

# Deaf-Blind Perspectives

Volume 9, Issue 3

Spring 2002

## He Didn't Listen

"Why would you want to adopt him?" the neonatologist asked 8 years ago.

"He'll never be more than a vegetable," he stated.

But Alex didn't listen, and now he jumps and shouts and laughs and loves his family.

"Alex may not ever be able to leave the hospital," the doctor said 7 years ago.

But Alex didn't listen, and it's been 4 ½ years since he was hospitalized.

"Alex will never eat or drink again by mouth," the experts told us 6 years ago.

But Alex didn't listen, and today he's eating and drinking, his G-tube 3 years removed.

"He may never walk," the therapist said 5 years ago.

But Alex didn't listen, and today he walks, runs, skips, and hops.

"He's profoundly retarded, incapable of much learning," the psychologist said 4 years ago.

But Alex didn't listen, and today he is learning to read.

"Even if he is legally blind and won't keep his glasses on, why are you trying contacts?"

He won't keep those in either," the vision specialist said 3 years ago.

But Alex didn't listen, and those contacts (that he leaves in) have opened up a new world of discovery.

"We'd like Alex to increase his expressive language vocabulary to ten words," his Mom stated at the I.E.P. meeting.

The teacher for the deaf and hard of hearing laughed! "He will never be able to do that," she stated 2 years ago.

But Alex didn't listen and today signs dozens of words and understands over two hundred.

"Maybe potty training is beyond him cognitively," the therapist said 1 year ago.

But Alex didn't listen, and today he rarely wets himself.

So what will Alex be told he can't do next? Whatever it is, I pray that he won't listen.

And I hope that I won't either.

*Jack Kemper, Alex's Dad*



**Alex**

We should all be so determined when the odds are stacked so high against us. Alex has touched and continues to touch a lot of lives. We believe he teaches us all a lot about the wonders of life, love, laughter, determination, and the need for patience. We can only hope that the people who are in his future are willing to learn along with him on his journey.

*Jack and Linda Kemper*

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## Grade One Braille for Students Who Are Deafblind

Dr. Linda Mamer

Communication development is one of the most important issues for individuals who are deafblind. Educational best practices focus on using a communication approach that allows for the inclusion of multiple communication methods that work for each unique student. Methods include environmental cues, touch cues, natural gestures, tactile cues, fingerspelling, sign language, object cues, picture cues, voice, print, and braille. The primary educational goal is to help children who are deafblind become interactive communicators. A variety of strategies that support communication should be considered.

Braille, however, is often not considered as a learning media for some individuals who are deafblind because of the complexities of the Grade Two Braille code, which may be difficult for some students to learn. Grade Two Braille makes use of many contractions that use braille symbols to represent more than one letter. Contractions can represent whole words (e.g., the use of the letter “b” for the word “but”), short form words (e.g., the letters “chn” for “children”), or partial words (e.g., “ing”). There are 189 contractions and many rules associated with their use.

Grade One Braille is much simpler. It uses braille symbols for letters of the alphabet, punctuation

marks, and numbers. It may be easier for many people to learn, including students who are deafblind. Grade One is also sometimes referred to as Braille One or Alphabetic Braille. Grade Two Braille is also called Braille Two or Contracted Braille.

### Advantages of Grade One Braille

At the International Conference on English Braille, Grade Two in Washington, D.C. in 1982, the need for use of a simplified form of braille was presented by Marjorie Troughton, who at that time was a braille teacher at the W. Ross Macdonald School, a school for students who are blind, visually impaired, or deafblind in Brantford, Ontario, Canada. In 1992, in her book, *One is Fun* (1992), Troughton further explained her support for the use of Grade One Braille. Her rationale was based on the findings of a number of researchers and included the following:

- Grade Two Braille interferes with language patterns.
- Speed of character recognition is directly related to a learner’s mental ability.
- Contractions do not reinforce basic phonics skills or allow students in regular education classrooms to sound out and spell words at the same time as their peers.
- Motivation of the learner and level of difficulty of the task is an important component in the ability to learn braille.

Troughton noted that many individuals would benefit from the use of Grade One Braille, including those

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Teaching Research Division  
345 N. Monmouth Ave.  
Monmouth, OR 97361

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[www.tr.wou.edu/tr/dbp](http://www.tr.wou.edu/tr/dbp)

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who are deafblind, are newly blind, are able to do some work with large print but also need braille, and those who have learning disabilities, limited intellectual ability, or limited tactual sensitivity. It also may be useful for someone just learning to read—a young child in primary school, an adult in a literacy program, or a person learning English as a second language.

Grade One Braille is easy for interveners, family members, teachers, and peers to learn. People involved in the life of a child who is deafblind need to learn many new things, including specific communication techniques such as sign language. Learning braille, especially Grade Two Braille, may seem overwhelming. People seem more willing to learn Grade One, especially if it is presented as merely representations of letters of the alphabet. The family, teachers, and peers can learn Grade One Braille at the same time that the child is learning it.

### Individualizing Braille Instruction

The team working with a child who is deafblind must conduct a complete and ongoing assessment of appropriate learning media and determine communication methods to be addressed. Some children may begin with Grade One Braille and eventually move on to Grade Two. For others, the most successful strategy is to stay with Grade One. Beginning with Grade One does not mean that a child is incapable of using Grade Two and staying with Grade One does not mean that a child has failed. Teachers and other team members need to individualize braille instruction to meet the needs of each child. The important thing is to build a foundation for successful communication. Grade One Braille may be an appropriate goal for a child who is deafblind.

Although many students ultimately move on to Grade Two, this may not be the case for every student. Ongoing, regular assessment of the student will guide the team when making that decision. Teachers may consider continuing with Grade One if it best meets the needs of the individual child. This may be different from what they learned in their teacher preparation programs or different from their experiences with children who are blind. Typically, teachers of students who are visually impaired have learned strategies for teaching braille that involve moving quickly on to Grade Two, or at least introducing some of the contractions fairly quickly. For some children, however, learning and staying with Grade One Braille may lay the foundation for a child's future success.

The speed at which a child learns is an important factor to take into consideration. Children who are deafblind often take a long time to learn something. It

is important that braille-learning criteria for students who have blindness as the primary disability are not the only criteria used for students who are deafblind.

