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ABSTRACT

These three issues of "Deaf-Blind Perspectives" feature the following articles: (1) "A Group for Students with Usher Syndrome in South Louisiana" (Faye Melancon); (2) "Simply Emily," which discusses a budding friendship between a girl with deaf-blindness and a peer; (3) "Intervener Update" (Peggy Malloy and Betsy Bixler), which summarizes services provided by a person with special training in deaf-blindness who works one-to-one on an ongoing basis with a child or young person who is deaf-blind; (4) "Team Structure for a Deaf-Blind Student" (Betsy J. Dunn), which discusses successful support teams and the different roles of team members; (5) "Tactile Learning Strategies for Children Who Are Deaf-Blind: Concerns and Considerations from Project SALUTE" (Deborah Chen; June Downing, and Gloria Rodriguez-Gil), which discusses activities and outcomes of Project SALUTE (Successful Adaptations for Learning To Use Touch Effectively); (6) "Parents Use a Research Technique To Help Their Children with Cortical Visual Impairments" (Karen Goehl and Georgia Hembrecht); (7) "NTAC Parent and Family Activities" (Kathy McNulty); (8) "Seattle Lighthouse for the Blind: Deaf-Blind Program Federal Funding" (Paula Hoffman); and (9) "Interactive Storytelling for Deaf-Blind Children" (Keith Park), which provides four examples of storytelling activities that have been made accessible for children who are deaf-blind and have cognitive disabilities. (Some articles contain references.) (CR)

# DEAF-BLIND PERSPECTIVES

## VOLUME 8
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## FALL 2000-SPRING 2001

Peggy Malloy, Ed.

# Deaf-Blind Perspectives

Volume 8, Issue 1 Fall 2000

## A Group for Students with Usher Syndrome in South Louisiana

Faye Melancon

To begin with, Usher syndrome among the Acadian French people in south Louisiana was something people knew the "about" of, but not the "what" or "why" of. They knew that generation after generation of children were struck mysteriously with deafness and eventually with partial-to-full blindness. It was something that was dreaded, but had to be endured. Again and again, cousins, aunts, uncles, and sometimes two or three children in a family were found to have the condition, but no one knew what to do, or what to call it.

The "what" and "why" of it was that the Acadian parishes of south Louisiana have a far higher percentage of Usher syndrome than anywhere else in the United States. This extraordinarily high percentage has been documented in several studies (English, 1978; Kloepfer, Laguaite, & McLaurin, 1966; Smith et al., 1992; Walters, Quintero, & Perrigin, 1982;). For example, Kloepfer et al estimated that 30 percent of the deaf population in the parishes of Lafayette, Vermillion, and Acadia had Usher syndrome. This high incidence is a result of several hundred years of intermarriage among this close-knit ethnic group. Inevitably two individuals, both carrying a recessive gene for Usher syndrome transmitted to them by a common ancestor, marry and have children with this condition.

The Acadians, or Cajuns, as they are called, were originally from Acadia (Nova Scotia) in Canada. In the 1700s they were expelled from that area by the English. They moved down along the east coast of America, finally settling along the bayous of several south Louisiana parishes. At first they were not readily accepted by people in the area and were somewhat isolated both by language and culture. With time, however, the Cajuns came into their own and have won admirers around the world for their music, love of fun, and never-to-be-forgotten cuisine.

Many students at the Louisiana School for the Deaf (LSD) come from the Acadian parishes resulting in a high incidence of Usher syndrome at the school. According to Joyce Russo, project director of the Louisiana Services to Children and Youth with Deafblindness at the Louisiana Department of Education, these parishes include Acadia, Vermillion, Lafayette, St. Martin, Iberia, St. Mary, East Baton Rouge, Livingston, Ascension, and Orleans. Fifteen to twenty percent of children on the Louisiana deaf-blind census for children birth through age 21 are known to have Usher syndrome (Usher 1) as compared to an average of 3 percent for all other states in the nation.

### In This Issue

When I became the counselor at the Louisiana School for the Deaf in 1974, I had no idea what Usher syndrome was. I wasn't aware that there was such a problem anywhere, much less at our school. I was a new counselor from the northern part of the state where there were no reported cases of Usher syndrome.

As time went on, students would offhandedly point out other students to me and hold both hands on either side of the face to describe them. It reminded me of how blinders on a horse would look. When I asked, "What do you mean?" they would answer, "You know, can't see on the sides."

At first I was confused and thought the students were wrong, but I found myself watching the ones they had pointed out. I decided to bring them into my office and do some informal testing, such as standing off to one side and waving my hands. It gave me goosebumps when I realized, "Yes! Those kids were right!"

One of the good things about working at a school for the deaf is that networking and sharing knowledge is the norm. As I looked around, unsure of what to do, several people came to my aid. First and foremost, I was steered in the right direction by the principal at that time, Jerry Stewart, who had originally been at the Florida School for the Deaf and Blind (FSDB). Because some of the Acadian people had drifted down the east coast to Florida when the British evicted them from Nova Scotia, there were deaf students at FSDB who had Usher syndrome.

Next, I got in touch with Steve Barrett, who was the regional representative for the South Central Region of the Helen Keller National Center. The ball started rolling then. Steve was very helpful, flying over from Dallas several times in the fall of 1976 to help assess the situation. It was apparent that a schoolwide visual screening program was needed.

Because interest was picking up around the country regarding the probability of a high incidence of Usher syndrome in Louisiana, we were able to get the University of Houston College of Optometry, headed by Dr. James Walters, to come and test our students over the next several years.

After this, things started happening. New programs were suggested and genetic counselors came from as far away as New York. We got our own social worker especially for deaf-blind students, workshops were conducted to teach parents and children about Usher syndrome, and I started a student group called "The Lucky 10" in 1978. The name came from "lucky to get out of class." It consisted of tenth, eleventh, and twelfth graders who had Usher syndrome. By 1981, there were 17 in the group.

The goals of the group included independent living skills development, learning about resources available for people with limited vision, proper eye care, understanding laws and civic responsibility, decision making, consequences of actions, money management, development of self-worth, and communication skills. We met every two weeks.

Every Usher syndrome student group since that time has focused on a combination of fun and seriousness. We have gone on picnics, swum at nearby recreation parks, and taken field trips to Lake Ponchartrain for the wild rides, the IMAX in New Orleans, and the Observatory at Louisiana State University. We've skated, bowled, had cakewalks, exchanged gifts at Christmas, eaten at every restaurant in town (almost), and had barbecues and crawfish boils at my house. We saw the movie *The Touch* about a man with Usher syndrome who was struggling to assert his independence, every year until it went out of print.

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The students planned the activities, took care of the paperwork needed to get permission for activities from the school and parents, arranged for transportation, planned meals through the cafeteria, and took care of other necessary arrangements. They gained good management and organizational skills from these experiences.

An orientation and mobility trainer became a part of our group and went with us on outings and activities. The students were not required to have O&M training, but it became natural to participate because the trainer took them to Louisiana State University to practice and then followed up with food at a nearby restaurant.

More serious activities included learning about career centers and schools for deaf-blind people. We also produced and participated in a number of workshops. The students were responsible for the workshops. They wrote letters, designed programs, led groups, and, in short, ran the show.

One recent workshop called "Walk in My Shoes," featured Sister Bernadette Wynne, from the Technical Assistance Center at Helen Keller National Center in Sands Point, New York. The purpose was to raise the awareness level of other students at the Louisiana School for the Deaf, in order to help them better understand Usher syndrome, and stop the occasional teasing and bullying of students who had Usher syndrome.

Another recent workshop, "Open Your Eyes and See Us!" featured Dr. Bronya Keats from the Department of Biometry and Genetics at the Louisiana State University Medical Center in New Orleans. It focused on the students' feelings that others don't understand the nature of Usher syndrome and what people with Usher syndrome have to endure. Harry Anderson, who has Usher syndrome and is a guidance counselor at the Florida School for the Deaf and Blind, guided us through an Usher syndrome simulation experience. Each of the participants including students, parents and LSD staff wore ear plugs and eye covers that simulated sight with increasingly smaller and smaller degrees of central vision, culminating in no vision at all. Consciousness raising was immediate. We all expressed feelings of extreme frustration, fear, awkwardness, and sadness. The most significant result of the workshops was the empathy and respect that others developed for those who had Usher syndrome.

Another fun activity that we did for several years was to communicate with another Usher syndrome student group in Sweden. The students became pen pals. They exchanged letters, e-mail, pictures, and brochures. Each side bragged about its own country. Each group invited the other to come and visit, and in fall of 1999, the Swedish group came to Louisiana. They stayed at the school for a week, and what a week it was! There were 14 visitors, 9 students and 5 adults. We showed them a Cajun good time. We hope to visit them in the future and several students are working on projects to raise money, including a website explaining the project and asking for donations.

The name of the student group changed twice through the years. In 1992, the group changed to "The Dice 12" because they said they had Usher because of the luck of the draw. In 1999, the group changed names again to "The Bravehearts," partly because of the movie that was currently showing in theaters and partly because they felt they had brave hearts.

The student group has filled an important need at the Louisiana School for the Deaf in this area of the country where there is such a high incidence of Usher syndrome. Over the years, the group has provided a wonderful opportunity for students develop skills, share experiences and support, and learn planning and organizational skills. The students worked hard to make this happen. They also provided an important service by educating others in the community about Usher syndrome and issues faced by people who have Usher syndrome.

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*Faye Melancon recently retired from the Louisiana School for the Deaf after 27 years. She is currently taking an extended trip across the United States.*

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## Note from the Editors

In this issue of *Deaf-Blind Perspectives* we are pleased to publish both a poem and a short story in addition to a number of other articles. We would like to extend our thanks to all of the writers who have contributed articles for this and past issues. We would also like to encourage others to submit articles for possible publication in the future. *Deaf-Blind Perspectives* is a forum for everyone to share their thoughts, feelings, and expertise. We welcome submissions of a variety of types including professional articles, reports, practical tips, essays, poems, stories, announcements, and letters. If you have an article or other item that you would like to submit, or if you have questions or comments, please contact:

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*The following story was written by Deanna Baxter about her sister Emily. Emily was born deaf-blind. The story describes a trip that their family took from their home in Kansas to Maryland, where Emily received some medical tests. It describes Emily's everyday life, how people treat her, and how she deals with her lifestyle. The story was written 2 years ago when Deanna was 12 and Emily was 10. Emily has some vision and hearing. She wears glasses and hearing aids. Depending on the situation, she may use either sign language or speech to communicate.*

## Simply Emily

Deanna Baxter

"Hello," said the doctor. I will be Emily's doctor for the week. We are going to start by taking a sample of Emily's blood."

"Emily, this man is going to take some of your blood, " said her mother.

"If you will step this way please."

Emily walked clenching her mother's arm. She was very frightened. Emily may be deaf, but she still has a brain.

Emily was born deaf-blind. Which is not in any way bad. Like they say, "Everyone is different in their own little way." She is just like anyone else; she can recognize a place if she has been there before. Or, like if there is a place you go quite often. Emily has been to many places like this. She is so terrified of hospitals, because so many things have been done to her in the past at these places.

"Ok, here we go, we are going to take your blood now," said the doctor.

Emily's mother says. "You're going to need a couple of other doctors to hold her down. Trust me she is very strong, when it comes to someone doing something to her that she doesn't like." Right about now Emily is screaming and kicking and trying to get loose. She cannot stand people holding her down, but there is no other way to get her blood taken.

She isn't a very big kid either. She is 10 years old and only weighs 59 pounds, but when it comes to people messing with her, and she doesn't want them to at the moment, she becomes very powerful.

"Just a few more minutes, you're doing great Emily," said her mother trying to comfort her.

Emily cries, "I want Deanna."

"I'm right here, Emmy. Hang in there," said Emily's big sister Deanna.

**L to R - Emily, Deanna, and their sister, Jessie (standing).**

"Yes, you did it. Great job, Emily," remarked the doctor.

Emily is not very happy at the moment, but in a few minutes she cools off, and she is ready to continue her day in a good mood.

"Emily, come on let's go and get you some ice cream. You were so good," Deanna told Emily.

The next day Emily had to go back and they performed some other kind of test on her. She continued to go to the doctor for awhile. Just like any other kid, she hated it with a passion.

On the plane on the way home, Emily and her mother were sitting by a young lady and her little girl who was 9 years old. She was so cute. Her name was Rachel. She really wanted to know a lot about Emily and what was wrong with her. She was interested to learn and try different things with her. She thought it was cool when Emily's mother was signing to her. Rachel told Emily's mother that she would love to learn how to sign. So Emily's mother showed Rachel how to do some simple signs.

Later during the flight, Emily and Rachel were asleep on each other's shoulders. They had become very close friends. Their mothers had been talking a lot about the two girls. Emily's mom told Rachel's mom that Emily didn't have very many friends. She said that people just don't know what to say. All they know how to do is stare. Rachel's mother agreed. "They treat my daughter the exact same way, but the only difference is that Rachel is a different color than them. She doesn't really understand why very many people don't like her. I have tried and tried to explain. It just doesn't work. I don't know if she is just too young to understand or if she doesn't want to try to understand."

A voice over the intercom interrupted them, "Please stay seated until the plane is landed. Thank you for riding with us. I hope you enjoyed your flight."

The two families said their good-byes and said that they would keep in touch so that the girls could get to know each other a little more.

"Hey, would you and Rachel like to come down and go to the fair with my family this year?" asked Emily's mother.

"Sure, that would be so much fun!"

The two families parted and they thought about each other constantly. They kept in touch and visited each other a lot. Let this be a good lesson to people who think that just because people look different, it doesn't mean that they're a bad person. So, just as the golden rule still reads, "Do unto others as you would like them to do unto you."

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# Miss(ed) Communication

Lisa Kozlik

*Everyday, strangers pass me by*
*without saying a word.*
*They use their voices to speak OF me,*
*- but don't take the time to speak WITH me.*
*I wonder why.*

*As I walk along the sidewalk, one person says*
*to another, "Look at her."*
*- they are pointing at me.*
*Suddenly, the voice disappears.*
*Where did it go?*
*I don't know.*

*While I'm in the mall shopping with friends*
*another voice says, "Look at her."*
*- they are talking about me.*
*But who spoke those words?*
*I never found out.*

*What I cannot see and hear,*
*I experience through touch.*
*Why isn't this good enough*
*for those of you who pass me by?*

*Sign language is my communication with the*
*world,*
*- just like the voices you use to speak of me.*
*Braille is my "information highway" to the*
*world,*
*- just like the fingers you use to point at me.*

*The next time you see me,*
*please*
*just don't look at me*
*- get to know me.*

### *About the Author*

My name is Lisa Kozlik. I am a 29-year old college student from Wisconsin. I am also deaf-blind. I have light perception and a severe hearing loss. My blindness and hearing impairment were caused by premature birth complications. I have been a dog guide user for the past 8 years. My current guide is a three-year old yellow lab from Leader Dogs. Five years ago, I sought training at the Center for Deaf-Blind Persons in Milwaukee, Wisconsin. Their help and support have given me the strength to believe in myself and to share this poem with you, the readers of *Deaf-Blind Perspectives*.

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# Intervener Update

Peggy Malloy, DB-LINK
Betsy Bixler, NTAC

The role of interveners in the education of deaf-blind children is receiving more and more attention these days. In February 2000 in San Diego, a group of individuals interested in exploring this topic met to discuss issues pertaining to the use of interveners—what intervention is, what the role of interveners is, and how they should be trained and supported.

The meeting was sponsored by Helen Keller National Center (HKNC) and facilitated by Joe McNulty, Director of HKNC. Present at the meeting were several individuals with expertise on the topic of intervention, parents of deaf-blind children, and representatives from HKNC, DB-LINK, NTAC, NFADB, and several state deaf-blind projects. The meeting focused primarily on the use of interveners in early intervention and educational settings.

At the meeting, the status of interveners in both the United States and Canada was discussed. Much of the discussion about what is happening in the United States focused on a review of a briefing paper about interveners written by Linda Alsop, Robbie Blaha, and Eric Kloos (2000) and recently published by NTAC. The paper provided an excellent basis for discussing the various issues of interest to the group. An overview of the Canadian system was provided by Linda Mamer.

