exit, he stays alert for a short period of time and looks closely for the sign. Using cues with children helps them anticipate and pull to attending so they can learn.

SURPRISE AS AN INDICATOR OF MEMORY

Building in a surprise or what has been called a mismatch of expectations (van Dijk, 1985) is a test for memory and learning. A mismatch occurs for the child when he anticipates his mother picking him up and playing a particular swinging game, but is treated to this same game by this father. The child registers his surprise by fluttering his eye lids and breathing more rapidly. The surprise elicits an intense alert state in which

associations previously learned are reviewed and compared with the new experience important learning has taken place for him. A child responds to a mismatch of expectations only because he remembers what should have happened.

Questions to ask related to assessing cognition (habituation, anticipation) include:

- Are there things the child used to orient and respond to that he now seems to notice?
- Does he stop responding after 2-3 times?
- Does he seem to pair things, events, and/or people together?
- Does the child show anticipation of what is about to happen?
- Does the child register surprise when there is a change in a familiar routine?
- Does the child seem to know familiar versus unfamiliar people?

As assessment tool that helps to provide this information is *Every Move Counts*.

WHAT CAN THIS CHILD DO TO IMPACT HIS ENVIRONMENT?

Since learning is something the child does with you and not something you do to him, it is critical to determine the easiest way for the child to respond so that he is able to successfully participate. Possible responses that these children might make are changes in affect, vocalizations, gaze shift, and body movements. (Korsten, 1993) Even if these responses are not intentional, you should identify a particular response he gives and try to shape it into a purposeful response. Systematically testing for these responses is an important part of assessment.

SYSTEMATIC INVENTORY OF VOLUNTARY MOVEMENTS

It is important to systematically observe the child in all the positions typically used with him and inventory the voluntary movements he can make. Some of these children are said to have no voluntary movements to use for instructional purposes. Typically this is not the case. When a child is observed in a variety of positions he may show a surprising number of movements. From this inventory of voluntary movements, the team can target a particular response(s) which will allow the child to participate in an activity.

Many children can make a particular movement easily in one position but not in another. Some positions are more stimulating or relaxing for a child and this effects their ability to attend. ("As soon as we put him in side-lying, he stops fussing.").

Additionally, some children, when moved from one position to another, experience a significant change in their biobehavioral state. They may find the experience frightening and need a period of time to recover before they can attend. These children could benefit from strategies to make the transition less aversive (e.g., touch cues which signal that they are about to be taken from their travel chair or slowing down the pace of the transition). Other children may be at their most alert following a change in position. It is an individual things.

Questions related to voluntary movement that can be addressed in assessment include:

- What specific voluntary movements does the child exhibit across positions?
- How do different positions affect the child's level of arousal or biohehavorial states?

Does transition from on position to another cause a significant change in the child's biobehavioral state.

Assessment tools that help to provide this information include:

- Every Move Counts
- * Assessment of Voluntary Movement Component
- Physical Therapy Assessment
- Occupational Therapy Assessment

USING THE ASSESSMENT INFORMATION IN DEVELOPING PROGRAMMING

PROGRAMMING STRATEGIES

Once this assessment information has been compiled the educational team should be able to draw on it in developing their program. Ann Silerrain suggested some strategies to follow in her 1991 article. These include:

- (1) Use assessment data to determine learning media that provides the appropriate level of stimulation---enough to be alert and not enough to cause withdrawal. We must forget about stimulation for the sake of stimulation. "Tolerating stimulation: is not an appropriate goal. Damaged nervous systems need the appropriate type and amount of stimulation; they do not need to be bombarded.
- (2) Develop activity routines which have a predictable sequence of steps, objects, or actions that evoke the orienting reflex to reengage the child throughout the activity and provide opportunities for the child to respond or take a turn. Remember pacing is critical in getting child response.
- (3) Use familiar objects and people in daily routines as a basis for instruction. Evaluate anticipatory responses to sensory cues to determine the appropriateness of the materials or actions used for cuing. As you cue the child, look for orienting reflexes to occur. Remember that you want to get an orienting reflex, follow with an activity of high interest or one that comforts or meets a basic need as a way of rewarding the child's response. Over time we should begin to see the child show signs of anticipation. All things we want the child to respond to should be real things or actions that are used by or with the child in everyday routines.
- (4) Design a daily schedule of predictable and pleasurable events or routines. With any activity, if we want to see an anticipatory response (evidence that the child remembers) the activity must have a strong emotional appeal for the child.
- (5) When we see the child anticipate events and show some awareness of the functional use of objects, then primitive communication choice systems can be used. When a child does such things as gaze at a preferred item then at you; tactually explores two objects and picks the relevant one in context; pushes an object toward you; pulls or pushes your body in a way that says "I want you to do this with me,: then you are beginning to move into the realm of intentional conversation.
- (6) When the child is consistently anticipating a particular object or action in a routine, toss in a mismatch to test awareness and communication. This check can only occur within the context of a stable routine. For example, the child is routinely expecting to have you present her red bib before meal time, but instead you put a hairbrush in front of her and her bib off to one

side. Will she realize there is a problem and try to communicate that to you? Will she try to get your assistance in resolving the problem? These are indicators of a readiness for more complex learning.

CONCLUSION

As the family and the other members of the educational team work together they become more able to recognize and respect the skills and strong personal preferences that children with the most profound disabilities show us. All the children have ways of showing us what they want more of and what they would like to avoid. It is our responsibility to develop the assessment expertise needed to be aware of those messages and to use them to build better learning environments for the child.

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SEE/HEAR Editor's Note: This article first appeared in the Fall 1996 edition of SEE/HEAR newsletter published by Texas School for the Blind and Visually Impaired and Texas Commission for the Blind. It was developed in response to requests we have had from teachers who are working with children who have the most profound disabilities. Typical assessment information provided little for the teachers to use in developing programming for this type of child.

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