## Strategies That Enhance Braille Learning

### Develop Fine Motor Skills

Tactile activities that help develop fine motor skills are critical. Children who are deafblind need to learn to use and trust their hands. Children may be seen as lacking ability when, in fact, they haven't had sufficient exposure and opportunity to use and develop their hands. When children are exposed to meaningful, functional fine motor activities and finger play, their ability to use their arms, hands, and fingers often increase.

### Develop Fingerspelling

Braille seems to be learned more easily when a child has developed some formal language, particularly fingerspelling. When hearing-sighted children learn to read, they are learning a new code (print) connected to a code they already know (speech). Braille, like print, is a code, not a language. Children learning braille need to be able to apply this new code to a previously learned code in order for it to make sense.

In my experience, Grade One Braille works most effectively when a child knows how to fingerspell. It enables the learner to make a one-to-one correspondence between a fingerspelled letter and a braille letter. When I've read stories about how Helen Keller learned to communicate, I have been struck by how many hours each day that Annie Sullivan spent fingerspelling to Helen. Yet fingerspelling is a part of the total communication package that is often neglected, or at least it is not given enough time and emphasis. Educators may feel that fingerspelling is not a viable mode of communication for many children who are deafblind. They may believe, for example, that it is not an option for children who have physical limitations of the hands or fingers, have insufficient vision to see the letter symbols clearly, are uncomfortable touching another person's hands, or do not have the necessary cognitive skill (it is presumed) to learn how to fingerspell. These considerations may be important and should be discussed by the educational team, but it is crucial that the determination of a child's abilities is based on a thorough evaluation rather than assumptions.

The use of braille, even as a labeling tool, can begin to change people's perceptions of a child's abilities, particularly cognitive abilities. When braille is introduced into the environment, parents, teachers, and others may begin to think that the child has a higher

cognitive level than they previously thought. Because braille is an academic tool, the child may then be viewed as a more formal learner. Another advantage of Grade One Braille is that spelling ability is likely to be reinforced and improved as the child learns both fingerspelling and braille.

### Label Items in the Environment With Grade One Braille Signs

Labeling items in the environment with printed words is commonly done for young sighted children who are learning to read. It is not expected that children will immediately be able to read the words, but rather that they will eventually learn them. Because braille is the equivalent code for children who cannot see, braille labels should be used in the same way. The easiest places to use braille labels are on concrete objects that the child is already familiar with, such as a cup, chair, toothbrush, nametag, ball, or table. The child is being exposed to braille at this point but is not reading the individual letters. However, we should believe that they might eventually either read the individual letters or read a word as a single unit. Ultimately, the child needs to make a one-to-one correspondence between the label and the object, just as he does when making a connection between a fingerspelled letter and a braille letter.

### Grade One Braille Materials

Grade One Braille materials are easy to produce. Labels and short phrases about a child's activities or that identify objects in the environment can be created using a Perkins Brailier or hand held labeler. When children who are deafblind first learn to read, they typically read books that are created especially for each child, usually with the child helping. These books include experience, trip, or memory books about things that the child has done. Braille words and sentences can be added to the pages of these books by embossing the braille sentences on self-adhesive braille paper. The sentences can then be cut out and stuck to the pages of a book. When the child is ready to read the books that the class is reading, this same method can be used to add the Grade One Braille to the pages of picture books and early reading books. More advanced reading materials can be created using braille printers and computer software programs that translate text into Grade One or Grade Two Braille. Some commercially produced Grade One Braille books are also available. The American Printing House for the Blind (800-223-1839; <http://www.aph.org>) and Seedlings (800-777-8552; <http://www.seedlings.org>) each carry a few Grade One Braille books.

## Research Findings

Although the use of Grade One Braille by children who are deafblind has not been formally evaluated, it has been evaluated for children who are blind. Sally Mangold (2000) reported the results of a policy adopted in one area of Minnesota that required teaching Grade One Braille during the first year of school, followed by a gradual introduction of Grade Two contractions.

Teachers involved in the program found that students who used Grade One Braille during the first year had higher academic achievement scores in reading rates and accuracy and greater academic and social interaction and participation with sighted students.

The Minnesota program also uses Grade One Braille for children with multiple disabilities and begins teaching Grade Two once they have thoroughly mastered the alphabet and have begun to read. Teachers have found a reduction in letter-reversal reading errors when Grade One is used for a longer period of time.

## Conclusion

Braille is a viable tool to add to the total communication approach for individuals who are deafblind, especially for students who already have the beginnings of a code such as sign language or fingerspelling. Grade One Braille is another tool to help students succeed.

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- Special thanks to Karen Nagel, STAR program, W. Ross Macdonald School, Brantford, Ontario Canada.*
- Linda Mamer can be contacted at:  
10300 Seacote Road  
Richmond, British Columbia  
Canada V7A 4B2  
or by e-mail at [Linda.mamer@shaw.ca](mailto:Linda.mamer@shaw.ca)



## Assessment as a Creative Action

Georgia Hambrecht, Ph.D.

Karen Goehl, M.S.

The Indiana Deafblind Services Project devoted its 2001 Family Learning Weekend to an exploration of the arts and creative expression. The focus was on art as a creative outlet and means of communication for students who are deaf-blind. After an initial discussion about the importance of creativity, master artisans from VSA arts of Indiana spent the weekend providing families with hands-on experiences with pottery and drum construction, large canvas painting, papermaking, and weaving.

At the end of the weekend, a reflective writing activity that we devised was used to allow families the freedom to express their feelings about the weekend in a playful and unrestricted way. Typical assessment procedures that use satisfaction surveys or group debriefing about the strengths and limitations of an experience would not have reflected the creative focus of the weekend. The writing activity used word tickets, described by Susan Wooldridge (1997) in a book about writing poems as taped, cut-out, printed words on “admit one” tickets. These tickets are “small, often colorful and valuable, allowing entrance to a special place.” Each parent or family team was given a random assortment of 10 to 12 word tickets to serve as their word pool. They were asked to reflect on the weekend by writing a paragraph that included any 8 of the word tickets in their pool. Each parent or family team had 10 minutes to complete the paragraph. Their reflections were then shared with the other families. Here is a sample reflection that used the words “milk”, “snapshot”, “adults”, “wish”, “Bang Bang!”, “vivid”, “design”, “glimpse”, and “sophisticated”:

We got time for the *adults* to gather without the kids around. Very nice! We got a *glimpse* into other lives affected by deafblindness. The cameras are a great idea. We will put the *snapshots* in the kids' idea books. We drank more *milk* this weekend than we ever have at home! I (Jane) discovered that *vivid* color can be as beautiful as a *sophisticated design*; sometimes more so. One *wish* would be to have a weekend with presenters to help us learn how to acquire/access the financial assistance that is available. How to get the “result,” not the “run around.” The weekend was *Bang Bang!* terrific, especially when you consider the drums! They were a huge hit!