This article summarizes some of the main points of the briefing paper. The paper itself goes into greater detail about each of these points as well as other relevant issues. A description of intervener services in Canada follows the briefing paper summary.

## Briefing Paper Summary

### What is an intervener?

An intervener is a person with special training in deaf-blindness who works one-to-one on an ongoing basis with a child or young person who is deaf-blind. The intervener is a consistent presence in the child's life and helps the child gain access to the world. Interveners do not work in isolation, but are members of Individualized Family Service Plan (IFSP) or Individualized Education Program (IEP) teams. In school settings they work under the direction of the classroom teacher. In early intervention settings they may be supervised by an early intervention specialist or other service provider.

### What is the role of the intervener?

Intervention is a process that provides access to visual and auditory information for a deaf-blind child. The role of the intervener is to facilitate that process. Deaf-blind children have unique needs that can be addressed by the process of intervention. These include

- ◇ Access to environmental information
- ◇ Communication
- ◇ Social and emotional well-being

Interveners provide clear and consistent *access to environmental information* by using strategies tailored to each child's unique capabilities to help them access information that is usually obtained through hearing and vision, but is unavailable or incomplete to deaf-blind children. They facilitate *communication* by being consistently available to the child to promote the development and use of communication skills. They serve as a link to help the child communicate with others. Interveners develop a trusting, interactive relationship with the child that promotes *social and emotional well-being*. This relationship can help motivate the child to be in contact with the world outside his or her own body.

Interveners also have additional responsibilities as determined by the goals of the IFSP or IEP. These include supporting the child during daily routines and activities and vary depending on the needs of the child. For example, an intervener working with an infant in the home may be involved in activities such as dressing and play. Responsibilities of an intervener working with an elementary school child may involve academic work and social activities. An intervener working with a high school-aged child may be involved in job coaching. During these times of additional responsibilities, however, the intervener's focus continues to be on promoting the process of intervention by meeting the child's needs of access to environmental information, communication, and social and emotional well-being.

### Does the deaf-blind child become dependent on the intervener?

Rather than create dependency, the intervener promotes the child's independence by facilitating access to information, providing opportunities that allow the child to solve problems, make his or her own decisions and choices, and interact fully with other people. The intervener acts as a bridge, not a barrier.

### What type of training and skills do interveners need?

Training for interveners should occur at two levels. The first is training that provides basic information about deaf-blindness including characteristics of vision and hearing loss, communication, concept development, and learning. The second level is training tailored to the specific needs of individual children. Child-specific training varies depending upon characteristics of the child, including age, severity of vision and hearing loss, presence of other disabilities, communication needs, and the setting (e.g., home, school, or community) in which the intervener's services are provided. Because interveners work as part of a team to develop and provide services for deaf-blind children, they should also receive training that will help them acquire teaming and collaboration skills.

### How do you know if a child needs an intervener?

The need for an intervener for a particular child is always determined by the IFSP or IEP process. This follows a thorough evaluation of the child's strengths and needs. An intervener is not automatically provided for a child or student who is deaf-blind, but should be a valid option on a menu of services available to support the implementation of the specially designed instruction of the child's IFSP or IEP.

### Is the word "intervener" spelled with an "er" or an "or"?

The term intervenor originated in Canada where the "or" ending is used. The authors of this briefing paper use the same term, but with an "er" ending. This was an outgrowth of practices in Utah where administrators and service providers officially adopted the spelling as intervener.

## Intervenor Services in Canada

At the meeting in San Diego, Linda Mamer described intervenor services for students who are deaf-blind. In Canada, intervention for people who are deaf-blind has been a service delivery model for more than 25 years. The Canadian Deafblind and Rubella Association (CDBRA) believes that every person identified as deaf-blind has the right to receive lifelong intervention services (Mamer & Munroe, 1999). The term "deaf-blind" as used by CDBRA refers to individuals with congenital or early-acquired deaf-blindness as this is the main area of their experience and expertise. McInnes (1999) defines intervention as a process that enables "the deafblind person to establish and maintain maximum control over his or her environment at a level appropriate to physical ability and level of functioning" (p. 76).

The Canadian Deafblind and Rubella Association has developed a working paper of national guidelines for intervenors. The guidelines promote intervention as an appropriate and viable model for deaf-blind individuals. CDRBA recognizes the significant impact that an intervenor can have on an individual's learning and experience and emphasizes that an intervenor enables the individual to access information, communicate, and fully participate in making choices (Mamer & Munroe, 1999). The intervenor should facilitate the deaf-blind individual's needs and desires.

School intervenor services are individualized and available for deaf-blind students throughout the educational years in many parts of Canada. In some areas, intervention services are also available after-school, weekends, and summers.

## Future Activities

Crucial needs identified by participants at the meeting in San Diego included development of a list of competencies for interveners and formalized training opportunities on a national level. A subgroup of the participants plans to pursue these objectives in the future. Another subgroup is developing a values/mission statement on the need for intervention services for deaf-blind children and youth. Participants at the meeting also identified a need for more widespread information about interveners and hope to promote awareness through publications like *Deaf-Blind Perspectives*.

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*Attendees at the San Diego Meeting*

Joe McNulty - Director, Helen Keller National Center

Linda Alsop - SKI*HI Institute, Utah State University

Betsy Bixler - Area Director, NTAC, Helen Keller National Center

Robbie Blaha - Education Specialist, Texas Deaf-Blind Project, Texas School for the Blind and Visually Impaired

Cathy Kirscher - Regional Representative, HKNC Southwestern Regional Office

Eric Kloos - Project Director, Minnesota Deafblind Project

Peggy Malloy - Information Specialist, DB-LINK

Linda Mamer - President, Canadian Deafblind and Rubella Association

Carrie Masten - Parent; Family Support Partner, Washington State Services for Children with Deaf-Blindness; Representative, National Family Association for Deafblind

Loretta McGraw - Project Director, Connections Beyond Sight and Sound

Pearl Veesart - Parent

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## AADB Convention 2000

Roma Vanduzer,
Chairperson, Arizona Association of the Deafblind of Tucson

The American Association of the Deaf-Blind convention held in Columbus, Ohio this year from July 29th to August 4th was, in my opinion, a tremendous success. Considering that more than 1000 people attended, things went along relatively smoothly. There were numerous well-presented, educational workshops. Many provided Braille handouts. There were also many enjoyable tours. So many activities were offered that it was difficult to choose among them. The only problem, from my personal viewpoint, was that most of the places selected for tours were so filled with fun things to do and see that I could have spent a whole week in each place!!

There were two big parties. The first, on Sunday, July 30th, was a celebration of the 25th anniversary of the first AADB convention held in 1975. The theme of the second party, on Wednesday evening, August 2nd, was "Let's Swing into the 21st Century." Large crowds attended both parties. Everyone danced exuberantly, ate and talked, and made new friends.

On Sunday, there was an opening ceremony in the afternoon. All who attended enthusiastically cheered the roll call of the states. Wednesday was entirely given over to business meetings. The new AADB bylaws were reviewed, discussed, and put to a vote. Late in the afternoon they were unanimously accepted. Considering that a large number of people attended the convention, I was surprised and disappointed that there were not more people at the meetings. Exhibits and crafts displays, however, were held at the same time. There was a great deal to see, including interesting product displays, beautiful crafts, and souvenirs like t-shirts. Despite all of the excitement, business was very competently taken care of and concluded, and that's what is important.

Overall, it was a great convention. The housing was comfortable, private, and very clean. The food was delicious and the transportation conveniently available at all times. Shuttle buses conveyed people to and from points of interest and other places they needed to go.

It is important to keep in mind that one of the major reasons for the success of the convention was the large number of volunteers (support service providers) who gave a whole week of their time, skills, and services with selfless dedication to assist us with anything at all when we needed help. We extend our heartfelt thanks to all of them!!

The banquet on the last evening was great. The food was excellent and expertly catered. Many awards were given and many people were recognized for their services to AADB. President Harry Anderson was his usual cheerful and amusing self.

On Friday, August 4th, transportation to the airport was well organized and efficient. Hey, no one in our group even lost any luggage!!

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The following article is reprinted with permission from the March 2000 issue of *VIEWS*, a monthly publication of the Registry of Interpreters for the Deaf.

# Team Structure for a Deaf-blind Student

Betsy J. Dunn, CSC, California

The successful educational experience of a student who is deaf-blind is always the result of a team effort. It would be impossible for any parent, teacher, support staff or administrator to single-handedly ensure the educational/social success of a student requiring extensive support. The complex and multi-layered educational and social needs, preferences and styles of a deaf-blind student mandate a sophisticated network of support that can only be provided by a team of professional individuals who listen carefully and respond appropriately to the deaf-blind student.

The individual needs of a deaf-blind student are as varied as each student, and yet, the structure of the support team needed by this widely varying group is very similar. A successful support team for a deaf-blind student includes the following individuals:

- Student
- Parent
- Administrator/Case Manager
- Primary Support Teacher
- Interpreters
- Vision Teacher
- Mobility Instructor

Team success requires that each team member have a clear understanding of their own role, the role of other team members, and how each member interacts and supports the other. Team members must actively share information and seek assistance from others. Equally important, they must be willing and able to put the needs of the student ahead of any personal issues or agendas. On-going team success requires constant communication, respect and competency in each and every role.

## Role Definitions

The first and most important member of the team is the **student.** The student's individual needs, preferences, and styles as they relate to communication and education must be addressed and accommodated by the support team's efforts. Individual profiles of interest, potential and skills provide necessary direction for the student's educational goals. As the student matures and is able to participate in his or her own IEP with increasing awareness and responsibility, the success of the support team will be reflected in the educational ownership and self-awareness of the student.

The **parent** is the driving force of his/her child's educational experience. Without strong advocacy from the parent, it is too easy for a deaf-blind student to be under-served or not served at all. The parent provides essential input and direction in the IEP. Some educators might prefer the parent simply rubber stamp decisions made by school personnel. This, however, is not the most effective relationship for student success. The parent is able to bring a wealth of background information to school personnel – and through this information, the school staff can better understand and guide the student to academic/social success. Even when a full ensemble of professionals has been brought together to provide educational support, the parent still continues to be a vital team member. The need for parent input and direction is never-ending.

The **administrator or case manager** acts as the school site coordinator for the services and personnel providing support to the deaf-blind student. From the student's perspective, the administrator/case manager may seem like a "silent partner" on the team. Although the case manager may not be the most visible team member, experience has proven that the case manager's support, guidance and administrative skills interfacing with the school district is a vital element necessary for the team's success. A good administrator can listen and learn about the issues of deaf-blindness and effectively oversee and coordinate these services.

The support team **"teacher"** may be called many different names: primary teacher, primary support teacher, teacher of the deaf, point person, or special education teacher. Whatever the name, this "teacher" is a pivotal team member who not only provides 1:1 teaching and tutoring, but also interfaces and coordinates with the general education teachers, interpreters, parents, and administration. Additionally, the primary support teacher must modify, adapt, and create materials necessary for the student to participate, understand and master the information presented in the general education and during 1:1 instruction periods. The teacher must work closely with the student and parent to ensure that the educational direction and needs of the student are represented in the IEP document.

To the general school population, the **interpreter** provides the most visible support to the deaf-blind student; it is also a complicated and often misunderstood position on the team. The school district employee title of "interpreter" is generally inadequate and does not represent the variety of duties required by this position. The interpreter's daily responsibilities are a blur of interpreter, tutor, social facilitator, and Service Support Provider (SSP) duties.

Functioning as the "interpreter," this team member facilitates and creates the information and communication bridge necessary for social opportunities and educational experiences to occur. Deaf-blind interpreting requires specific knowledge and skills beyond those necessary for sign language interpreting. The interpreter literally brings the world to the student and the interpreter's ability to clearly and accurately convey visual and auditory information – as well as social nuances – will determine the level to which the student can rise. Sensitivity, awareness, and training in deaf-blind issues and needs are required for the interpreter to successfully support the deaf-blind student. The individual needs, desires, and preferences of the student must be respected and accepted during interpreting situations.

Educational interpreters sometimes find themselves in the dual job description of interpreter/tutor. This blurring of roles can be confusing not only to the student, but also to the interpreter and general education teacher. Clear definition and distinction are necessary for the successful blending of these roles.

While interpreting in a social setting, the interpreter for a deaf-blind student is called upon to "facilitate" social interaction with the general school population. This is an appropriate and necessary role to embrace, and yet it adds additional confusion of the interpreter's roles and responsibilities. Continued professional development and growth are vital for the development of skills necessary to discern when and how to function as a facilitator while also maintaining respect and regard for the deaf-blind student's social/emotional development and abilities.

In addition to functioning as interpreter, tutor, and social facilitator, the interpreter for a deaf-blind student also serves the student as a Service Support Provider (SSP). As an SSP, the interpreter will act as the deaf-blind student's guide, lunch partner, or companion. The student's personal needs or preferences for support will determine how and when the interpreter functions as an SSP.

Deaf-blind interpreters work under unusually close and intimate conditions with the deaf-blind student. This unusually close working relationship - as well as the intensity, which often accompanies it - is important to acknowledge and support. Too often, interpreters reach "burn-out" because these issues have not been anticipated, addressed, or supported. For this reason, it is preferable for the deaf-blind student to receive alternating services from at least 2 interpreters throughout the day.

The **Braille and Mobility Instructors** both provide specific training and expertise for the student and other team members. Their input regarding specific skills and strategies related to deaf-blindness are beneficial to all team members.

### Communication of Role Definitions

Various methods may be used to define, establish and communicate the role of each team member within the team as well as to the general educators or other persons who are part of the larger support network. The roles and responsibilities of team members may be introduced to the general education teachers through an orientation meeting, which takes place before the beginning of each school semester.

During an orientation meeting, or in a 1: 1 setting, a one to two-page "fact" sheet can be utilized to provide information addressing these questions/topics:

- ◇ Who is the student? What does s/he like to do?
- ◇ Functional aspects of vision and hearing: How much can s/he see or hear?
- ◇ Types of educational materials used: does s/he read Braille or print or both?
- ◇ Communication options in the classroom: sign language through the interpreter, writing, or gestures/body language.
- ◇ Define the interpreter's role, responsibilities, and duties: Visual and auditory information is relayed and tutoring assistance is provided as necessary. Classroom behavior management is the responsibility of the teacher.
- ◇ Identify special space/environmental considerations: What seating arrangement is appropriate? Use of the over-head projector and movies.
- ◇ Describe how the student will complete class assignments: describe the 1:1 study support s/he receives.
- ◇ Indicate who and how the student will be graded.
- ◇ Provide a list of the names and phone numbers of all team members.

Role-playing may also be successfully employed during a teacher orientation as a means to demonstrate and clarify the role of the interpreter/tutor in the classroom setting.

Due to the fact that team members will naturally change over the years, and substitute teachers and interpreters will also require orientation information, a basic interpreting/teaching guide of practical information which addresses deaf-blind interpreting in general, and the individual student's needs specifically, should be disseminated to facilitate the smooth transition of new or substitute team members.

Topics addressed in the interpreter/instructor guidelines for a deaf-blind student may include:

- **Interpreter dress:** Clothing which contrasts the skin tone of the instructor/interpreter. If a particular color is preferred, this should be clearly stated.
- **Getting started:** What to do when first meeting with the deaf-blind student.
- **Sign Language:** Preferences of the student.
- **Lighting:** Optimal conditions and alternatives.
- **Interpreting:** Guidelines, techniques, and strategies for deaf-blind interpreting; defining the expanded deaf-blind interpreter's role as an "SSP" for the student; as well as identifying the language and communication preferences of the student.
- **Mobility:** Strategies, techniques, and student preferences.
- **Social Etiquette:** Student preferences/needs; general deaf-blind courtesies.

Technical support and assistance available through various national organizations, and schools serve as invaluable resources to the professional development and role definition of the student's support team. Team members should be encouraged and challenged to define, communicate, and nurture their professional skills so that they may better provide the support structure needed for student's success.

Some parents may dream of finding an "Anne Sullivan" for their deaf-blind child; a person who might magically bring the "world" to their child. However, the strength and knowledge of a team provides a more powerful and dynamic educational experience than any single parent or teacher could ever dream of giving an individual who is deaf-blind.

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## Meet the NTAC Staff

NTAC, the National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind provides technical assistance to families and agencies throughout the United States. NTAC's mission is to provide assistance that enables people and agencies in each state to work together to improve the quality of early intervention and educational services provided to children and young adults who are deaf-blind. NTAC's ultimate goal is to assist states to improve outcomes for deaf-blind students to meet challenging standards and be better prepared for adult life. Technical assistance activities include setting up training opportunities for families and service providers, consultations, and facilitating collaboration among agencies and organizations within a state.

Technical assistance activities are planned through each state's deaf-blind project and are provided to agencies and organizations that provide services for children and youth who are deaf-blind (birth to 28 years). These include state deaf-blind projects, family or consumer organizations, and state education, early intervention, and adult service agencies.

NTAC combines the resources and expertise of two organizations, Teaching Research at Western Oregon University and the Helen Keller National Center (HKNC) in New York. NTAC is funded by a grant from the U.S. Department of Education to Teaching Research.

Staff are located in four regions. Each office provides technical assistance for the states in their region.

**Region 1** (AK, AZ, CA, CO, ID, HI, MT, NV, NM, OR, Pacific Basin, UT, WA, WY), Teaching Research, Monmouth, OR

**Region 2** (IA, IL, IN, KS, MI, MN, MO, NE, ND, SD, OH, WI), Shawnee, Mission, KS

**Region 3** (AL, AR, FL, GA, KY, LA, MS, NC, OK, Puerto Rico, SC, TN, TX, Virgin Islands), Atlanta, GA

**Region 4** (CT, DE, DC, MD, MA, ME, NH, NJ, NY, PA, RI, VA, VT, WV), HKNC, Sands Point, NY

### Administrative Staff

Administrative staff are located in both the Oregon and New York offices. The principal investigators of the NTAC grant are *Joe McNulty*, Director of Helen Keller National Center and *Vic Baldwin*, former Director of Teaching Research.

*Kat Stremel* (Oregon), the Director of NTAC has a master's degree in speech pathology and audiology. She has written and directed 15 federal grants and has served as a federal grant reviewer. She has also served on disability task forces, the Mississippi Parent Training and Information Board, and as a governor-appointed chair of the Mississippi Interagency Coordinating Council. Kat is an expert in the area of communication development and has written numerous publications and taught extensively on this topic.

*Kathy McNulty* (New York) is NTAC's Associate Director and the Area Director for Regions 3 and 4. Kathy has a master's degree in education and worked as a classroom teacher for 7 years. She began working at HKNC in 1986 on the HKNC-TAC (Technical Assistance Center) grant. Her initial responsibilities included a parent survey project and coordination of a national workshop on advocacy for parents of deaf-blind children. She later became a program associate, providing technical assistance to states in the area of transition, and then assistant project director.

*Betsy Bixler* (New York), Area Director for Regions 1 and 2, has a master's degree in education from Boston College, with a focus on the education of deaf-blind and multihandicapped students. Prior to joining the NTAC staff she was the program administrator for Overbrook Friedlander Programs, a private nonprofit agency that provided group home, community living arrangements and vocational and community-based programs for persons with developmental disabilities and blindness or deaf-blindness.

*John Killoran* (Oregon), NTAC's evaluation and early childhood specialist, has a master's degree in education and over 20 years of professional experience in public and higher education. John previously worked as an early intervention coordinator in both Oregon and Utah and was the co-director of the Utah Project for Children with Dual Sensory Impairments prior to moving to Oregon. His teaching experiences range from preschool to graduate school and he has directed numerous federal personnel preparation and model demonstration projects.

*Nancy Flax* (New York) serves as liaison between NTAC and the HKNC regional representatives.

### Technical Assistance Specialists

Technical assistance specialists in the four regional offices each work directly with approximately six states to coordinate assistance.

In the Oregon office are *Paddi Davies* and *Shawn Barnard*. Paddi has a degree in business administration and international studies. Her training in deaf-blindness has come through many years of summer institutes and workshops, as well as self-study. She has worked in the field of deaf-blindness for 9 years. Paddi is currently enrolled in a distance learning design and development certificate program through the University of Washington. Shawn has undergraduate degrees in sign language interpreting and psychology and a master's degree in rehabilitation counseling with the deaf. She previously worked as a mental health counselor with deaf high school aged students and as a living, vocational, and interpersonal skills teacher with young deaf-blind adults.

In the New York office are *Susie Morgan* and *Kristen Layton*. Susie has a master's degree in rehabilitation counseling for the deaf from Gallaudet University. She is also an RID certified interpreter and has developed materials on tactile sign language and worked as an interpreter for individuals who are deaf and deaf-blind. She previously worked at HKNC as a rehabilitation counselor, placement specialist, and counselor for the summer teen program. Kristen has a bachelor's degree in elementary education and a master's degree in special education with a concentration in severe disabilities, including deaf-blindness, from Hunter College. She has previously worked both as a preschool teacher in California and as an instructor of independent living skills at HKNC.

*John Eisenberg* in the Georgia office, also has a master's degree in special education with a focus on severe disabilities and deaf-blindness from Hunter College. Before coming to NTAC he worked as a teacher for young adults who are deaf-blind, as a teacher for young adults with behavior disorders and severe disabilities, and as a vocational coordinator for school-to-work programs including transition planning.

In the Kansas office are *Jamie McNamara* and *Jon Harding*. Jamie, who is deaf-blind, has a master's degree in social work. Prior to coming to NTAC she worked with deaf children in an inclusive school setting and with deaf adults in a community living setting. She has also worked closely with local deaf-blind communities and is on the board of directors of the American Association of the Deaf-Blind. Jon has a bachelor's degree in social studies and a master's degree in learning disabilities. He previously worked for 4 years in the field of assistive technology on a project that provided information and training to local school district personnel in Missouri.

**Support Staff**

*Bernie Samples* has worked at Teaching Research in Oregon for more than 30 years on a wide variety of projects. At NTAC she is responsible for much of the coordination of and arrangements for the annual Project Director's Meeting as well as other topical workshops. Her other responsibilities at Teaching Research include assisting with preparation of grant proposals.

*Robbin Hembree*, in the Oregon office, is NTAC's Deaf-Blind Census Coordinator and Data Specialist. She is currently working on a Master of Education degree with a focus in information technology. She has managed the National Deaf-Blind Census for the past 10 years. She maintains all project evaluation data and performs analysis procedures on the census and project evaluation data.

*Randy Klumph* and *Peggy Malloy* also work in the Oregon office. Randy provides computer and technical support to staff in all four regions. He has a bachelor's degree in psychology and brings a unique combination of skills to the project including computer expertise, social service experience, desktop publishing, and technical illustration. Peggy provides assistance with NTAC's publication projects. She is a librarian and in the past has also worked as a writer and as a registered nurse. Both Randy and Peggy also work for DB-LINK.

Additional support is provided by *Kathy Michaels* and *Nancy Ganson*. Kathy is the administrative assistant in the New York office. She has a wide variety of responsibilities including assisting with budgeting and accounting details and materials preparation. She has worked at HKNC for 10 years. Nancy is a research assistant in the Oregon office and NTAC's travel coordinator. She has a bachelor's degree in theater and communications and, prior to coming to NTAC, worked in the travel industry. Additional part-time clerical support is provided by *Mary McInerney* in Kansas and *Tammy Halloran* in Georgia.

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# Australia's Fifth National Deafblindness Conference

Dr. Michael Steer
Renwick College,
Royal Institute for Deaf & Blind Children

Sharon Barrey Grassick
Western Australian Deafblind Association

The Australian National Deafblind Conference, *Deafblindness: Keeping in touch beyond 2000*, was held at the Esplanade Hotel in Fremantle (one of the world's most remote cities) April 7-10, 2000. It was hosted by the Western Australian Deafblind Association (WADBA). The event drew a record number of participants, including 22 delegates who have varying degrees of deafblindness. New Zealand was strongly represented.

Provision of best possible access for all participants was a priority of the conference organizers. There were 24 professional interpreters available during all formal sessions. Support was also provided for deafblind delegates during breaks and social activities. These arrangements involved a massive undertaking for WADBA, a tiny organization with the equivalent of only 1.4 full-time staff.

Each participant who required interpreting was matched with two interpreters who supported each other throughout the event. Communication methods used included two-handed tactile fingerspelling, short-cut signs, Braille, and Auslan read through close vision, tracking or tactile signing. Six volunteer typists rotated, to make presentations accessible to delegates using Telebrailles or computer monitors with enlarged print.

Intensive Volunteer Support Provider (VSP) and interpreter training for the event commenced in the preceding November. There were 22 VSPs, each available throughout the conference to support the specific communication and guiding requirements of the individuals with whom they had been carefully matched.

The conference began with a "Welcome Cocktail Party" on the first evening, sponsored by the National Relay Service and was formally opened the next morning by the Hon. Paul Omedei, Western Australian Minister for Disabilities.

## Professional Program

Keynote speakers included Graham Hicks, of SENSE in the United Kingdom, who spoke on individuality and the need for appropriate supports and services. Dr. George Williams from New South Wales addressed the importance of what we say and how we say it, with regard to the skills involved in communicating information about a child's condition to parents.

An array of concurrent sessions on such topics as employment, technical devices, communication, and education was offered in the afternoons. These included a session on cortical vision impairment by Caroline Palmer of Flinders University in South Australia, a session by Dr. Rod Beattie of Renwick College in Sydney on action planning, and a workshop on equipment for vision stimulation by Aynsley Kingstone from the Western Australian Vision Impairment Service.

Six papers were presented by deaf-blind delegates, including a session on The Link, an exciting computer access initiative in the state of Victoria. Irene McMinn, President of the Australian DeafBlind Council presented an update on the work of the World Federation of the Deafblind.

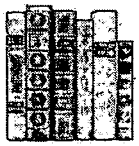
Copies of all conference papers are available on the Australian DeafBlind Council's web site at http://internex.net.au/~dba

## Other Events

Sunday was designated a Social Day, starting with brunch at the poolside. Other social events included a jazz cruise on a paddle steamer and a wine and cheese cruise on one of eight luxury power launches or sailing yachts, organized through the Royal Freshwater Bay Yacht Club. All skippers offered their boats and time without cost to the organizers.

It was unanimously agreed that the event was Australia's best-ever deafblindness conference. New South Wales will host the 6th National Deafblind Conference in Sydney in 2002.

An open-captioned video of conference highlights and impressions is available at a nominal charge from:
Western Australian Deafblind Association
PO Box 14
MAYLANDS Western Australia 6931
Tel. (08) 9272 1122
TTY (08) 9370 3524
Fax (08) 9271 3129
wadba@nw.com.au



## For Your Library

**Communication at Home and in the Community: Helpful Strategies & Suggestions From Parents & Families With a Child Who is Deaf-Blind.** *The National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC).* This booklet contains suggestions from parents and family members who attended the 1999 National Parent Workshop sponsored by NTAC and the National Family Association for Deaf-Blind (NFADB). Available on the web (http://tr.wou.edu/ntac) or by contacting: NTAC-HKNC, 111 Middle Neck Rd., Sands Point, NY 11050, Ph: 516.944.8900 x311, TTY: 516.883.9059, Email: ntac@wou.edu

**Creative Constructions: Technologies That Make Adaptive Design Accessible, Affordable, Inclusive and Fun.** *Campbell, M. & Truesdell, A. Cambridge, MA: Creative Constructions, 2000.* This book presents ideas and plans for simple, custom-made assistive technology items. Includes concrete suggestions, photos, and case studies. Available from Creative Constructions, 659 Green Street, Cambridge, MA 02139; 617.972.7520. Email: mollycampbell@mediaone.net

**A Guide to the Individualized Education Program.** *Office of Special Education and Rehabilitative Services, U.S. Department of Education, 2000.* This guide includes information about how to develop an individualized education program (IEP). Topics include: IEP contents, IEP team members, and how to write and implement the IEP. It also describes the special education process under the Individuals with Disabilities Act (IDEA). Available on the web www.ed.gov/offices/OSERS/OSEP/IEP Guide) or from ED Pubs, Editorial Publications Center, U.S. Department of Education, P.O. Box 1398, Jessup, MD 20794-1398; Tel. 877 4-ED-PUBS; TTY 877.576.7734; Fax 301.470.1244. Available in alternative formats.

**Promoting Learning Through Active Interaction: A Guide to Early Communication with Young Children Who Have Multiple Disabilities.** *Klein, M. D., Chen, D. & Haney, M. Baltimore: Paul H. Brookes Publishing Co., 2000.* The Promoting Learning Through Active Interaction (PLAI) curriculum is designed primarily for infants, preschoolers, and young children with severe or multiple disabilities (including deaf-blindness) who are not yet initiating symbolic communication and who have a limited

repertoire of communicative behavior. It can also be used with older children who have not yet developed intentional communication. The curriculum consists of a Caregiver Interview to identify a child's current communication abilities and 5 modules. It also provides handouts and recording sheets in both English and Spanish. A video (*Promoting Learning Through Active Interaction: An Instructional Video*) is also available in English and Spanish. Available from: Paul H. Brookes, P.O. Box 10624, Baltimore, MD 21285-0624; 800.638.3775;
http://www.brookespublishing.com

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## Conferences

### World Congress & Exposition on Disabilities
**November 10-12, 2000**
**Atlanta, Georgia**

*Contact*:
210 Route 4 East, Suite 403
Paramus, NJ 07652
Tel. 877.923.3976
Fax 201.226.1236
wcdinfo@wcdexpo.com
http://www.wcdexpo.com

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### Zero to Three 15th National Training Institute
**Because Babies Are Our Future**
**December 1-3, 2000**
**Washington, DC**

*Contact*:
Meeting Management Services
1201 New Jersey Ave., NW
Washington, DC 20001
Tel. 202.271.1296
http://www.zerotothree.org

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### 2000 Annual TASH Conference
**Moving the Edge**
**December 6-9, 2000**
**Miami Beach, Florida**

*Contact*:
Kelly Nelson
29 W. Susquehanna Ave., Suite 210
Baltimore, MD 21204
Tel. 410.828.8274 ext. 105
Fax 410.828.6706
knelson@tash.org
http://www.tash.org/2000Conference

### 5TH Deafblind International European Conference On Deafblindness
**Self Determination: A Life Long Process**
**July 24-29, 2001**
**Noordwijkerhout, The Netherlands**

*Contact*:
Anneke Balder
Stichting 5th DbI European Conference on Deafblindness
P.O. Box 222, 3500 AE UTRECHT
The Netherlands
Tel. +31 30 2769970
Fax +31 30 2712892
sdg@wxs.nl
http://www.deafblindinternational.org

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## New Deaf-Blind Education Listserv®

Teaching Research, NTAC and DBLINK are the co-sponsors of a new Listserv on the topic of Deaf-Blind Education. The idea for this list developed from inquiries from participants at several different conferences, including the Deafblind International Conference in Sydney, Australia. Conference members were looking for a a place to discuss the latest information on best practices, new ideas, problem solving, and other issues. The list is open to all persons interested in deaf-blind education.

To subscribe to the Deaf-Blind Education Listserv (DBED-L) send the following command as an e-mail message

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Leave subject line blank if possible and do not include a signature. Send the e-mail to

`LISTSERV@TR.WOU.EDU`

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- ☐ **Technical assistance provider**
- ☐ **Higher education teacher/researcher**
- ☐ **Regular education (non Spec.-Ed.)**
- ☐ **Therapist (*e.g.*, OT/PT/speech)**
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- ☐ **Government personnel**
- ☐ **Medical professional**
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# Tactile Learning Strategies for Children who are Deaf-Blind: Concerns and Considerations from Project SALUTE

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California State University, Northridge

Without reliable access to clear visual and auditory information, children who are deaf-blind must rely on additional modes of learning, such as learning through touch. For many of these children, touch is a primary mode of communication. Although a variety of tactile strategies are frequently used with children who are deaf-blind, there is little research-based evidence that validates their use. Identifying effective tactile strategies for deaf-blind children who also have cognitive or physical disabilities is particularly challenging. Project SALUTE (Successful Adaptations for Learning to Use Touch Effectively), a federally funded model demonstration project, is addressing the need for a more informed approach to the use of these methods. The goal of the project is to identify, develop, and validate tactile instructional strategies for children who have hearing loss and no functional vision, plus additional cognitive and physical disabilities.