Staff examined the paragraphs to evaluate the participants' satisfaction with the weekend activities. Posi-

tive, negative, or neutral statements and themes were identified.

Statement analysis (positive, negative, or neutral):

- We got time for the *adults* to gather without the kids around. Very nice! (Positive)
- We got a *glimpse* into other lives affected by deafblindness. (Neutral)
- The cameras are a great idea. We will put the *snapshots* in the kids' idea books. (Positive)
- We drank more *milk* this weekend than we ever have at home! (Negative)
- I (Jane) discovered that *vivid* color can be as beautiful as a *sophisticated design*; sometimes more so. (Positive)
- One *wish* would be to have a weekend with presenters to help us learn how to acquire/access the financial assistance that is available. How to get the “result,” not the “run around.” (Neutral)
- The weekend was *Bang Bang!* terrific, especially when you consider the drums! They were a huge hit! (Positive)

Themes noted:

- Adult learning
- Awareness of others with deafblindness
- Creative experiences/ideas from weekend
- Food/Accommodations
- Future
- Unique individual expression

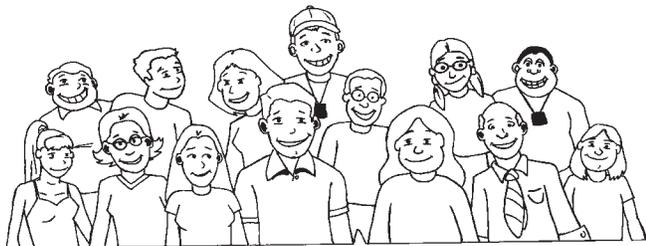
The use of a nontraditional assessment procedure provided the staff with useful evaluation information needed to determine the value of the activity and participant satisfaction. Participants had the freedom to identify matters they wished to address rather than respond to issues presented by the staff. We will continue to use and examine this and other alternative assessment techniques in an effort to obtain a broad range of information for program evaluation. We urge others to move beyond comfortable current evaluation procedures and search for new and creative assessment actions. For additional information, contact Karen Goehl at 800-622-3035.

## Reference

Wooldridge, S. L. (1997). *Poemcrazy: Freeing your life with words*. New York: Three Rivers Press.



AADB



## Mentoring Pilot Project

### AADB Mentoring Pilot Project

Ashley Benton, Project Coordinator  
Jamie McNamara, Project Director

**T**he American Association of the Deaf-Blind (AADB), a national organization of deaf-blind people, is currently working on a four-year mentoring pilot project that is funded, in part, by DB-LINK. The project is consistent with DB-LINK's ongoing work to provide deaf-blind children and young adults, their families, and professionals access to information—an essential key to effective decision-making and quality of life.

The purpose of the project is to train deaf-blind adults to be effective mentors to deaf-blind youth. Mentoring offers deaf-blind youth an opportunity to gain knowledge, skills, and perspectives that hearing-sighted youth might routinely get from listening to the radio, watching TV, or listening to dinner conversations. It is our belief that the best role models are deaf-blind adults, who can show they lead successful lives despite hearing and vision loss.

The project design has four components:

1. Two groups of 5 to 6 deaf-blind adults will be trained to be mentors.
2. Each of these trained mentors will then mentor a deaf-blind youth for a year.
3. After one year the mentors will receive additional training on how to train other deaf-blind adults to be mentors.
4. During the last year of the project, a handbook on mentoring deaf-blind youth will be developed and disseminated through DB-LINK.

This project requires collaboration between state deaf-blind projects or supporting agencies and state or local deaf-blind organizations. The collaborations involve working together to match deaf-blind youth and adults and sharing the expenses necessary to support the mentoring experience.

We are pleased to announce that the mentoring pilot project had a very successful start. Five deaf-blind adults from Illinois, Indiana, Ohio, Texas, and Virginia received training on effective mentoring practices, and they are now mentoring deaf-blind youth. This first group of mentors consists of highly motivated individuals representing a cross-section of the diverse deaf-blind community. It includes individuals with Usher Syndrome Type 1, Usher Syndrome Type 2, and optic atrophy. Their communication methods include tactile, close up, and distance signing and speech/ lipreading.

The mentor training took place in Columbus, Ohio, September 8-9, 2001. The Great Lakes Area Regional Center for Deaf-Blind Education (GLARCDDBE) graciously allowed use of their spacious classroom. Terri Gilliam from the Ohio Mentoring Project and Maricar Marquez were the two main speakers. Terri presented the effective mentoring component and focused on such things as general mentoring concepts and listening techniques. Maricar, who is deaf-blind, presented another component on topics relevant to working with deaf-blind youth, such as self-determination and recreation. AADB President Harry Anderson gave a motivational speech, and Ashley Benton discussed the expectations of the project.

The format of the training included a presentation on the concept of mentoring, role-playing, interviewing, and small group discussions. The presenters did a wonderful job and were very informative. We hope to continue to use the same presenters as a resource throughout the project.

The mentor training was not all work. There were opportunities for socialization during breaks and in the evenings. We gave all who participated a surprise gift, T-shirts with an AADB Mentoring Pilot Project logo. On the last day of training everyone wore their T-shirts and smiles for lots of pictures.

Now each mentor is busy hooking up and building relationships with the deaf-blind youth whom they will mentor for a year. The mentors are required to be in contact with the youths at least once a week through e-mail or instant messaging and to meet them for a face-to-face activity once a month. Based on the monthly reports we have received, things are going really well. Monthly activities have included ice skating, cooking, attending a holiday party at a deaf-blind organization, and learning American Sign Language.

Next steps are for the same mentors to gather again for the second mentor-training workshop about how to teach other deaf-blind adults in their states to be mentors.