This article discusses key issues and concerns regarding the use of tactile strategies based on Project SALUTE's initial activities—a review of publications and input from focus groups. This preliminary examination has identified that there are large gaps in what is known about tactile methods and has revealed more questions than answers regarding the use of touch with children who are deaf-blind. For example, what are the most effective ways to present information in this mode? How should children be taught to use their hands for exploration, learning, and communication? What adaptations are needed for the child who requires tactile information, but has severe physical disabilities and cannot easily control hand movements?

The following literature review and focus group findings serve as a basis for the work of the remaining three years of Project SALUTE. We hope that it also stimulates discussion and sharing of ideas and resources among families and professionals who are interested in this topic and encourages those who are using tactile strategies to analyze their use in a systematic way.

## Literature Review

We identified a number of tactile strategies commonly used with children who are deaf-blind by reviewing publications in the areas of visual impairment and blindness, deaf-blindness, occupational therapy, developmental and biological psychology, and related topics. For the most part, these strategies are not based on research, but rather on the experiences or opinions of the authors or on anecdotal reports. Few research studies have focused on tactile adaptations for children who are blind with additional disabilities (one exception is Rowland & Schweigert, 2000) . Consequently, there is little empirical evidence validating tactile strategies that are used frequently with children who are deaf-blind. The specific strategies we identified are discussed below.

### In This Issue

**Hand-over-hand guidance**. Hand-over-hand guidance is a common strategy in which an adult puts his or her hand over a child's hand to help the child explore an object, act on an object, or make a gesture or sign (Freeman, 1985; McInnes & Treffry, 1982). This "hand-over-hand" strategy should be used only when necessary and with sensitivity to the child's reactions. Some children dislike having their hands manipulated and feel threatened by the lack of control. Others become passive and prompt-dependent. They learn to wait for an adult's hand on their own as a prompt to initiate an action (Downing, 1999; Miles, 1998). However, hand-over-hand guidance may be an essential strategy for children who have severe physical disabilities because they often need assistance to manipulate and explore objects.

**Hand-under-hand guidance**. This is an alternative to hand-over-hand guidance. Using this method, an adult places his or her hand slightly under the child's as they explore objects together (Dote-Kwan & Chen, 1999; MacFarland, 1995; Miles, 1998). The adult may also gently rest a hand underneath the child's and wait for the child to initiate an interaction. One strategy for introducing unfamiliar objects using the hand-under-hand method involves placing the child's hand on top of the adult's hand while the adult grasps an object. The adult then slowly rotates his or her hand so that the child is gradually introduced to the shape of the object. Another strategy involves gradually withdrawing the adult hand until the child's fingers touch the surface of the object or texture being explored (Dote-Kwan & Chen, 1999). In order for hand-under-hand strategies to be effective, the child must be willing and able to keep his or her hand on top of the adult's hand.

**Adapted signs**. Adapted signs are tactile adaptations of visually-based manual signs (Chen, 1995). Adaptations involve how the sign is made (hand shape, orientation of the hands in relationship to the body, movement of the hands from one point to another, and area of the body where the sign is produced) and received by a child who is deaf-blind. This is a developing area of knowledge and the terminology can be confusing. Some methods of adapting signs include the following:

- ◇ *Tactile signing*. The receiver places his or her hands on the signer's hands in order to perceive the signs (Reed, Delhorne, Durlach, & Fisher, 1995). This is a hand-under-hand method. It is also called interactive signing (Alsop, 1993; Watkins & Clark, 1991). Tactile or interactive signing provides a means of communication input (receptive communication) for the child who is deaf-blind.
- ◇ *Coactive signing*. A type of adapted signing in which an adult physically guides the child to produce signs using a hand-over-hand method (Watkins & Clark, 1991). This is a means of communication output (expressive communication).

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- *Body signing*. The signer produces signs on areas of the child's body other than the hands (Joint, 1998). For example, the sign for EAT may be placed against the lips. Body signs are based on manual signs that are symbols or words. The child may perceive the sign as a touch cue, however, and not recognize a particular sign as a word.
- *Key word signing*. The use of selected signs (e.g., nouns and verbs) to communicate main ideas or messages (Chen, 1999). Many children who are deaf-blind with additional disabilities have very short attention spans and limited communication. The majority of hearing adults who communicate with them are usually limited in their sign language skills unless they have a background in deafness. For these reasons, most children who are deaf-blind who have additional disabilities are exposed to key word signs rather than to American Sign Language (with its own grammar) or manually coded English (uses English syntax). For example, WANT PLAY are key word signs for "Do you want to play?"

A common terminology and systematic study of the methods used to adapt manual signs for children who are deaf-blind is needed. Questions that need to be answered include: How should manual signs be adapted to encourage receptive and expressive communication? What criteria should guide decision-making when considering whether adapted signs are an effective communication option for a particular child?

**Tactile representation**. Tactile representations must make sense to a child in order to convey meaning (Downing & Eichinger, 1990; Rowland & Schweigert, 1998). For example, using a toy car to represent "going for a ride in a car" may be completely nonsensical from a child's tactile point of view. A seatbelt may be a more meaningful association based on the child's experience. Adults should think from a tactile rather than a visual perspective when selecting tactile representations.

**Touch cues**. Touch cues or tactile signals are an important communication strategy to use with young children who are deaf-blind during the early stages of communication development (Klein, Chen, & Haney, 2000; Rowland, Schweigert, & Prickett, 1995). The intended meaning of a touch cue is derived from the specific context and situation. The use of touch cues should be consistent. A child will not be able to decipher the meaning of a touch cue if different people use it for a variety of messages. For example, patting or tapping a child on the shoulder may express any of the following:

- positive feedback ("Great job")
- a request or directive ("Sit down")
- information ("Your turn")
- comfort or reassurance ("Don't cry, you're OK")

A child will not be able to discriminate the meaning of a touch cue if there is competing tactile input or if he or she does not like being touched. For example, touching a child's lips while patting his or her hand is confusing if the message is " here is your drink." Touch cues should be used selectively, conservatively, and consistently so that the child can develop an understanding of what they represent. Our literature review and focus group discussion raised a number of questions regarding touch cues. What is the difference between a touch cue and an object cue from the child's perspective? Is touching the child with the nipple of a bottle a "touch cue" or an "object cue" if what the child's perceives is pressure on the lip? What is the difference between a "touch cue" and a "body sign" from the child's perspective? Is making the sign for CANDY on the child's cheek a "body sign" or a "touch cue" if what the child perceives is pressure on the cheek? How should touch cues or body signs be made (place on the child's body, type, and duration of touch) to help the child associate a cue with its meaning?

**Object cues**. Object cues are objects or parts of objects used in activities or associated with a particular person. They are used to give information, make requests, and provide feedback. Initially object cues should be used during activities and selected so that the child can easily make an association between an object and the activity it represents (Chen, 1995; Rowland, Schweigert & Prickett, 1995). For example, a small cardboard container of juice may be used to represent "time for snack." As the child learns to associate an object with an activity, object cues can become smaller and more abstract. An object other than the one used in the activity (e.g., an empty juice container), a piece of the object (e.g., lid of the container), a partial representation of the object (e.g., piece of cardboard), an associated object (e.g., a straw), or a model of the object (e.g., a miniature juice box) may be used instead.

Object cues are meaningful only if the child can recognize what they represent. For example, miniatures usually provide visual representations that cannot be seen by a blind child. In addition, very small objects provide limited tactile information and may be more difficult for a child who has a physical disability such as cerebral palsy to handle and explore. Sometimes arbitrary object cues are used if there is no logical object related to a specific activity. For example, if a child changes from one classroom to another every day, a piece of felt on the classroom door may be used as an arbitrary object cue. With experience, the child learns to associate the piece of felt as a landmark for that particular classroom (Rowland, Schweigert & Prickett, 1995).

Essential considerations in selecting object symbols or tangible symbols (Murray-Branch & Bailey, 1998) include the following:

- ◇ Tactile saliency (ease of recognition)
- ◇ Types of objects preferred by the child (encourages exploration)
- ◇ Whether the objects or tangible symbols can be reduced in size so that they are portable and can be used in a variety of settings
- ◇ How easily the object or texture can be discriminated from others used in a group of tangible symbols

Textured materials such as sandpaper or bubblewrap, are often used as abstract tangible symbols to promote communication with nonverbal children and adults who are blind or deaf-blind (Murray-Branch & Bailey, 1998; Rowland, Schweigert, & Prickett, 1995). These tangible symbols are used on communication boards to give information, elicit requests, and provide choice making opportunities. Selection of materials is typically based on the saliency of tactile characteristics. Little is known about effective strategies for assisting a child who is deaf-blind with additional disabilities to associate meaning with abstract tactile symbols.

## Focus Group Findings: Current Practices and Issues

Four focus group meetings were conducted in California. The 33 participants included English-speaking and Spanish-speaking family members and service providers (both English-speaking and bilingual) of children who were deaf-blind or blind with additional disabilities. Although SALUTE focuses on children who are deaf-blind with additional disabilities, we also wanted to learn from individuals who interact with children who are totally blind and have cognitive or physical disabilities.

Participants were asked to identify the tactile strategies that they use and to discuss their successes, challenges, and needs. Many of the strategies and issues identified by the literature review were also raised during the focus group meetings. In addition, the participants shared their own experiences and suggestions for enhancing tactile methods of teaching and communication. They also identified areas where more information, guidance, and clarity regarding this topic are needed.

**Individualized approach.** Each child who is deaf-blind has unique needs and preferences. Participants stressed the importance of using an individualized approach when determining the best teaching practices and when selecting specific activities and materials. Several reported that children preferred tactile input that had a functional purpose, a simple design, and a concrete form (e.g., a wooden box with a lid or uncooked beans). Many reported that in general, their children tended to dislike tactile input that was unpredictable, indistinct, complex in form, light, sticky or that was extreme in temperature or texture (e.g., sand, feather dusters, water paint). On the other hand, a few indicated that their children liked to handle these types of materials. Overall, participants said that they used a trial and error approach to determine what works best for a particular child. They identified a need for the development of guidelines and other tools to help them determine effective tactile strategies.

**Meaningful instruction.** The importance of meaningful instruction emerged as another overriding theme. Participants felt that children who are deaf-blind learn most effectively when instruction occurs within familiar routines, activities, and environments. The use of real items that have a useful purpose instead of fabricated or artificial ones (e.g., a real orange rather than a plastic one) was mentioned repeatedly as essential for enhancing concept and language development.

**Supportive and positive instruction.** The importance of using a very positive and respectful approach when interacting with children who are deaf-blind was also emphasized. Participants felt that children should not be forced to manipulate objects or engage in other tactile learning activities. They should be approached with sensitivity and given ample time to receive tactile information. Repeated use of words such as "rapport building" and "non-intrusive" underscored the importance of this approach.

Awareness of what motivates a child and how to pair that motivation with an unfamiliar tactile item was identified as an effective strategy. For example, some children are motivated by an activity such as music or movement, in which the tactile exploration of objects could be encouraged. Preschoolers who have some hearing and enjoy music may cooperate with handling playdough if the adult sings "This is the way we roll the playdough, roll the playdough, roll the playdough . . . " Consideration regarding the type of touch and where on the body the child likes to receive tactile information was also stressed. Instead of demanding that a child hold and examine an item, participants felt that they should follow the child's lead, offer opportunities for the child to come into contact with materials, and invite the child to handle items in shared activities.

**Systematic instruction.** Participants stressed the importance of routines and repetition to support learning. Consistency in the presentation of information across different settings (e.g., both at home and at school) enable children to generalize concepts and skills. They seem to better understand activities that have a clearly marked beginning, middle, and end. Participants also indicated that the use of instructional prompts (e.g., holding the child by the wrist to encourage exploration of an object) and cues (e.g., touching the child's hand with an object) help children use tactile strategies. Prompts should be withdrawn gradually as the child learns to respond to natural cues.

**Adapting from the visual to the tactile mode.** Despite their acknowledged expertise, comments from most participants suggested that adapting visual materials is very challenging. It is difficult to convey adequate information about many concepts or objects through tactile adaptations alone. For example, information about objects that are very large (e.g., a car) or very small (e.g., an ant) or that move quickly (e.g., a bird flying), require explanation. Participants indicated that in these cases they provided a spoken or signed explanation about the tactile adaptation to the child.

Concepts that are easy to understand when seen, such as identifying facial expressions or recognizing feelings, are much more difficult to recognize through touch. The imitation of physical actions is another visually-based learning strategy that is difficult to adapt to a tactile mode. Typical tactile adaptations in these situations are to guide the child through specific actions or movements (hand-over-hand guidance) or to let the child feel another person's movements or actions (hand-under-hand guidance). At best, these strategies provide tactile modeling or demonstration. Imitation requires that the child use tactile information to mimic what he or she has experienced.

Although tactile learning often refers to the use of one's hands to learn, focus group participants viewed this as a very narrow interpretation. They advocated an expanded definition to include the use of the feet, chest, stomach, face, and the whole body in addition to hand use. While this may be particularly critical for children with significant limitations in hand use, participants also indicated that learning through other body parts was helpful for children whose hands were hypersensitive to tactile input.

**Confusing terminology.** Throughout the focus group meetings, participants used many different terms to describe tactile strategies. Some terms such as tactile signals, touch cues, motoring, physical prompting, and tactile signing were defined in different ways. This variety and confusion in terminology also emerged from the literature review. For example, as broadly defined by Rowland and Schweigert (2000) the term "tangible symbols" includes both two- and three-dimensional symbols (pictures, textures, and objects). However, in the traditional augmentative and alternative communication literature, "tangible symbols" are restricted to those symbols that can be discriminated on the basis of shape, texture, or other tangible properties; therefore excluding pictures and other two-dimensional symbols (Beukelman & Mirenda,1998; Downing, 1999). The use of vocabulary from multiple disciplines has produced similar terms with different meanings and multiple terms with similar meanings. This is an area where standardization is needed.

## Conclusion

Our review of the literature and comments from focus group participants have raised complicated questions regarding the use of touch with children who are deaf-blind. In the next three years, SALUTE will address these questions through the systematic use of individualized tactile learning strategies with children who are deaf-blind and have additional disabilities. We would like to invite readers to share their questions, concerns, and resources related to the use of tactile strategies with children who are deaf-blind.

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## Project Information

Working with a National Advisory Committee, focus groups and selected children in California, Project SALUTE staff will identify, develop, document, and validate tactile learning strategies for children, infants through elementary school age. One focus group was conducted with Spanish-speaking families in order to produce materials that are culturally responsive. Materials will include a manual and videos (closed captioned and in English) demonstrating activities in both home and school environments. The video of home activities will also be in Spanish. Project SALUTE is a model demonstration project funded by the U.S. Department of Education grant #H324T990025 to California State University, Northridge.

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## Web Site for Post-Secondary Deaf-Blind Students

*http://www.peersupportdb.com*
This is a resource for students who are deaf-blind attending post-secondary institutions, such as colleges, universities or technical schools. It is primarily intended for students in British Columbia, Canada, but contains information that may be of use to others as well, including causes and types of deaf-blindness, how to access post-secondary services, funding, an overview of resources, and using adaptive technology.

## Research-to-Practice

# Parents Use a Research Technique to Help Their Children with Cortical Visual Impairments

Karen Goehl
Georgia Hambrecht

In the truest sense of the idea of "research-to-practice," the Indiana Deafblind Services Project developed and co-sponsored a program to train parents to use a single-subject research design to improve specific skills of their children with cortical visual impairments (CVI). The single-subject design is a research method well known to behavioral scientists and clinicians. It is used to examine a specific behavior of an individual (the "subject"), introduce some form of intervention, and evaluate any resulting change in behavior. This design is often used in situations where it is important to reduce or eliminate behaviors that interfere with a student's ability to function, such as self-stimulation or hitting others. Alternatively, it may be used to increase desired or useful behaviors such as paying attention to tasks or participation in social activities.

There are several different types of single subject designs. One common type, applied behavior analysis, begins with taking baseline measures. A baseline is the frequency (e.g., number of times in a day) or intensity that a target behavior (e.g., tantrums) occurs prior to any intervention. An intervention strategy (e.g., communication training) is then implemented. Target behaviors continue to be charted on graphs during and after the period of intervention. The graphs depicting behavior change are reviewed to determine whether a change occurred due to the introduction or withdrawal of the intervention strategy.