A second group of new mentors will be selected in 2003 for the same opportunity as the first lucky bunch. If you would like more information or materials to apply to be included in the second group or if you would like to order a T-shirt, contact:

Ashley Benton, Coordinator  
PO Box 131  
Falkland, NC 27827  
ashleybenton@aol.com



## National Curriculum for Deaf-Blind Persons and Interpreters

Mark J. Myers

**O**n behalf of Northwestern Connecticut Community College and the Rehabilitation Services Administration of the United States Department of Education, we are very pleased to announce the completion of *The National Curriculum for Training Interpreters Working with People Who Are Deaf-Blind*.

The curriculum is a collaborative effort created by experienced and knowledgeable professionals in the field of program services and interpreting education. The goal is to provide curricular materials that train individuals to better serve persons who are Deaf-Blind. The curriculum consists of nine in-service training modules and a four-credit college course. The printed curriculum is presented in regular print, large print, braille formats, and also on diskette in ASCII. There are five videotaped programs that complement the curriculum.

This curriculum addresses the beginning, intermediate, and advanced levels of training needed. It enhances participants' familiarity with the basics such as the various etiologies represented in the Deaf-Blind community, tactile communication, interpreting visual information, comfort with touch, and sighted guide techniques. Beyond the basics, training focuses on more complex skills, such as making linguistic modifications for tactile communication, clarifying the roles and responsibilities of interpreters and support service providers (SSPs), and highlighting

cross-cultural relationships between the Deaf-Blind, Deaf, and hearing cultures.

Copies of *The National Curriculum for Training Interpreters Working with People Who Are Deaf-Blind*, published by DawnSignPress, have been shipped to more than 125 interpreter education programs in colleges and universities across the nation and to the National Clearinghouse of Rehabilitation Training Materials. For a list of all the interpreter education programs, contact DB-LINK (800-438-9376 or 800-854-7013 TTY). If you are interested in the curriculum or have questions, please feel free to contact one of your local interpreter education preparation programs or Project Director Mark J. Myers via e-mail at [mmyers@nwcc.commnet.edu](mailto:mmyers@nwcc.commnet.edu) or by phone at 860-738-6382.



**We'll find the information to answer your questions.**

**Call us!**

**DB-LINK**

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**N**TAC, The National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind, provides technical assistance to state deaf-blind projects, families, and agencies throughout the United States. The content of technical assistance is quite varied and is based on individual state needs. It has been an exciting first year for NTAC's new grant. This column describes some recent state and regional activities.

### Area 1

NTAC is working with states in Area 1 on a number of technical assistance activities on topics such as training and system development for postsecondary transition, addressing multicultural issues in service provision, family support provider training, and the use of technology to deliver technical assistance and training programs. An ongoing collaborative effort with the Oregon Deafblind Project provides one example.

The Oregon Deafblind Project is developing an intervener training initiative. A task force is addressing the following issues: 1) development of an Individualized Education Program (IEP) decision-making process to consider interveners as a service option; 2) development of a training system that makes use of the time and expertise of the project's regional deafblind consulting teachers; and 3) development of a competency based curriculum for individuals who work one-to-one with students who are deaf-blind. Other issues that will be addressed include administrative support, classroom teacher participation and support, and parent awareness. Three model sites are being established to implement the intervener training system.

In addition, the Oregon Deafblind Project and the Oregon Commission for the Blind have developed and are currently field testing an informative and easy to use *Family Transition Notebook*, a practical guide for transition teams. It provides guidelines and timelines about how to use the IEP process to address transition issues.

*Reported by Shawn Barnard*

### Area 2

Area 2, in the middle region of the United States, is busy with a number of new long range technical assistance plans. NTAC is collaborating with states in the region on plans that address a variety of topics including transition, paraprofessionals, communication, and Usher Syndrome. A regional meeting is scheduled for August 2002 in Chicago. The meeting will focus on two topics—dealing with personnel shortages and effective post-secondary transition services.

*Reported by Jamie McNamara*

### Area 3

Technical assistance activities in Area 3, in the southeast, also address a variety of topics. The Mississippi project is focusing on the development of an intervener pilot program with assistance from Texas Deaf-Blind Project staff. In Florida, the state project is involved in a pilot study on employment. Three individuals in transition and their teams are receiving intensive technical assistance and support to find jobs in their communities. The goal is to influence policy development in order for youth with severe disabilities to find meaningful community employment. Several states are continuing ongoing activities. Georgia is providing person-centered planning training at various locations throughout the state. Arkansas is continuing comprehensive follow-up and personalized training to teams who previously received IEP training. And South Carolina is continuing a training program on transition practices. A regional meeting will be held in August 2002. The primary topic will be building collaborative relationships with vocational rehabilitation and other adult service systems.

*Reported by Amy Parker*



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## E-Mail Discussion Groups About Deaf-Blindness

**T**he Internet is a wonderful means of communication for people with shared interests but who live far apart from each other. E-mail discussion groups (also called e-mail lists) are one Internet tool that give deaf-blind people, family members, and professionals opportunities to share ideas, support, and points of view about many issues related to deaf-blindness. The following is a list of some e-mail groups that are currently active. If you are aware of others, please let us know by contacting DB-LINK (800-438-9376 or 800-854-7013 TTY).

### Groups That Focus on Deaf-Blindness as a General Topic

**Deafblind Mailing List.** The purpose of this list is to share information, inquiries, ideas, and opinions on matters pertaining to deaf-blindness. The list is open to professionals, persons who are deaf-blind, and to their families and friends. To subscribe send the following in the body of an e-mail message: SUBSCRIBE DEAFBLND firstname lastname (note that "deafblind" is the correct spelling). Send to listserv@tr.wou.edu. For assistance contact Randy Klumph (klumphr@wou.edu).

**Deaf-Blind Education Mailing List (DBED-L).** The purpose of this list is to share information, inquiries, ideas, and opinions about deaf-blind education. To subscribe send the following in the body of an e-mail message: SUBSCRIBE DBED-L firstname lastname. Send to listserv@tr.wou.edu. For assistance contact Randy Klumph (klumphr@wou.edu).

**National Family Association for Deaf-Blind List.** This list is for parents and families. To subscribe, send a blank e-mail to nfabd@mailservice.cpd.usu.edu making sure that the word "subscribe" is in the subject line.

**DBTeens.** This is a private list for teenagers and young adults who are deaf-blind to share information, questions, ideas, and opinions about deaf-blindness and other issues. Contact Randy Klumph (klumphr@wou.edu) for subscription information.