Sixteen families (28 family members) participated in the Indiana project. All had children with CVI who were six years old or younger. Eight of the families had deaf-blind children. The family members attended a workshop where they learned about new strategies to promote the development of functional vision that are proving to be effective when used with infants and toddlers who are visually impaired. Family members were also taught to use a formal process to select and apply these strategies to help their children acquire specific skills and behaviors. Essentially, the families learned to become active participants with research teams.

Several weeks prior to the workshop, eight education professionals received training as facilitators. The role of each facilitator was to help family members take their ideas and turn them into doable single-subject studies. They helped each family interpret technical language, go through the process of designing a study, develop an intervention, understand how to observe their children's behaviors, and develop a method to collect and record data.

Facilitator training was conducted by Georgia Hambrecht of the Department of Communication Disorders and Special Education at Indiana State University, and Karen Goehl, Project Director of the Indiana Deafblind Services Project. They reviewed several topics with the facilitators including single-subject research designs, data collection methods, and strategies for encouraging use of functional vision in young children with CVI.

During parent training, the 16 families were divided into 8 groups (2 families per group). Each was assigned to one of the facilitators. Most of the families were accompanied by one or more of the service providers who worked with them (e.g., developmental therapist, occupational therapist, speech therapist). Parents were guided through a specific process that began with describing their children's vision and hearing abilities, and concluded with a description of their baseline and training procedures.

Each family submitted a completed research design by the end of the workshop. Parents and family members determined which behaviors of the child were important to focus on (e.g., visual tracking, reaching, lifting head, scanning objects, attending to other people), and specific tips or procedures to use at home to help improve or change the behaviors. Family members had to describe how they would record the targeted behaviors, and what form of data (percentages, rates) they would use to examine changes over time. *(See next page for an example of a design created by one family—the child's name and other identifying information have been changed).* The families then used specific data reporting forms to chart their children's progress.

Family-centered programs such as this one give parents and care providers a sense of control and involvement, realistic expectations, and the direct experience of shared success. This project provides an example of a commitment to empower families by giving them access to tried-and-true methods to promote skill development in their own children. The Indiana Deafblind Services Project is continuing to gather data that family members submit about their progress. For additional information, contact Karen Goehl at 800-622-3035.

## Cortical Visual Impairment: Linking Information to Strategies

### To Do Form

**Name of Child:** *Kevin*

**Age of child:** *2 years 6 months*

1. **Write a brief description of your child's vision and hearing abilities.**
   - ◇ **Vision:** *Light sensitive, more in left eye; seems to turn to light, no tracking, no functional vision. Right eye too damaged.*
   - ◇ **Hearing:** *Mild loss left, moderate right. He can localize; discriminates words, voice discrimination.*
2. **Expand the definition of the behavior you wish to change.**
   - ◇ **Behavior:** *Roll to favorite toy (Elmo toy squeaky worm) and reach for it.*
   - ◇ **Definitions:** *The caregiver will be 3-5 ft. from Kevin and the toy will be presented visually & auditorily and with verbal encouragement; with tactile cue/sign.*
   - ◇ **Example:** *Kevin will roll to the toy when it is presented visually and auditorily and with verbal encouragement and he will reach for it.*
   - ◇ **Iffy instances:** *Auditorily or visually attends, or complains without moving toward the toy; rolls in wrong direction.*
3. **Write the three "tips" you are considering.**
   - ◇ *Facilitate graduated steps through the activity.*
   - ◇ *Use song/exaggerated intonation when we describe his act.*
   - ◇ *Allow him time to process auditory information.*
4. **Write the one "tip" you want to try.**

   *Sing command to London Bridge Tune, "You are rolling to the toy."*
5. **What are some reasons (examples or facts) why you picked that "tip"?**

   *He loves music.*
6. **Write your "Best Guess" idea. (Start with a general "Best Guess" idea in the following form: If I use (tip) then (child's name) will (behavior).**

   *If we use this individualized song, Kevin will localize and roll & reach for the toy/person.*
7. **Decide how you will count the behavior.**

   *Rolls to toy and reaches for it (3-5 ft).*
8. **Select the data form (percentage, duration, rate).**

   *Percentage.*
9. **Describe in detail how you will implement your "Best Guess" idea (who, what, when).**

10. **Describe your procedure for Baseline and Training including time for each (number of days you plan to do "old way" and with new "tip").**
    - ◇ **Baseline** *3 consecutive days – lay him down, squeak toy 3 ft away and observe response.*
    - ◇ **Training**
11. **Identify who will be responsible for sending the data to the Deafblind Project.**

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# DB - LINK

## A Special Library

Gail Leslie
Peggy Malloy

*Susan is a special education teacher. In two weeks, a 5-year old deaf-blind boy will be enrolled in her class. She has never worked with a deaf-blind child before. She is anxious to learn as much as she can about deaf-blindness and teaching strategies for this student.*

*David is 17 and has Usher syndrome. He is planning to go to college and needs information about how to make sure the school he attends is able to meet his needs.*

*Annette and Robert are the parents of a 3-month old son, Danny. Danny was born prematurely and has severe vision and hearing loss. They want to make sure that Danny gets the best possible education and know how important it is to start early. They need information about early learning and communication.*

*Jennifer is a graduate student. She is writing a research paper about the impact of deaf-blindness on learning. She needs help locating what has been written on this subject.*

These examples show the range of information requests that DB-LINK staff receive on a typical day. When the federal government launched plans for a clearinghouse specific to deaf-blindness in 1992, its intent was to make information about this disability widely available. Today, DB-LINK responds to requests from people throughout the United States and is nationally recognized as the central source for the collection and distribution of information about deaf-blindness.

Two aspects of information management have been essential to our success. First, DB-LINK was designed to combine features of both clearinghouses and libraries to create a service that makes us unique among information providers. Second, we were fortunate that our development occurred at the same time that information technology was expanding. This made it possible for us to take full advantage of computers and the Internet.

### Clearinghouse/Library Design

A clearinghouse is an information center that traditionally functions by making general information about a specific topic available to anyone. Clearinghouses usually maintain a small selection of publications and resource lists, and are often expert at providing their customers with referrals to meet more specific needs. As a clearinghouse DB-LINK has developed topical publications that meet the general needs of our customers and we maintain information about a network of service providers for referral. These include agencies, support groups, schools, and consultants. We have also developed a level of service and a focused, deep collection of materials that is not typical of most clearinghouses. In this way, DB-LINK functions more as a special library.

A special library is a library that has a unique focus and develops a comprehensive, in-depth collection of materials about a specific topic. Special libraries are found in government agencies, private companies, museums, hospitals, and other similar organizations. The mission of a special library is to organize and manage a body of information not readily available anywhere else or to meet the needs of a particular group of people.

Prior to the establishment of DB-LINK, it was hard to find in-depth information about deaf-blindness. State deaf-blind projects had small resource libraries, but they were not comprehensive or widely available to parents and teachers. Because deaf-blindness occurs in a small number of people, it is a topic rarely included with the education or disability information found in most libraries. Before DB-LINK, much of what was written about educational methods and research in the field had no visible network for distribution. For these reasons, it was important that DB-LINK comprehensively collect all available useful information about deaf-blindness and make it easily accessible.

Currently, our library includes books, articles, videos, newsletters, conference proceedings, research findings, and catalogs. By using such standard library practices as collection development, database creation, centralization of resources, and reference service, DB-LINK has created greater visibility and accessibility for information about deaf-blindness. We also collect information from other subject areas that deepen our ability to support the specific informational needs of our customers. Topics in these areas include special education, disability law, medicine, assistive technology, and funding opportunities.

Most important to our customers, is the responsive nature of our service. DB-LINK information specialists research and deliver specific responses to questions. We provide articles, resource and curricula lists, and locate information online. Our customers include parents, deaf-blind individuals, teachers, researchers, IEP teams, and technical assistance providers. We support families and teachers with information that can make a difference for their child or student. Our ability to respond uniquely to each request makes it possible for anyone, regardless of geographic location, to access our library.

### The Influence of Technology

Emerging technologies have allowed us to format information and provide a range of services that were not even a twinkle in the federal government's eye when they initially planned this project. We were fortunate to begin in 1992, when few people were anticipating the information explosion that would follow in the next few years. As we developed, the fact that we were unburdened by a history of established practices made it very easy to take advantage of computers and advancing technologies.

Timing, knowledgeable staff, and supportive institutions have been key to integrating our use of technology, affording us the opportunity to move information into the hands of a much wider community of users. Our web site offers full access to our databases and publications, and current information about research projects, training opportunities, and conferences. It also provides a starting point for locating additional information on the web. Familiarity with computers and the Internet is not necessary to access DB-LINK, however. The majority of our customers still contact us by phone.

DB-LINK also uses technology to manage a variety of e-mail discussion groups. These give families, professionals, and consumers an opportunity to exchange personal experience and knowledge via e-mail.

Additionally, technology has made it possible for DB-LINK to operate as a consortium. Three primary agencies work together on DB-LINK: Teaching Research at Western Oregon University, Perkins School for the Blind, and the Helen Keller National Center. Electronic databases, a rotating 800 telephone number, and the ability to move large amounts of information via the Internet has made it possible for us to remain geographically separate, yet provide unified service delivery.

Technology has helped to create a network that extends the impact of information and is transforming the field of deaf-blindness. DB-LINK is now part of a community that is developing information resources and increasing awareness about deaf-blindness throughout the world.

### What You Can Do

At DB-LINK, we collect information in a variety of ways. We subscribe to journals and newsletters. We attend conferences and collect proceedings. We search online databases and the Internet. We collect information produced by research projects and state deaf-blind projects. At every step of the way, your partnership is critical to our mission to provide service and access to quality information. You can help. Send us notices or copies of new products such as books, articles, manuals, and videos, so that we can add these to our collection and publicize their availability. Send us materials you develop for training programs or conferences. If you run support groups or work for schools, agencies or organizations that provide services to deaf-blind individuals, help us keep our resource database up-to-date. Call us or check the resource database on our web site to see if your organization is currently listed and the information is accurate. Contact us if you have expertise in deaf-blindness and are interested in being listed as a consultant in our database.

Think of us as your special library and spread the word about DB-LINK. Let families, teachers and other people who work with deaf-blind children and youth know that we are available by phone, TTY, e-mail, fax, and on the web, to assist in meeting their information needs. Tel: 800-438-9376,
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## Personal Perspectives

Peggy Malloy

With this issue of *Deaf-Blind Perspectives* we begin what will hopefully be an ongoing column about deaf-blind people, their families, friends, and the people who work with them. In each column we will profile one to two individuals to find out about their lives, their work, and what they think is important for the field of deaf-blindness. The purpose is to give readers an opportunity to learn more about each other and to give individuals an opportunity to share their personal views about deaf-blindness. I want to thank Barbara McLetchie at Boston College for suggesting this idea. For this first column, I talked to Barbara Miles, a private consultant who specializes in communication issues, and Janie Neal, a private consultant, teacher, and speaker in Seattle.

### Barbara Miles

Through her work as a consultant, teacher, and writer, Barbara Miles helps deaf-blind children learn and communicate by teaching their parents, teachers, and other professionals effective teaching methods. As a private consultant with expertise in communication issues, she provides training about individual deaf-blind children to teachers and parents. Her goal is to inspire the people that she works with and give them perspective on their teaching methods. She sees her role as supportive and says that the real heroes are the parents, and the teachers who work directly with deaf-blind children. Barbara also does presentations at conferences and workshops and works for the Hilton/Perkins Program in Asia (mainly Indonesia and Malaysia) and Latin America, helping to establish classrooms for deaf-blind children.

Prior to starting her consulting business, Barbara was a teacher of deaf-blind children at Perkins School for the Blind. She developed an interest in deaf-blindness when working as a volunteer at a school for disabled children in Rutland, Vermont. She was fascinated by the challenge of making genuine contact with deaf-blind children and found that she needed to learn to experience the world differently in order to communicate with them. This experience inspired her to obtain a master's degree in deaf-blind education at Boston College.

Barbara told me that her work is very important to her because she believes that deaf-blind children have important things to teach us about ourselves. She said that deaf-blind children, "Teach me to value every person, to slow down, to notice really small things, to pay attention to my hands and their hands, to value nonverbal communication, to be aware of the miracle of language, and to not pity myself." She quoted Martin Prechtel, a Mayan teacher, who spoke at a workshop she recently attended. He said, "If you want to be blessed, you should go to a person in the society who is shunned or discounted and ask them to bless you." Barbara says that every time she meets a person who is deaf-blind, she receives a blessing.

Barbara is a wonderful writer. She has written three fact sheets for DB-LINK: *Overview of Deaf-Blindness*, *Talking the Language of the Hands to the Hands*, and most recently, *Literacy for Persons who are Deaf-Blind*. She said that writing *Talking the Language of the Hands to the Hands*, about how deaf-blind children learn about the world and communicate with their hands, was particularly important to her. It gave her an opportunity to express her feeling that hand-over-hand teaching techniques don't work. She believes that controlling children's hands is not helpful. Writing the fact sheet gave her an opportunity to think and write about alternative teaching methods. Along with Marianne Riggio, Barbara also edited and contributed to a book called *Remarkable Conversations: A Guide to Developing Meaningful Communication with Children and Young Adults who are Deafblind*, published in 1999. She is grateful to have had the opportunity to work with Marianne on the book. She also wanted to mention that she is also grateful for the influence of Sara Gaar who first made her aware of the importance of genuine conversations with deaf-blind children.

When asked how educational and other services for deaf-blind children and adults could be improved, Barbara said that as a society we need to show that we value deaf-blind children. One way to do this is to start paying teachers, paraprofessionals, and all other service providers excellent salaries. Good support services for parents, families, and teachers are also important. Additionally, professionals must really listen to deaf-blind people, ask them again and again what they need, and question assumptions that professionals know what is best for deaf-blind people.

Barbara has a dog named Rosie who has been with her to many important deaf-blind events. Barbara wanted to take this opportunity to say thanks to Rosie, Uncle Steve, Marianne, and all of Rosie's friends in the deaf-blind community. She says that the community of deaf-blind people and the people who work with and for deaf-blind people is really amazing and she feels fortunate to have met so many wonderful people.

### Janie Neal

Janie Neal, a consultant, teacher, and speaker, has been incredibly active in raising awareness about deaf-blindness and improving services for deaf-blind people. She was diagnosed with Usher Syndrome Type 1 when she was 13 years old (six of her cousins also have Usher 1). She attended the Tennessee School for the Deaf and then went on to receive a bachelor's degree in psychology from Gallaudet University and a master's degree in special education from Georgia State University.

In the past, Janie worked as a teacher for deaf children. More recently, her efforts have focused on deaf-blind issues. She has taught workshops at schools, colleges, and conferences about communication methods and adaptive equipment used by deaf-blind people and has spoken to interpreting students about deaf-blind interpreting. She also consults with agencies that need information about deaf-blindness and provides peer support to other people with Usher syndrome. She has worked as a vocational rehabilitation teacher, was Project Coordinator for a Seattle Deaf-Blind Service Center recreation and leisure project, and twice served as Director for the Seattle Lighthouse for the Blind annual Deaf-Blind Retreat. She currently serves on the board of the American Association for the

Deaf-Blind and is a member of numerous committees for agencies such as Seattle Deaf-Blind Service Center, King County Sound Transit, and Helen Keller National Center. She is a past president (two terms) of Washington State Deaf-Blind Citizens.

Janie believes that deaf-blind adults can serve as role models for deaf-blind children and that it is very important for deaf-blind children to be in contact with deaf-blind adults on a regular basis. Parents of deaf-blind children can also benefit from socializing with deaf-blind adults. She also has a number of suggestions for improving education for deaf-blind children. She suggests hiring deaf-blind adults familiar with educational objectives as consultants to assist with Individualized Education Program (IEP) development for deaf-blind children. She advocates the use of intervenors and/or support service providers beginning early in life to help deaf-blind children develop their potential to the fullest. She encourages parents to explore the use of all types of communication including sign language (visual and tactile) to communicate with their children.