**Great Plains Deafblind List (Great Plains DB).** This list is a support group for deaf-blind people, families, and professionals in the Helen Keller National Center Region 7 Great Plains states (KS, MO, NE, and IA) to share common experiences and interests. Discussions should primarily relate to giving support to people experiencing or in some way connected to deaf-blindness. To subscribe, send a blank e-mail to: GreatPlainsDBList-subscribe@topica.com. Or subscribe

online at  
<http://www.topica.com/lists/GreatPlainsDBList>.

**Deaf-Blind Mailing List (Sordoceguera).** This list is entirely in Spanish. It is for deaf-blind people and families, volunteers, professionals, and educators. To subscribe send the following in the body of an e-mail message: SUBSCRIBE sordoceguera firstname lastname. Send to listserv@listserv.rediris.es. For assistance contact Ricard Lopez (talking3@teleline.es).

**Deafblind Women Chat List.** This list aims to support women who live with the daily challenges of deaf-blindness. Issues discussed may include such things as fashion and relationships, but the most important purpose is support. To subscribe send a blank e-mail to: dbwomenchat-subscribe@yahoogroups.com. To access via the Web, go to <http://groups.yahoo.com/group/dbwomenchat/>. For assistance contact Michelle Stevens (msteven5@bigpond.net.au).

### Groups That Focus on Specific Syndromes Associated With Deaf-Blindness

**Usher's Syndrome Mailing List.** A list for people with Usher Syndrome, their parents, friends, spouses, and service providers. To subscribe send the following in the body of an e-mail message: SUBSCRIBE USHERS firstname lastname. Send to listserv@tr.wou.edu. For assistance contact Randall Pope (Ushers-request@tr.wou.edu).

**CHARGE List.** The topic of this list is CHARGE Syndrome. To subscribe, contact Casey Fisher (charge@neti.saber.net) or Lisa Weir (gweir@nbnet.nb.ca).

**Rubella Discussion List (HKNC\_Rubella).** This group is a vehicle for parents, consumers, and professionals to share information about any aspect of rubella and to provide support to those living or working with someone who has congenital rubella syndrome. To subscribe contact Nancy O'Donnell (HKRegistry@aol.com).

**Retinal Degeneration Discussion List (RPLIST).** A forum for discussion, questions, and opinions related to retinal degeneration. To subscribe send a blank message to: rplist-subscribe-request@maelstrom.stjohns.edu. To access via the Web, go to <http://www.dixonvision.com/rplist>.

**Refsum's Disease Mailing List.** Refsum's Disease is a genetic disorder characterized by retinitis pigmentosa, anosmia, peripheral neuropathy, hearing loss, and less commonly, congenital abnormalities. To subscribe, send a blank email to: refsums\_discussion-subscribe@yahoogroups.com. For assistance contact: refsums\_discussion-owner@yahoogroups.com.

The following is an abridged version of an article that originally appeared in *The Deaf-Blind American*, 41(1), 2002. Reprinted here with permission. —Ed.

## Birth of The World Federation of the Deafblind

Jeffrey Bohrman  
Jamie McNamara

**D**id you know we, the deaf-blind, never had our own world deaf-blind organization until October 12, 2001? The deaf have their World Federation of the Deaf (WFD), and the blind have their World Blind Union (WBU). It was a proud moment in deaf-blind history to witness the birth of The World Federation of the Deafblind in Auckland, New Zealand among more than 300 participants: 114 deaf-blind and 204 supporters, from 46 countries. The meeting followed the 7th Helen Keller World Conference. The countries with the most participants were Sweden, which sent 91 people overseas and New Zealand, being the host, had 62 people. USA participants included 5 deaf-blind and 10 interpreters/SSPs. It was truly inspiring to meet deaf-blind people from all over the world who came together to add their voices to “Yes, we need WFDb!”

The founding general assembly of WFDb began on Thursday, October 11, 2001 with discussion of the draft charter constitution. This took up a bit of time because of language barriers in translations and different strong opinions from various countries. It was fascinating to watch all the translations of different languages (Japanese, Spanish, English, etc.) and the communication modes used (different sign languages, finger braille, fingerspelling, speech, etc.) for deaf-blind participants as well as the kinds of governments people came from (democracy, socialism) and their personal backgrounds (education level, employment, kind of deaf-blindness, etc.). Anyone can get an idea how unique it was to have this first general assembly!

There were nominations made for representatives from each region: North America, South America, Europe, Africa, Asia, and the South Pacific. Also there were nominations for other committees. With the exception of the charter constitution, only one delegate representing one country voted by secret ballot for the officers, regional representatives, and committee members. Jeffrey Bohrman was the delegate representing the United States and the American Association of the Deaf-Blind (AADB).

Election results for the following officers were announced: President, Stig Ohlson of Sweden; Vice

President, Daniel Alvarez Reyes of Spain; Secretary General, Lex Grandia of Denmark; and Treasurer, Jeffrey S. Bohrman of the USA. Other election winners for regional representatives were also announced. Our North America regional representative is Craig MacLean of Canada.

The general assembly approved the following resolution for WFDb: “In line with all United Nations conventions on human rights, we, representatives of deafblind people of the world, united in Auckland at the Founding General Assembly of The World Federation of the Deafblind on October 12, 2001 urge all governments:

- To recognize deafblindness as a unique disability.
- To recognize all persons with deafblindness as persons with the right to full participation in all areas of society including education, information, communication, employment and political life.

To ensure the quality of life and full participation of all persons with deafblindness, we urge all governments to provide the necessary services including special education, guide services, interpreter services, accessible information, accessible communication and accessibility in the entire environment.”

For more information contact [wfdb@wfdb.org](mailto:wfdb@wfdb.org).



## Meeting Helen Keller ... a miscellany of first encounters

Compiled by Dana Cook

**Martha Graham, dancer and teacher**

*Perceiving the dance*

It was through Katharine [Cornell] that I met Helen Keller, who could not speak, see, or hear. Her speech was difficult to understand for those who did not know her. She was granted the ability to perceive life through her own unique awareness. She was a great lady, and very funny, too. She was, perhaps, the most gallant woman I have ever known.

Helen used to come to my school at 66 Fifth Avenue. She felt as if she was watching the dancing. What she was focusing on were the feet on the floor and the direction of the voices. She could not see the dance but was able to allow its vibrations to leave the floor and enter her body. She said to me once, in that funny voice of hers, “Martha, what is jumping? I don’t understand.” (New York, late 1930s)

From *Blood Memory: An Autobiography*, by Martha Graham (Doubleday, 1991).

**Julian Huxley, scientist*****How I 'felt'***

... the dropping of the first atomic bomb on Hiroshima. . . deeply jolted our moral conscience, and when, shortly afterwards, I was invited to an enormous meeting at Madison Square Garden in New York, to speak on the future of this terrifying weapon, I accepted at once.

Behind the scenes I met other participants. . .and also that phenomenal creature, Helen Keller, who was struck with complete blindness and deafness at a few years of age. She had been brought out of this total immurement by a gifted woman who enabled her to communicate by spelling out sign language on her hand—and even taught her to speak, though the complete deafness to the sound of her voice made her utterance harsh and difficult to understand. Helen Keller was a very intelligent woman, with indomitable courage; she had won a college degree, and traveled all over the world in unending efforts to improve the condition of people deprived as she was.

She still relied largely on touch: when she asked if she might stroke my face I felt slightly embarrassed, but was delighted when she said: "I am so glad to know you, you feel just as I thought you would!" (New York, 1945)

From *Memories: Vol. I*, by Julian Huxley (George Allen and Unwin, 1970).

**William L. Shirer, journalist*****'Listened' to my broadcasts***

Instantly I found Helen Keller beautiful and gracious, and before I realized it we were deep and passionately in a conversation. . . .

I was so carried away by her personality and wonderfully quick mind that I did not recall until later just how it was we conversed. As I remember it, I could not understand very well Miss Keller's words. They were spoken in a well-modulated voice (which of course she could not hear), but the words were blurred. So Miss Thomson repeated them. Sometimes when I spoke, Miss Thomson tapped out my words on the hands of Miss Keller. At other times, when our talk became animated, as it often did with such an eager and passionate woman, Miss Keller would put her fingers to my lips and lip-read.

To my surprise, she said she had been an "avid listener" to my broadcasts from Berlin (and to those of Ed Murrow from London), and she wanted to know, she said, how I had managed to survive the long years in Nazi Germany. She of course had not actually heard our broadcasts, but Polly Thomson had communicated them to her by what they called the "manual alphabet"—the tapping out of the words on her hand. (New York, 1947)

From *A Native's Return 1945-1988: A Memoir of a Life and Times*, by William L. Shirer (Little, Brown, 1990).

**Yousof Karsh, portrait photographer*****Inspired hope for humanity***

When I met Miss Keller, we shook hands, and then, ever so lightly, she laid her fingers on my face, that she might photograph it in her mind, as I was studying her face through my eyes. Then, as we talked, her companion, Polly Thomson, translated my words by touch into the palm of Miss Keller's hand. I knew that my ideal picture would have to include not only that luminous, serene, yet vivid face, but those sensitive hands, together with the devoted concentration of her companion. To keep all these elements in the right proportion would be a challenge. I felt I must try, too, to transmit something even beyond this—the importance of her tremendous victory for humanity. Only a very insensitive person could leave Helen Keller's presence without feeling hope for humanity and faith in the Infinite. (New York, late 1940s)

From *In Search of Greatness*, by Yousof Karsh (University of Toronto Press, 1962).

**Patty Duke, child star actor*****Jolly grandma***

Easily the most memorable visit to result from *The Miracle Worker*. . .was my meeting with Helen Keller. . .

When I first saw Helen walking down the stairs, she looked almost regal. She was wearing a blue dress, pearls, and what I found out were her favorite red shoes. She was close to eighty years old by then, but she carried herself very straight. She had alabaster skin, very thin white hair, almost like an angel's hair, and was very buxom with small hips and great-looking legs. And a terrific smile. And she was so jolly, like a jolly grandma. I'd expected serious or sweet, but got jolly. Not someone who was so much fun. Not someone who loved to laugh, and about everything, even the fact that we'd come before she'd had a chance to take her bras—rather large bras, I might add—in off the laundry line.

Helen hugged me and I hugged her and she told me that she'd heard from some friends how wonderful I was as her. Occasionally she would spell to me, just to be gracious and indulge me because I wanted her to, but mostly she would talk out loud. Her voice was very hard to understand, like a computer talking; she said she'd never been happy with the way it sounded. To understand me, she would put her thumb on my lips and her fingers on different vibration points. She didn't miss a thing. (Aachen Ridge, Conn., 1960).

From *Call Me Anna: The Autobiography of Patty Duke*, by Patty Duke with Kenneth Turan (Bantam, 1987).





## For Your Library

### Calendars for Students with Multiple Impairments Including Deafblindness

*Blaha, R. Texas School for the Blind and Visually Impaired, 2001.*

This resource guide about the use and development of calendars describes the benefits of calendar systems, provides information about calendar programming, and suggests ways for staff and families to help students expand their skills. Available from Texas School for the Blind and Visually Impaired, Business Office, 1100 West 45th Street, Austin, Texas 78756-3494. Phone: 512-206-9183. Web: <http://www.tsbvi.edu>. Cost: \$30.00.

### Communication Fact Sheets for Parents

*McNulty, K. (Ed.). Monmouth, OR: National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC), 2002.*

This booklet of fact sheets about communication (available later this summer) will cover a wide variety of topics including communication development, different communication methods, and assistive technology. For ordering information contact NTAC or check the NTAC web site after July 1<sup>st</sup>. Address: NTAC, Teaching Research, 345 N. Monmouth, Ave., Monmouth, OR 97361. Phone: 503-838-8808. TTY: 503-838-9623. E-mail: [ntac@wou.edu](mailto:ntac@wou.edu). Web: <http://www.tr.wou.edu/ntac>.

### Ethics in Deaf Education

*Beattie, Rod G. (Ed.). San Diego: Academic Press, 2001.*

This book is about ethics concerning education and deaf children and their families. Topics include ethics of assessment, educational placement, curriculum considerations, and personnel preparation. Available through bookstores. Cost: \$69.95.

### Orchid of the Bayou: A Deaf Woman Faces Blindness.

*Carroll, C. & Fischer, C. H. Gallaudet University Press, 2001.*

This is the story of Catherine (Kitty) Fischer who discovered as an adult that she had Usher Syndrome. The book addresses her upbringing and Louisiana Cajun heritage, early adult life, and how she coped with the diagnosis of Usher syndrome. Available through bookstores or from Gallaudet University Press. Phone: 800-621-2736. TTY: 888-630-9347.