Janie says that she uses humor to deal with the minor and major challenges that deaf-blind people face every day when encountering things that other people take for granted. She believes that it is important to enjoy your life to the fullest and never lose your sense of humor.

* * *

NTAC

## NTAC Parent and Family Activities

Kathy McNulty
NTAC Associate Director

One of the main objectives of NTAC (The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind) is to provide technical assistance to parents and families. During the past 4 years of our current 5 year funding cycle, this objective has been met in several ways: an annual national parent workshop in collaboration with the National Family Association for Deaf-Blind (NFADB), cooperative work with key groups and agencies on activities that provide parent and family related technical assistance in specific states, and production of resource materials designed by and for parents and family members.

With the requirements set by the Individuals with Disabilities Education Act (IDEA'97) regarding parent/family participation in all aspects of the education of children who have disabilities, the year 2000 found NTAC searching for ways to maximize and expand its parent/family technical assistance activities. This article summarizes these efforts and hopefully captures our strong commitment to working with and for families of deaf-blind children and youth.

### Workshops

NTAC supported three family-focused workshops in 2000. The first, *Family Specialists: Self-Discovery - Impact on Families*, was held June 24-25, in Minneapolis. This workshop, jointly sponsored by the Hilton-Perkins National Program and NTAC, was designed for family specialists who work for state deaf-blind projects and the 10 Regional Directors of NFADB. The Regional Directors are parents who sit on the NFADB board and are responsible for working with families and parent organizations in their assigned regions. The primary planners and presenters of the conference were Marlyn Minkin (deaf-blind consultant), Cathy Kirscher (Helen Keller National Center Regional Representative), Nancy O'Donnell (Helen Keller National Center), and Steve Perreault (Hilton-Perkins). The goal was to help each participant gain knowledge and awareness of conflict resolution strategies and greater understanding of the interrelatedness of power and position in relationships. Viewed as a follow-up to a family specialist workshop offered in 1997, it helped to enhance and strengthen an emerging network among the participants.

The second workshop, *Negotiating the Maze: Strategies for Effective Family Technical Assistance*, also in Minneapolis, was held June 26-27. The need for this workshop, attended by professionals from state deaf-blind projects throughout the United States, was identified by a survey of state project personnel earlier in the year. The program agenda included a strong blend of related topics that artfully combined the academic and human aspects involved in delivering technical assistance to families. Gwen Beegle (Beech Center, University of Kansas) spoke about how to translate current research on parent and family issues into effective practice. Kate Moss (Texas Deaf-Blind Outreach Project), Kathy McNulty (NTAC), and Sally Prouty (Minnesota Deafblind Project) gave a presentation on the who, what, where, when, and how of providing technical assistance to parents and families. Minnesotan parents Susan Smith, Liz McDevitt, Karen Wojcik, and Sally Prouty, and Arizona parent, Kim Lauger, participated in a panel presentation on parent perspectives. Gwen Whiting, family trainer and mental health consultant, spoke about grief and how to maintain both professional and personal balance when working with families.

The third workshop, *Transitions - They Happen All the Time*, held August 10-12 in Salt Lake City, was co-sponsored by NTAC and NFADB. The topic, transition planning, was chosen based on the results of a national parent/family interest survey conducted by NTAC during the winter of 2000. The term transition is most often associated with young adults preparing to leave school, but NTAC and NFADB recognized that there are additional, equally important stages of transition. We designed a workshop to address different types of transitions throughout the educational years of children with deaf-blindness. The agenda focused on: issues that arise and stresses that may be experienced during any time of transition, strategies to alleviate stress and conflict, IDEA and effective transition practices for different age groups, and resources and services needed for a successful transition. To make the workshop more meaningful for parents, participants were divided into groups according to the age of their child: Early Intervention to Early Childhood, Early Childhood to School Age, School Age to Secondary, and Secondary to Adult Life.

To help offer training on transitions across a variety age ranges, we assembled what we considered the "dream team of presenters:" Marlyn Minkin, a deaf-blind consultant on mental health issues; Dr. Gene Edgar, a consultant on transition and special education and a professor at the University of Washington; Linda Alsop, an early childhood consultant from the Ski-Hi project at Utah State University; Sue Olsen, an early intervention specialist in Utah; David Wiley, a transition specialist with the Texas Deaf-Blind Outreach Project; and Dr. Jennifer Grisham-Brown, a consultant on alternate assessment and functional curriculum for students who are deaf-blind, and a professor at the University of Kentucky.

The results of the workshop were extremely gratifying. Nearly 100 parents from over thirty states and staff from twelve state deaf-blind projects attended. Networking among parents began almost immediately and, with the knowledge and guidance provided by the excellent presentations, action plans were developed by each parent before leaving for home. As one parent wrote on an evaluation form, "I loved the networking with other parents! I learned so much. I can hardly wait to take it back to my state."

## State-Specific Technical Assistance

In addition to conducting workshops during the past year, NTAC has also worked cooperatively with people involved in deaf-blind education in numerous states to provide parent/family related technical assistance. This included such activities as working with parent/family organizations, helping individual state deaf-blind projects provide effective family technical assistance, and encouraging the inclusion of parents in state-wide training events that involve NTAC participation.

## Resource Materials

NTAC has developed a number of resource and training products during the past year. Two were specifically designed by and for parents and families, *Communication at Home and in the Community: Helpful Strategies and Suggestions from Parents and Families with a Child who is Deaf-Blind* and *Transition Tool Kit for Parents.*

## Future Activities

As NTAC moves into the fifth and final year of the current funding cycle, new activities under the parent objective are already under way. Work within individual states will continue and it is anticipated that a workshop for new family specialists will be offered. A set of communication fact sheets for parents and a fact sheet on family issues are in progress and scheduled for distribution this year. And last, but not least, something new and exciting is being planned for the National Parent Workshop in 2001. On August 2-4 in Miami, Florida, NTAC, NFADB, and the Hilton-Perkins International Program will host an International Parent/Family Workshop. Thirty parents from Latin America will join parents from across the United States to share their experiences of parenting and educating a child who is deaf-blind. As always, this coming year will find NTAC continuing its efforts to provide technical assistance to parents and families.

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**Looking for information about conferences?** We ran out of room in this issue. Please contact DBLINK for a current listing. Tel. 800-438-9376, TTY 800-854-7013, dblink@tr.wou.edu, or go to http://www.tr.wou.edu/dblink/data

# Book Review

Charlotte Cushman, M.Ed.
Catholic Charities Maine/New England Center
Deafblind Project

**Creative Constructions: Technologies that Make Adaptive Design Accessible, Affordable, Inclusive and Fun.** *Molly Campbell and Alex Truesdell, 2000.*

"Think creatively. Plan collaboratively. Build economically." That's the philosophy of the authors of *Creative Constructions*, a new book that offers a wealth of practical information about creating adaptive materials and equipment for individuals who have special needs. This helpful book is a resource for therapists, teachers, parents, and others looking for light technology options to solve problems or create opportunities for individuals who have disabilities. The authors share their views about working as members of a team, assessing assistive technology needs, and establishing adaptive design workspaces. The materials and techniques used to make customized assistive devices are described in a clear, straightforward manner. Topics include cardboard carpentry, paper-based technology, woodworking, fabric and foam use, plastic construction, and basic electronics. Examples of successful projects from their personal experiences are included to stimulate the reader's own creative ideas.

Alex Truesdell and Molly Campbell have extensive experience in the field of adaptive design. Both have worked as coordinators of the Adaptive Device Center at Perkins School for the Blind in Watertown, Massachusetts. Each brings a different perspective to their work. Alex is an education consultant specializing in teaching adaptive design. Molly is an occupational therapist with extensive experience in pediatrics, developmental disabilities, and adaptive design. They have taught workshops on the basic techniques of adaptive design around the United States and abroad.

*Creative Constructions* contains something for everyone. Educators and speech therapists will be interested to find information about tangible symbol cards based on the ideas of Dr. Jan van Dijk and the tangible symbol systems he developed for deafblind children in the 1960s. The purpose and function of tangible symbol cards are included as well as specific directions on how to make them.

There are numerous ideas for seating and positioning equipment that physical and occupational therapists will welcome, such as step-by-step instructions for building a corner chair. There are suggestions for sensory motor equipment including sensory exploration boards and weighted blankets. Orientation and mobility instructors will find directions for making the Connecticut pre-cane. A range of activity centers are described, using many different types of materials. The authors outline some of the therapeutic benefits students gain from inviting and stimulating environments.

One of the greatest qualities of *Creative Constructions* is a friendly and approachable style that makes it easy to use. It is full of clear line drawings, lists of suggested tools and equipment, and photographs of materials and projects. The tone is inviting. It empowers the reader with a "can do" attitude. This book is equally valuable to novices needing gentle encouragement and to more experienced readers needing a quick review or suggested resources.

*Creative Constructions* is a practical, straightforward resource book that is a must for anyone looking for creative, low-cost ways to design and make customized materials for individuals with disabilities. It is a welcome addition to the field and highly recommended for anyone with an interest in adaptive design.

*Creative Constructions* is available for $24.95, plus $5.00 shipping and handling for one book and $2.00 for each additional book. Make checks payable to Molly Campbell.
Creative Constructions
659 Green Street
Cambridge, MA 02139
617-972-7520
mollycampbell@mediaone.net

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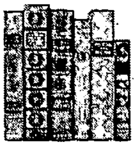

# For Your Library

**Tangible Symbol Systems, 2nd Ed.**
*Rowland C. & Schweigert P., Portland, OR: Oregon Health Sciences University, 2000.*
Describes how to teach people who are unable to communicate using speech, manual sign language or other abstract symbol systems to use two-and three-dimensional symbols to communicate. The book has been revised based on recent research involving individuals with deafblindness, mental retardation, autism spectrum disorders and multiple disabilities. A companion 75-minute video (2nd ed., published in 1996) is also available. Order via the web at http://www.designtolearn.com or contact Mayling Dixon, OHSU Center on Self Determina-

tion, 3608 SE Powell Blvd., Portland, OR 97202; Tel. 503-232-9154, ext 108, dixonma@ohsu.edu Cost: $25.00 (book); $15.00 (video).

### The Intervener in Early Intervention and Educational Settings for Children and Youth With Deafblindness (NTAC Briefing Paper)

*Alsop, L., Blaha, R. & Kloos E. Monmouth, OR: NTAC, The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind, 2000.*

This paper includes: a discussion of the needs of children who are deaf-blind and how interveners can meet those needs; how to determine the need for an intervener during the IFSP or IEP process; logistical issues such as training, supervision and support; and commonly asked questions. Available on the web (http://www.tr.wou.edu/ntac/publications.htm) or through DB-LINK: Tel. 800-438-9376, TTY 800-854-7013, dblink@tr.wou.edu

### The Preemie Parents' Companion: The Essential Guide to Caring for Your Premature Baby in the Hospital, at Home, and Through the First Years

*Madden, S.L. Boston: The Harvard Common Press, 2000.*

This book includes information about caring for premature infants, parenting in the hospital, home care, infant development, and financial issues common to premature births. It also reviews common medical complications and discusses how to cope with difficult situations. Appendices include growth charts, infant CPR, immunization schedules, and other resources for parents. Available through bookstores.

### Where Do I Begin? Developing Communication With Children Born Deafblind (Video)

*Open-captioned. 23 minutes. West Australian Deafblind Association, 2000.*

Focuses on key communication development strategies including making contact, building rapport, acknowledging communication efforts, tactile cues and symbols, tactile signing, routines, and choice-making. Available in both PAL (Australian format) and NTSC (US and Canadian format). Available from: WA Deafblind Association, 6th Avenue and Whatley Crescent (PO Box 14), MAYLANDS, Western Australia 6051, Australia; Tel. (08) 9 272 1122, TTY (08) 9 370 3524, wadba@nw.com.au Cost: $27.50 (PAL) plus $5.00 postage within Australia or $10.00 outside; $35.00 (NTSC) format, plus $10.00 postage outside Australia. Checks or money orders in Australian currency only are accepted.

### Charge Syndrome: A Management Manual for Parents

*Hefner, M. & Davenport S.H.L.(Eds.) Columbia, MO: CHARGE Syndrome Foundation, Inc., 1999.*

Contains a history of the CHARGE Syndrome Foundation, stories from families, a brief section on development, extensive information on the medical problems of CHARGE, a glossary, and resources. Available from: CHARGE Syndrome Foundation Inc., 2004 Parkade Blvd., Columbia, MO 65202-3121, Att. Marion Norbury; Tel. 800-442-7604 or 573-499-4694, http://www.chargesyndrome.org, marion@chargesyndrome.org Cost: $20.00 (includes postage).

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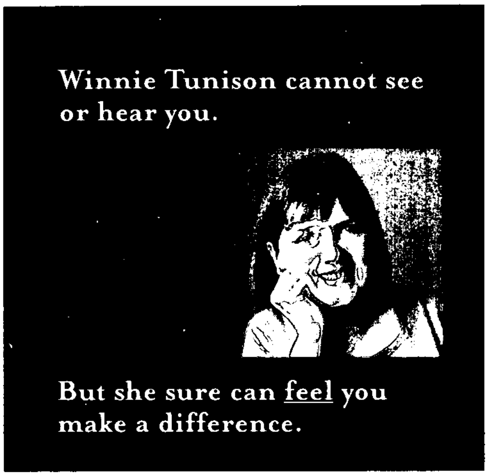

### New LISTSERV® for Deaf-Blind Teens and Young Adults

DBTeens -- A Private Deaf-Blind Discussion List for Teenagers and Young Adults. The purpose of this list is to share information, inquiries, ideas and opinions about deaf-blindness and other issues. This is a private list for teenagers and young adults. To subscribe, contact owner Randy Klumph <klumphr@wou.edu>.

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# Deaf-Blind Perspectives

Volume 8, Issue 3 Spring 2001

## Your Perspective on *Deaf-Blind Perspectives*

We are considering reducing *Deaf-Blind Perspectives* from 3 issues to 2 issues per year. We need to know what you think of our publication as we consider its future. Do you look forward to receiving it? Do you ever refer back to it? Do you find it to be of value? How? Does it contribute to your family, work, and thinking? In short is *DBP* useful or important to you in any way?

Without the feedback of our readership we are left to only imagine *DBP's* utility. Please let us know what you think either by **email** (malloyp@wou.edu or reimanj@wou.edu), **fax** (503-838-8150), **phone** (800-438-9376 voice or 800-438-7013 TTY), or **letter** (Attn: Peggy Malloy or John Reiman at Teaching Research, 345 N. Monmouth Ave., Monmouth, OR 97361).

## Seattle Lighthouse for the Blind

### Deaf-Blind Program Federal Funding

Paula Hoffman

For nearly 30 years, the Seattle Lighthouse has provided a wide range of services and support to Deaf-Blind people in the areas of employment, skills training, social activities, leadership development, interpreting, and much more. Over the years, the Deaf-Blind community in Seattle has grown significantly, and demand for services has increased. To enhance and expand our current program, we requested funding from the federal government and in June 2000 received a federal appropriation of $1,849,000 for services for Deaf-Blind people. In this article I will share with you the process involved in obtaining the funding and how the money will be used.

### Previous Funding Sources

The Seattle Lighthouse Deaf-Blind Program was initially funded for three years in the early 1970s by seed money from the Helen Keller National Center. The program later grew to be self-sufficient through Lighthouse business operations—the sale of products manufactured at the Lighthouse and business service contracts. For example, we have a large aerospace contract with the Boeing Company to manufacture over 10,000 parts. We also have manufacturing and business service contracts with the General Services Administration (GSA) to make a variety of products including easel boards, paper trimmers, canteens, and safety clothing. And we have a custom business product line that includes awards, certificates, rubber stamps, and business cards. The sales of these products and services pay for such business expenses as machinery, payroll, building space, and until recently, our services. Another small source of funding comes from state rehabilitation and telecommunications access program dollars.

### In This Issue

As the Deaf-Blind community grew, largely because of the relocation of Deaf-Blind people to Seattle from other states, demand for our services increased beyond the capacity of the funds received through business operations and other sources. We also felt that it was not wise to have our services so largely dependent on business operations funds, which can fluctuate if there is a lull or downturn in business. In 1996 the Lighthouse made a commitment to seek funding to support growth in services, augment operations dollars, and protect services through downturns in business cycles.

## The Funding Request Process

In the late 1990s, I attended two national conferences that focused on legislative education. One was sponsored by the National Industries for the Blind, and the other, the Josephine L. Taylor Leadership Institute, was sponsored by the American Foundation for the Blind. Both conferences, held in Washington DC, emphasized the importance to organizations serving blind individuals of meeting with and educating legislators about their organizations' activities and needs. The conferences covered topics such as how to make appointments with and talk to legislators and included visits to Capitol Hill. Using this information, our staff at the Lighthouse began to visit our legislators every time we traveled to Washington, DC, for conferences, business, or personal vacations.

We began by meeting with senators and representatives from Washington State. Many were already familiar with the Lighthouse name but were amazed to learn about the variety and scope of our training programs and support services. Congressional staff expressed great interest in and support of our program and understood that, although the services were located in Seattle, they had a national impact. In 1999, two of Senator Patty Murray's staff visited the Lighthouse. At the end of the visit we were thrilled when one said, "The Lighthouse rocks!! How can we help?"

We were fortunate that both of our senators from Washington State (one Democrat and one Republican) were on the Senate Appropriations Committee and on the Labor, Health, and Human Services (LHHS) subcommittee. They introduced our request and supported it during committee discussions. Our team, led by Mark Landreneau, included Deaf-Blind people from Seattle and other states. Our program has always embraced and lived a philosophy of empowerment. Therefore, it was critical to us that visits to legislators include blind and Deaf-Blind people who were employees, staff, or participants in our programs. We deeply appreciated the support of Janie Neal, Maria Garden, Jeff Foster, and others, who made personal visits to the offices of all the committee members. We provided

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training and practice sessions to our team members on how to give effective presentations. The team visited congressional offices on both the Senate and the House sides. Overall, we made more than 60 personal visits, all with Deaf-Blind people making presentations.

We used interpreters from the Seattle area who knew the people making the presentations, who knew about our community and our organization, and who understood the signs and acronyms we commonly used. There were at least six interpreters, both Lighthouse staff and freelance, who provided incredible interpreting, guiding, and support services for Deaf-Blind team members.

Our team knew that we had to be flexible. Congress is a place where things happen at the very last minute, and there were many things that we could not control. Sometimes we weren't able to meet with the people we expected to meet. We were often in environments where we couldn't control factors that affected communication, such as lighting, glare, and seating arrangements. We were working with people who were not used to communicating via interpreters and who talked quickly and asked lots of questions. Meetings were sometimes very short but were always important, and we learned to say what we needed quickly. We let them know who we were and what we did, and we asked for their support for our funding request. Often, the people we spoke with became so interested in what our Deaf-Blind presenters were saying that they extended the appointment time.

We developed printed materials to give the legislative staff more details about our request, background information about the Lighthouse, and contact information. We also brought "props" with us to demonstrate some of the products we make and the unique adaptive technology that we utilize.

During the time that we were making our funding request, we also contacted supporters of the Lighthouse (Deaf-Blind people, family members, friends, and interpreters) from other states who had senators and representatives on the appropriations committees. We asked them if they would be willing to write letters of support to their senators. Because the Lighthouse has always included Deaf-Blind people from other states and nations in its services, we had a large network to draw from. We also received letters of support from national organizations. We were able to show members of Congress that we provided a valuable national service through our programs.

Once the deliberations of the subcommittee to which we had made our request were completed, we had to wait throughout the summer and early fall while the entire Senate Appropriations Committee made its final decisions.

Finally the Senate finished its work on the appropriations budget and supported our request for 4 million dollars. The budget then went to the House for discussion and approval, and there our request was reduced to 2 million dollars. In November 1999 the appropriations budget was finalized, and Congress decided to award 2 million dollars to the Seattle Lighthouse for its services for Deaf-Blind people. Congress also decided that the appropriate department to oversee this funding was the Department of Education under the Rehabilitation Services Administration. As part of later overall budget cuts, the amount was reduced to $1,849,000. We have five years in which to use these funds.

## How the Federal Funds Will Be Used

Seventy-five percent of the new federal funds will be used to hire new staff, expand existing services, and fund new projects. Twenty-five percent will be used to maintain existing services. We currently have 15 staff members and serve between 175 and 200 Deaf-Blind people annually through our community-based services. Prior to receipt of the federal funds, our annual operating budget was just over a million dollars.

It has become necessary for us to expand our services for two reasons. First, we have experienced a steady growth in the number of people requesting and receiving our services, without having experienced an increase in staffing. Second, a large proportion of Deaf-Blind people in Seattle have Usher Syndrome, a condition in which vision loss is progressive. As vision decreases, so does each individual's need for more training and new technological adaptations. For the Lighthouse, this requires increased services, staff, interpreters, and time.

The type of new and expanded services was determined by direct feedback from Deaf-Blind people, and they include services that Deaf-blind people have repeatedly requested. The purpose of some of the new projects is to share information with agencies and organizations outside of the Seattle area that would like to replicate our service models as well as other service models in the Seattle Deaf-Blind community. We have received numerous requests for this from Deaf-Blind people from other states. Until now, our ability to assist others in developing their own community services has been hampered by insufficient funding.

The following sections describe some of our preexisting services, services that are being expanded, and new projects.

### Preexisting Services

**Employee Support.** The Lighthouse currently employs 300 people. Forty-three of these employees are Deaf-Blind. Employee support includes vocational assessment and training, technical assistance on the topic of deaf-blindness, and provision of information about work-related issues such as co-worker communication.

**Independent Living Training.** We have a variety of independent living classes that teach such skills as banking, cooking, managing personal documents, and home buying.

**Other Services.** Other preexisting services include interpreting, orientation and mobility training, and telecommunications and equipment support. We also offer training and skill-building activities to interpreters and other professionals.

### Expanded services

**Deaf-Blind Community Class.** This class meets every two weeks during the school year and is attended by between 25 and 35 Deaf-Blind people, who select and develop the topics. The new federal funds will be used to increase staffing, to train and support volunteer interpreters and other volunteers, and to provide some summer class activities. We are also now able to fund a core interpreting team, and we have added a much needed Deaf-Blind Community Class assistant position.

**Dog Guide Support Groups.** This is a new program offered through our orientation and mobility services. It will give dog guide users an opportunity to get together to review responsibilities, learn more about caring for their dog guides, and to commiserate and laugh about daily experiences. Twelve support groups will meet over the duration of the grant. The initial groups will each have five members and will grow as additional dog guide users join the group.

**Internship Coordination.** We have provided interpreter internships for two decades, but during the last few years we have only been able to provide them infrequently because of other demands on our interpreting staff. We will now be able to offer more frequent internships, which will make it possible to train more interpreters skilled in the specialty area of deaf-blindness. The service also has the potential to offer internships to Deaf-Blind people who are interested in teaching or coordinating events such as retreats, large meetings, and community classes.

**Computer Training.** There has been a high demand for classes on personal computer use. As part of our independent living training program, we will now offer computer training that will focus on home computer use, troubleshooting, setting up equipment, and learning about e-mail, the Internet, on-line banking and grocery shopping, and transportation planning. Further expansion of this program, pending funding, will concentrate on work-related computer training.

**Deaf-Blind Weekend Retreats.** Our annual Deaf-Blind retreat is usually only able to accommodate approximately 50 to 55 people and we have always had more applicants than we have been able to accept. For the last 23 years it has been open to Deaf-Blind people throughout the United States and from other countries. This year we have already had 45 out-of-state and international applicants. Our local community has grown so large that more recreational and peer support opportunities are now needed. We are adding two weekend retreats per year, plus an additional weekend retreat designed to meet the needs of developmentally disabled Deaf-Blind adults.

**Health, Exercise, and Nutrition Classes.** Weekly exercise classes will be offered beginning in March 2001. Six to ten Deaf-Blind participants will join the initial exercise class. A water aerobics class is planned later in the year.

**Research and Development of Adaptive Equipment.** The Lighthouse has unique needs for adaptive technology in our production and business services departments. Much of what we need does not exist elsewhere. For example, machinists use a measurement tool called a caliper. The ability to use calipers skillfully is one of the steps toward upward mobility for machinists. Calipers generally come with a digital display, which cannot be read easily by people who have low-vision or are fully blind. Calipers have been adapted by the Lighthouse to incorporate voice read-out, so that blind people are able to utilize them. Now, we are researching and developing new technologies to also enable Deaf-Blind people to use calipers. In addition to needing a Braille display, they must be lightweight and portable. Braille displays are exceedingly sensitive to dust, grease, and other environmental factors. This new technology is being designed and tested with Deaf-Blind people.

### New Projects

**Louisiana Deaf-Blind Community Leadership Project.** We have had repeated requests from members of the Louisiana Deaf-Blind community in the Lafayette area to provide training and support to help them replicate some of our service models in their state. The Louisiana community has the largest population of individuals with Usher Syndrome Type 1 in the country. Members of this community have made frequent trips to Seattle for the Deaf-Blind retreat, job evaluations, and other services. They are comfortable with the way our services are designed and implemented. Training for people from Louisiana is a high priority for us because of the potential positive impact for a large number of Deaf-Blind people.

**Washington, DC Interpreter Training in Deaf-Blindness Project**. In response to requests from Deaf-Blind people in the Washington, DC, area, and added to our own observations and those of Congressional staffers regarding a need for interpreters skilled in the specialty of deaf-blindness, we have developed an intensive training course in Deaf-Blind interpreting. The first course took place in February 2001. Two interpreters from Washington, DC, participated in workshops and provided interpreting in supervised settings including our Deaf-Blind Community Class, large employee meetings, and a weekend Deaf-Blind retreat. Deaf-Blind people served as presenters and provided support to those trainees. Videotaped and printed materials were developed to support the training. We are working with the Metro Washington Association of the Deaf-Blind (MWADB) to provide future training opportunities.

**Leadership Training**. Training similar to that being offered to the Louisiana group will be offered to a small number of Deaf-Blind individuals from other areas. The format of the training will be an extended weekend and will involve skills training, observation, and peer support. Due to the high volume of interpreting and other supports needed to provide these trainings, the number of participants will be small.

**Community Support Projects**. Projects in Seattle that we are supporting include support service provider training offered by the Deaf-Blind Service Center, and web site development for Washington State Deaf-Blind Citizens.

## Next Steps

The Seattle Lighthouse Deaf-Blind Program is part of a coalition of individuals and agencies in the Seattle Deaf-Blind community working together as part of a Deaf-Blind task force to develop future federal funding opportunities. The other task force participants include Parents and Friends Together for People with Deaf-Blindness, the Deaf-Blind Service Center, Washington State Deaf-Blind Citizens, the Helen Keller National Center Regional Office, as well as other organizations.

The Seattle Deaf-Blind community and the Deaf-Blind Program at the Lighthouse have a well-deserved national reputation for quality services, expertise, leadership by Deaf-Blind individuals, and employment opportunities that draw Deaf-Blind individuals, service providers, and interpreters from throughout the United States. We are honored to have this distinction and this wonderful national treasure in our own backyards. We believe that our community-based model deserves long-term support from government sources, as well as from private individuals and foundations. We will continue to work together toward pursuing funding from these sources.

*Seattle Lighthouse web site:*
http://www.deafblindlh.com

*Paula Hoffman is the Director of External Affairs and Rehabilitation Services at the Seattle Lighthouse for the Blind. She has managed the Deaf-Blind Program for 12 years. Paula first became involved in the Deaf-Blind Community in 1980 when she was an interpreting student and volunteered at the Deaf-Blind Retreat and Deaf-Blind Community Class. She joined the Lighthouse staff in 1984 and has had wonderful opportunities to learn from Deaf-Blind people. She is an honorary lifetime member of Washington State Deaf-Blind Citizens.*

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# Interactive Storytelling for Deafblind Children

Keith Park

*Meat of the Tongue*, a Swahili story from Angela Carter's collection of fairy tales (1991), tells of a sultan whose unhappy wife grew leaner and more listless every day. The sultan saw a poor man whose wife was healthy and happy, and he asked the poor man his secret. "Very simple," answered the poor man, "I feed her meat of the tongue." The sultan immediately ordered the butcher to buy the tongues of all the slaughtered animals of the town and fed them to his wife. The queen became even thinner and more melancholy. The sultan then ordered the poor man to exchange wives. Once in the palace, the poor man's wife grew thin and pale. The final part of the story goes as follows:

> The poor man, after coming home at night, would greet his new (royal) wife, tell her about the things he had seen, especially the funny things, and then told

> her stories which made her shriek with laughter. Next he would take his banjo and sing her songs, of which he knew a great many. Until late at night he would play with her and amuse her. And lo! the queen grew fat in a few weeks, beautiful to look at, and her skin was shining and taut, like a young girl's skin. And she was smiling all day, remembering the many funny things her new husband had told her. When the sultan called her back she refused to come. So the sultan came to fetch her, and found her all changed and happy. He asked her what the poor man had done to her, and she told him. Then he understood the meaning of meat of the tongue. (p. 215)

Storytelling, it seems, is a vital ingredient of human experience. But if this is so, how can we do storytelling with people who have sensory losses and additional disabilities? Why should we bother? Jean Ware (1994) provides an answer when she suggests that, in choosing activities for people with profound and multiple disabilities, the aim should be "enabling the child to participate in those experiences which are uniquely human" (p. 71). Storytelling is one of these uniquely human experiences. Whether it is legend, myth, folktale, fairy story, poem, novel, film, or play, the principle is the same: everyone everywhere enjoys stories. According to the story *Meat of the Tongue*, this need is universal.

## Interactive Storytelling

I work as an advisory teacher for Sense (the National Deafblind and Rubella Association of the United Kingdom) in Greenwich and Lewisham (South London). As part of my work, I support children and young people between birth and 19 years of age who have a wide range of sensory losses, including deafblindness, and who may also have cognitive or physical disabilities. I began to adapt stories and poems for interactive storytelling for two main reasons. First, classroom teachers were asking me to suggest activities that could be used with their whole group. Second, I was considering the implications of the story *Meat of the Tongue* and wondering if it were possible—at a time when so much of an individual education program is based upon meeting the different needs of each person—to develop group activities based upon what people have in common: being human. Although children who are deafblind and have cognitive disabilities may not be able to understand the actual words of a story, they can still participate and be involved in the activity of storytelling. Introducing their adaptation of Homer's *Odyssey* for individuals with severe and profound disabilities, Grove and Park (1996) ask, "How necessary is verbal comprehension to the understanding of poetry and literature? We know that people with profound learning disabilities can enjoy music, so why not the music of words? Do we have to *comprehend* before we can *apprehend*? Does the 'meaning' of a poem or story have to be retrieved through a process of decoding individual words, or can it be grasped through a kind of atmosphere created through sound and vision?" (p. 2). How can such an atmosphere be created for deafblind children, who have incomplete access to sound and vision? One possible way is to make the interactive storytelling percussive: to use stamping and clapping or musical instruments to accentuate the vibro-acoustic element of the activity.

Grove (1998) states that "Meaning is grounded in emotion, or affect, which provides the earliest and most fundamental impulse for communication" (p. 15). The basis of interactive storytelling is to emphasize meaning by generating an emotional response to the story.

Following are four examples of storytelling activities that have been made accessible for children who are deafblind and have cognitive disabilities. All of the stories are were written specifically for the children mentioned and for the group they are in at their various schools. For these children, rhythm, repetitive patterns, and percussive methods are used to emphasize the meaning and feeling of each story. Participants in the story include the children, their teachers, other staff members, and parents or visitors who wish to be involved.

### Little Red Riding Hood

A version of this famous folktale was designed for Joe who is four years old and deafblind, although he has some useful vision. The story consists of three games in which the children take turns acting out the parts of the Wolf, Little Red Riding Hood, and Grandmother. Each game tells a part of the story using a call-and-response method. This means that one person or part of the group calls out one line and then the others call out the response line or carry out an activity such as knocking. The first game is called "Grannie To Go."