Web: <http://gupress.gallaudet.edu>. Cost: \$24.95.

### The Teen Scene

*Dell, S. J., LaPlante, T., Seamans-Terzian, S., & Cox T. L. Rhode Island Services to Children with Dual Sensory Impairments, 2001.*

A comprehensive list of items and devices that might be enjoyable and stimulating for teenagers with disabilities, including vision and hearing loss. Available from Sherlock Center, Rhode Island College, 600 Mount Pleasant Ave., Providence, RI 02908. Phone: 401-568-8072. TTY: 401-456-8773. Cost: \$5.00. The document is also available in alternative formats and on the web at <http://www.ric.edu/uap/publications/teen.pdf>.

### Understanding Deafblindness: Issues, Perspectives, and Strategies.

*Alsop, L. (Ed.). North Logan, UT: Hope Publishing, Inc., 2002.*

A comprehensive 2-volume curriculum for parents, interveners, and service providers working with children and young adults who are deafblind. All aspects of deafblind programming are covered such as communication, concept development, vision, hearing, touch, sensory integration, intervention, family issues, physical education, additional disabilities, orientation and mobility, community support, and evaluation. Individual chapters were written by professionals with expertise in their respective subject areas. Available from Hope Publishing, Inc., 1856 North 1200 East, North Logan, UT 84321. Phone: 435-752-9533. E-mail: [hope@hopepubl.com](mailto:hope@hopepubl.com). Web: <http://www.hopepubl.com>. Cost: \$160.00



## Early Hearing Screening and Intervention Web Sites

### Early Hearing Detection and Intervention (EHDI) Program

<http://www.cdc.gov/ncbddd/ehdi>

This site describes the Centers for Disease Control EHDI Program. The program promotes early detection of hearing loss, tracking of infants and children who are deaf or hard of hearing, and the initiation of effective intervention systems in order to ensure that all newborns have the opportunity to communicate from birth. EHDI programs are implemented at the state level with collaboration and support from federal, state, and private organizations. There are currently programs in about 15 states. The web site contains a wealth of information about screening, state data, and research projects. Information in Spanish is also available.

### National Campaign for Hearing Health <http://www.hearinghealth.net>

Part of the mission of the National Campaign for Hearing Health is to advocate for universal newborn hearing screening. A document listing screening practices in each state (*State Report Card*) as well as additional information about newborn hearing screening can be found at this site.



## Conferences and Events

### Colorado 2002 Summer Institute on Deafblindness June 26-28, 2002

The title of this program, presented by Phil Schwiegert, is *Using a Tangible Symbol System with Children with Severe and Multiple Disabilities, Including Deafblindness*. Cost: \$75.00 registration fee for out of state personnel, plus costs of lodging, evening meals, and transportation.

**Contact:**  
Tanni Anthony  
Colorado Department of Education  
201 E. Colfax  
Denver, CO 80203  
Phone: 303-866-6681  
E-mail: [anthony\\_t@cde.state.co.us](mailto:anthony_t@cde.state.co.us)

### Family Learning Weekend: "Treasures" June 28-30, 2002 Harrisburg/Hershey, Pennsylvania

This event is for families in Pennsylvania who have a child who is deaf-blind or at risk for deafblindness. It is sponsored by Hand in Hand in Hand: A Partnership Serving Families, Educators, and Service Providers of Children and Youth who are Deafblind (The Pennsylvania Deafblind Project).

**Contact:**  
Nancy Lehr  
Hand in Hand in Hand  
Phone: 800-360-7282, ext. 3115 (PA only)  
E-mail: [nlehr@pattan.k12.pa.us](mailto:nlehr@pattan.k12.pa.us)

### Strategies to Communicate, Learn, and Interact by Moving and Doing July 31 - August 2, 2002 Pennsylvania State University at State College, Pennsylvania

This summer institute presented by Therese Rafalowski Welch and Carolyn Monaco will provide instruction on communication strategies including learning about and constructing at least one of the following: schedule systems, tangible object symbols, experience books, and low-tech applications.

**Contact:**  
Juli Baumgarner  
Hand in Hand in Hand (Pennsylvania Deafblind Project)  
Phone: 724-443-7821, ext. 238  
E-mail: [jbaumgarner@pattan.k12.pa.us](mailto:jbaumgarner@pattan.k12.pa.us)

### Association for Education and Rehabilitation of the Blind and Visually Impaired (AER) International Conference: AERLoom Weaving a Tapestry of Services July 17-21, 2002 Toronto, Canada

This conference will include more than 100 hours of professional development opportunities, along with networking and socializing.

**Contact:**  
AERBVI  
PO Box 22397  
Alexandria, VA 22304  
Phone: 703-823-9690  
Web: <http://www.aerbvi.org>

### Visions 2002: Seeing the Light August 22-24, 2002 Chicago, Illinois

Visions 2002 is the annual national conference of the Foundation Fighting Blindness. It will include current research reports, resources, coping sessions, and networking and social functions.

**Contact:**  
The Foundation Fighting Blindness  
11435 Cronhill Drive  
Owings Mills, MD 21117-2220  
Phone: 888-394-3937  
TTY: 800-683-5551  
E-mail: [info@blindness.org](mailto:info@blindness.org)  
Web: <http://www.blindness.org>

### Deaf-Blind Access of the South (DBAS) Camp October 3-6, 2002 Winder, Georgia

The camp will be held at the Will-A-Way Group Camp, Fort Yargo State Park. Activities include workshops, games, horseback riding, fishing, boating, crafts, hiking, and much more. Space is limited to 50 campers plus 70 to 80 support service providers and volunteer staff. Cost: \$80.00. Registration forms and pictures from the 2001 camp are available on the Web site.

**Contact:**  
Phone: 770-388-9809  
TTY: 770-823-7437  
E-mail: [deafblindaccess@aol.com](mailto:deafblindaccess@aol.com)  
Web: <http://www.hometown.aol.com/deafblindaccess/index.html>

**20th Annual Closing The Gap Conference**  
**October 17-19, 2002**  
**Bloomington, Minnesota**

Topics will cover a broad spectrum of technology as it is applied to all disabilities and age groups in education, rehabilitation, vocation, and independent living. Participants include people with disabilities, special educators, rehabilitation professionals, administrators, service providers, personnel managers, government officials, and hardware/software developers.

*Contact:*  
 Closing The Gap, Inc.  
 PO Box 68  
 Henderson, MN 56044  
 Phone: 507-248-3294  
 E-mail: [info@closingthegap.com](mailto:info@closingthegap.com)  
 Web: <http://www.closingthegap.com>

**Zero to Three National Training Institute**  
**December 6-8, 2002**  
**Washington, DC**

The National Training Institute is a multidisciplinary conference designed for experienced professionals (practitioners, trainers, supervisors, and leaders) in the infant/family field.

*Contact:*  
 Zero to Three: National Center for Infants, Toddlers and Families  
 2000 M Street, NW, Suite 200  
 Washington, DC 20036  
 Phone: 202-638-1144  
 Web: <http://www.zerotothree.org>

**International TASH Conference**  
**December 11-14, 2002**  
**Boston, Massachusetts**

The theme of this year's conference is "Our Quest: Opportunity, Equality, Justice." There will be over 350 breakout sessions that include cutting-edge, practical information about changing images, attitudes, and systems to empower individuals with disabilities and their families.

*Contact:*  
 TASH  
 29 W. Susquehanna Ave., Suite 210  
 Baltimore, MD 21204  
 Phone: 410-828-8274  
 TTY: 410-828-1306  
 E-mail: [info@tash.org](mailto:info@tash.org)  
 Web: <http://www.tash.org/2002conference>

**American Association of the Deaf-Blind (AADB)**  
**2003 Conference**  
**July 12-18, 2003**  
**San Diego, California**

AADB is a national consumer advocacy organization that promotes better opportunities and services for deaf-blind people. The 2003 conference will be held at San Diego State University. The cost is estimated to be around \$800.00.

*Contact:*  
 AADB  
 814 Thayer Ave, Suite 302  
 Silver Spring, MD 20910-4500  
 TTY: 310-588-6545  
 Fax: 310-588-8705  
 E-mail: [aadb@erols.com](mailto:aadb@erols.com)



## Announcements

### New Project SALUTE Website

The new website of Project SALUTE (Successful Adaptations for Learning to Use Touch Effectively), <http://www.projectsalute.net>, provides (a) a description of the project and procedures, (b) an annotated bibliography and related links, and (c) information sheets related to project activities. This latter section, called "What We've Learned," includes the following topics:

- Definitions
- Tactile strategies
- Cues
- Symbols
- Signs
- Early literacy
- Working with Spanish-speaking families

The website contains a discussion board for posting and answering questions. We invite family members and service providers of children who are deaf-blind to join our discussion on issues related to tactile strategies.

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### Helen Keller National Center Registry of Persons Who Are Deaf-Blind

Have you ever wondered how many deaf-blind people there are in the United States or what the most common causes of deaf-blindness are reported to be? Do you know what kind of jobs deaf-blind adults have? The Helen Keller National Center (HKNC) maintains a voluntary registry of deaf-blind people of all ages. The purpose of the registry is to collect basic

information about the population of deaf-blind people in the United States. This information is used as a census of the population, to identify the needs of those who are deaf-blind, as a planning tool for services, and for research purposes.

In order to have the most accurate information possible, we need your participation. If you would like to be included in the registry or know someone who may wish to be included, contact Nancy O'Donnell or check out the website listed below. All identifying information is confidential. Written consent of the individual or guardian is required before it will be shared outside of HKNC.

Nancy O'Donnell  
Helen Keller National Center  
111 Middle Neck Road  
Phone: 516-944-8900, ext. 223  
TTY: 516-944-8637  
E-mail: HKRegistry@aol.com  
Web: <http://www.helenkeller.org/national/registry-shortform.htm>

### **American Printing House for the Blind Initiative**

The American Printing House for the Blind would like to announce its federal initiative designed to expand the knowledge and use of APH products and services, and to invite those with an interest in deaf-blindness to participate.

The National Instructional Partnership was initiated in 2000 to provide training in the use of APH products and information regarding related curriculum areas and instructional skills helpful when using APH products. APH is sponsoring the development of partnerships with experts in the field of blindness and deaf-blindness to initiate state and regional training opportunities for parents, consumers, and personnel who serve children who are visually impaired or who are deaf-blind. APH is currently contacting and contracting with successful APH product users in various arenas and curriculum areas.

The goal at APH is to partner with individual states and regions to offer dynamic training opportunities. APH will be responsible for coordinating presenters, travel arrangements, product delivery, and materials. If your state is interested in partnering with APH in planning a training event related to blindness or deaf-blindness or for more information, contact Field Services Representative Sandi Baker at 800-223-1839, ext. 266, or e-mail her at [sbaker@aph.org](mailto:sbaker@aph.org).

## **Jamie McNamara Named Executive Director of AADB**

**(Press release from AADB President Harry C. Anderson)**

**T**he American Association of the Deaf-Blind (AADB), a national consumer organization of, for, and by deaf-blind Americans, is pleased to announce the appointment of Jamie McNamara as Executive Director of AADB. This is the first time that AADB has ever had an Executive Director. In recent months, the AADB Home Office has gone through critical staff shortages, prompting the AADB Board of Directors to act in order to keep AADB viable. This emergency action resulted in the appointment of Ms. McNamara to oversee the Home Office.

Ms. McNamara, herself deaf-blind, has been an active member of the AADB Board of Directors since 1997. She has been involved with numerous projects to make AADB a strong organization where deaf-blind people have a national voice. Ms. McNamara is committed to taking AADB to higher levels and helping the organization grow when she starts the job on May 6th. Her priorities will be focused on membership outreach; connections with legislators, manufacturers, service providers and deaf- and blind-related organizations; 2003 conference planning; and fundraising.

AADB is thrilled to have a strong deaf-blind leader for the Home Office and a role model for deaf-blind people everywhere. It's a great day for the national deaf-blind community to have a skilled deaf-blind Executive Director at AADB! Please feel free to contact or visit the AADB Home Office to say hello, ask how you can help or be involved with AADB activities, or how we can assist you with any questions.

AADB  
814 Thayer Avenue, Suite 302  
Silver Spring, MD 20910  
TTY: (301) 588-6545  
Fax: (301) 588-8705  
E-mail: [aadb@erols.com](mailto:aadb@erols.com)





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All issues of *Deaf-Blind Perspectives* are available on the Internet at [www.tr.wou.edu/tr/dbp](http://www.tr.wou.edu/tr/dbp) 0502

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