#### Game 1: Granny To Go

*Storyline: Little Red Riding Hood has gone to see her Granny, but the Wolf has gotten there first.*

The children and staff sit in a circle. The Wolf played by one of the children, prowls around the inside of the circle. He pretends to be Little Red Riding Hood and has a dialogue with the rest of the group, who are all Grannies, as follows (all call-and-responses are chanted as the rhythm is stamped on the floor or pounded on drums):

| Call | Response |
|---|---|
| "I knock on the door." | (knock four times) |
| "She says 'Who's there?'" | "Who's there, who's there?" |
| "Red Riding Hood." | "Red Riding Hood." |
| "And I go IN." | |

At the beginning of the last line, the Wolf points to a victim, approaches him, and then "gets" him. The group can be divided into call-and-response parts in any combination, so that each child can have a turn doing the call line (initiating the communication) and the response line (responding to a communication). Each call line and response line is of equal duration (four beats). Although Joe does not verbally participate in the call-and-response, what is important for him is not the verbal comprehension of the story itself, but the rhythm of communication within the context of the story. By being involved in the storytelling activity, he learns important communication skills: awareness of others, anticipating his turn, developing an awareness of rhythm, and developing an anticipation of the end of each section of the story, when he is either caught or "got" (a particular favorite for Joe) or does the "getting" himself (as the Wolf, for example). When Joe takes his turn at being the Wolf, he is supported in moving around the circle.

### The Three Little Pigs

Daniel is six-years old. He is totally blind but has a little hearing. Before this storytelling activity started, he was very tactile defensive. He would throw objects, but he didn't like to handle them. One of the aims for Daniel was to encourage him to reach for, feel, explore, and release objects. I decided to explore this activity within the context of a popular folktale. When enacting the story of *The Three Little Pigs*, Daniel and the children in the group each have a small box of objects and a basket. The box is placed to the left of each child and contains some bits of straw, several sticks tied together (for the roof of sticks), some pieces of brick for the house of brick, a piece of fake fur for the wolf, and a sprayer for a staff member to use with the group as the wolf falls in the cooking pot. At the beginning of each activity, the children are encouraged to reach and grasp the appropriate pieces of material, hold them, and then release them into the baskets placed on their right side, and then activate, with the same movement, a communication aid (a switch device containing a prerecorded message) that has a crash sound recorded on it. The narrator speaks the introductory line, and the rest of the story follows in call-and-response style, each line of which (apart from the final section) is twelve beats. The strong repetitive rhythms, combined with the call and response, encourage children to become more engaged in the activity. As with all the other story activities, the aim is not an understanding of the storyline, but an engagement in the communication implicit within the storytelling. Following is the first of the four episodes of the story:

> Once upon a time there were three little pigs. The first pig built a house of straw. The wolf came to the door, and said:
>
>> Little pig, let me in, little pig, let me in! (mime knocking on the door)
>>
>> No, no, no, by the hair on my chinny chin chin! (signing "no, no, no")
>>
>> Little pig, let me in, little pig, let me in! (mime knocking on the door)
>>
>> No, no, no, by the hair on my chinny chin chin! (signing "no, no, no")
>>
>> Then I'll huff, and I'll puff, and I'll blow your house down (holding then releasing the straw)
>>
>> And he huffed (gasp), and he puffed (gasp), and he blew the house down! (Everyone falling sideways to drop the object and activate their switch that says "crash!")

### The Story of Joseph (from Genesis 39-45)

Several years ago while on holiday in Denmark, I participated in a "circle dance." This, I was told, was a traditional Scandinavian method of storytelling (and not really a dance at all) where the storyteller stands in the middle of a circle of people and chants a story. The story itself usually has a strong rhythm and quite often an eight beat line. The storyteller chants two or three lines, and then the participants reply with an equally rhythmic chorus. As the story progresses, the circle of people moves around and around the storyteller. My enjoyment of the social activity was not affected by my almost nonexistent Danish. I was able to witness and experience the hypnotic power of the rhythm of the story, the repetition of particular phrases, and the responses of the participants.

In 1855 Henry Wadsworth Longfellow read a translation of the epic myth cycle of Finland, *The Kalevala*, and he was inspired by its pounding rhythm to write his poem *Hiawatha*, using a similar technique:

> Should you ask me, whence these stories,
> Whence these legends and traditions,
> With the odors of the forest,
> With the dew and damp of meadows,...

He continues to the introduction of the main character:

> There he sang of Hiawatha,
> Sang the Song of Hiawatha,
> Sang his wondrous birth and being,
> How he prayed and how he fasted,...(Longfellow, p. 13-15)

Like its inspiration, *The Kalevala*, this is a poem for reading aloud—for performance and participation. So, back in Greenwich and Lewisham, I adapted some of these techniques of traditional storytelling to use in the classroom, using the three R's: rhythm, response, and repetition.

Jon is 16-years old and has severe vision and hearing loss. He needs support when walking because he is very unsteady on his feet, but he does enjoy walking. Since Jon seems more alert when walking, we decided to try to develop his communication skills within the context of a story and while "on the move": moving round in a large circle during the story. This version of the story of Joseph, written for Jon and his group, is taken from Genesis 39-45 (using, with only slight adaptations, the language of the King James Bible) and uses this same *Hiawatha* meter (plus a fourth line of six beats as the response) to provide the rhythm for the step dance. It uses a call-and-response technique—a rhythmic exchange of commentary between the storyteller and the story participants. This is the first of six sections, the rhythm of which should be apparent on reading out loud:

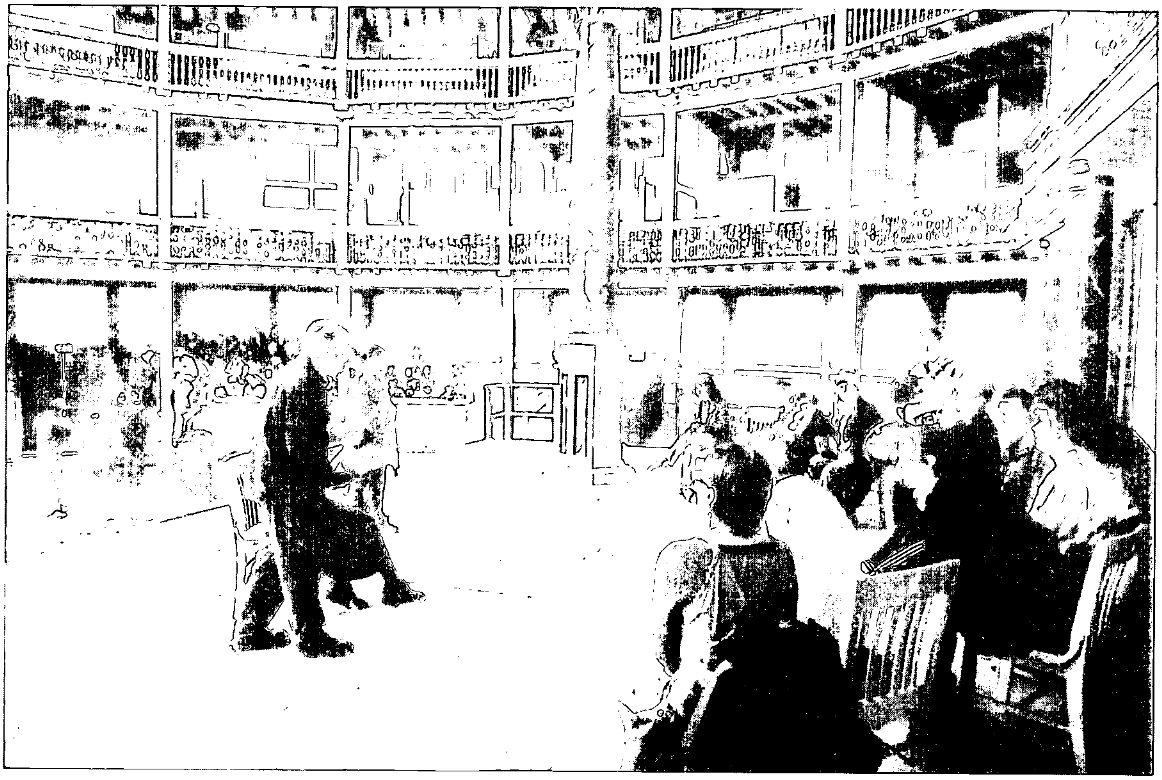
> Joseph was the son of Jacob
> Jacob dwelt within the country
> Where his father was a stranger
> In the Land of Canaan
> Born to Jacob in his old age
> Jacob loved his son called Joseph
> More than all his other children
> In the Land of Canaan
> All the brothers hated Joseph
> With his coat of many colors
> For his dreams and for his stories
> In the Land of Canaan
> "What is this dream that thou hast dreamed?
> Shall we bow down ourselves to thee?"
> And so his brothers envied him
> In the Land of Canaan
> Then they said to one another
> Look this dreamer cometh to us
> Shed no blood but let us sell him
> In the Land of Canaan
> Took the coat of many colors
> Dipped the coat in blood of goat and
> Brought it to their father Jacob
> In the Land of Canaan
> "This have we found" and Jacob saw
> "Joseph has been rent in pieces"
> Thus his father wept for him
> In the Land of Canaan.

### Macbeth

Three years ago I went to the newly opened Shakespeare's Globe Theatre to see a performance of *Henry V*. Before the play started, all the actors came out onto the stage, faced the audience, and then began, slowly and rhythmically, to beat wooden staves on the stage floor, summoning the attention of everyone in the audience to the beginning of the play. The effect was dramatic in every sense of the word. The wooden stage is 40 feet (13 meters) long and resonated very loudly. The thought came to mind: Why not try a Shakespeare workshop, using the vibro-acoustic properties of the stage at the Globe Theatre?

Nicole is 13-years old and deafblind. To include her in the group, an ocean drum is placed on her lap onto which the rhythm of the storyline is tapped. An ocean drum is a large tambourine with ballbearings inside it. When moved, it produces a sound effect similar to waves breaking on a beach. Staves, first heard in the *Henry V* production, are used to drum the rhythm of the call-and-response exchanges onto the stage. Here is an extract of poetry from the *Macbeth* poetry workshop that we stamp out on-stage. Like all of the examples, this is easier to do than it is to describe, so I would recommend that readers try it for themselves. A steady beat (one beat per second) combines with the words to create a powerful atmosphere. Nicole enjoyed her experience of conducting the group in the recital, and the participants demonstrated a greater awareness of her as a member of the group.

> Double, double toil and trouble
> Fire burn and cauldron bubble.
> Fillet of a fenny snake,
> In the cauldron boil and bake:
> Eye of newt and toe of frog,
> Wool of bat, and tongue of dog,
> Adder's fork, and blind-worm's sting,
> Lizard's leg, and howlet's wing,
> For a charm of powerful trouble,
> Like a hell-broth, boil and bubble.
> Double, double toil and trouble,
> Fire burn and cauldron bubble.



Shakespeare workshop at the Globe Theatre

## Conclusion

We are experimenting with many other adaptations of stories and poems, including traditional folktales, poetry, and literature. Anyone who would like more information is welcome to contact me at the e-mail address below. We would particularly like to hear from anyone in the United States who would like to collaborate on adapting American stories and poetry.

Angela Carter suggests that "for most of human history, 'literature,' both fiction and poetry, has been narrated, not written—heard, not read" (1991, p. ix). The literature of fiction and poetry from around the world has existed in oral form for many thousands of years, long before the development of the comparatively recent forms of writing, printing, radio, TV, cinema, and the Internet. The oral narration of stories was, and often still is, a social event in which the story was sung, spoken, or chanted, or in other words, performed. Just as storytelling has been the precursor of reading and writing, the starting point for the appreciation of literature may be in the performing of stories. For people with sensory impairments and for those with cognitive disabilities, the challenge is finding a means of access.

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## Personal Perspectives

### Peggy Malloy

"Personal Perspectives" is a column about deaf-blind people, their families, friends, and the people who work with them. This column features John Reiman, director of DB-LINK and executive editor of *Deaf-Blind Perspectives.* Also in this issue is an article by Dr. Mike Steer that gives a historical perspective of Alice Betteridge, a deaf-blind Australian woman who lived from 1901 to 1966.

John Reiman first became involved with deaf-blind people when he lived in Tallahassee in the early 1970s. While working as a therapist at the Florida State Hospital, he was in contact with many deaf patients but at that time did not know how to sign. Through the Tallahassee Association of the Deaf, John met Nora and

David Lawrence (deaf and deaf-blind respectively), who subsequently invited him to live with them. During the two-plus years he lived at the Lawrence's home (a hub of the deaf community), he learned American Sign Language and met, worked, and socialized with many deaf and deaf-blind people. Those early experiences led to years of involvement with deaf-blind people and work related to deaf-blindness.

John has had an interesting and varied career. He has master's and doctoral degrees in counseling and has worked as a therapist in private practice and for public and private agencies. He has also worked as an interpreter and as a director of educational programs and projects. He was director of the first associate of arts degree program in interpreting for hearing students at Gallaudet University, director of Oregon's Residential Mental Health Program for the Deaf (Woodstock House), and later, director of the Rehabilitation Counseling in Deafness Program at Western Oregon University. Currently, he works at Teaching Research, also at Western Oregon University, where he is director of the National Information Clearinghouse on Children Who Are Deaf-Blind (DB-LINK) and is involved with other research and service projects.

In recent years, John has established a private practice as a mediator, focusing on mediation in family, special education, and Americans with Disabilities Act compliance situations. He also works as a mediation specialist on a federally funded technical assistance mediation project called CADRE (Consortium for Appropriate Dispute Resolution in Special Education). Throughout his career he has been involved with hearing, deaf, and deaf-blind people, and he hopes that this trend will continue in his mediation work.

John met his wife, Carol Hennessy, at an American Association of the Deaf-Blind convention in Seattle in 1984 when they both attended as interpreters. They have two children, Nathan and Kayla, and a golden retriever puppy named Nikki. Everyone in the family plays an instrument and enjoys music. John began learning to play the mandolin several years ago and says it is one of his favorite activities.

John has several suggestions for improving services for deaf-blind people. First, he believes that the integrity of deaf-blind language and culture must be maintained and respected. Deaf-blind children should learn about and be included in this culture. Second, more deaf-blind adults should be working in professions related to helping deaf-blind children, including teaching, technical assistance, research, and personnel preparation. Third, he would like to see the establishment of an information center, similar to DB-LINK, that focuses on the information needs of adults who are deaf-blind.

John told me that he has been fortunate, that throughout his life, many work and other opportunities have seemed to open up for him at just the right time. He has been involved in a number of different types of activities, but through it all there has been a thread linking him to deaf and deaf-blind people. He says this has been a wonderful opportunity to learn about and participate in unique cultures that he would not otherwise have experienced.

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## Personal Retrospective

### Alice Betteridge
### Australia's Helen Keller

Dr Mike Steer
Renwick College
Royal Institute for Deaf and Blind Children

In Australia, the Royal Institute for Deaf and Blind Children at North Rocks, a suburb to the north of Sydney, is widely regarded as one of the nation's major private-sector special educators. It provides a wide array of educational services and supports to children and young people who have significant hearing and/or vision loss, including children who have additional disabilities. It is also one of Australia's oldest major charitable organizations, founded in colonial Sydney, New South Wales, in 1860.

Alice Betteridge, sometimes affectionately referred to as Australia's Helen Keller, was an outstanding student of the Institute's school, then called the New South Wales Institute for the Deaf, Dumb, and the Blind, from 1908 to the 1920s. She was born in 1901 at Sawyer's Gully in the Hunter Valley, a major wine-producing district. As a child, she lost both her sight and hearing as a result of meningitis. Her teacher was Roberta Sinclair Reid, a Sydney University graduate (1904), whose role and career are in several ways analogous to those of Anne Sullivan, Helen Keller's teacher.

In 1903, Roberta, or Berta as she was affectionately known, was appointed teacher at the New South Wales Institute for the Deaf, the Dumb, and the Blind, at that time located in Darlinghurst, next door to Sydney University, in a very handsome building that has since become university property. No other school existed in the colony at that time to educate children who were blind, and there were no teacher-training courses with the necessary content. So, untrained the new mistress at the institute certainly was. At the age of 20, she found herself in charge of the "Blind School," as it was known, and of its 13 pupils.

She tried hard (mostly perhaps by trial and error) and learned quickly. Early in 1905, Alice arrived with her mother for an interview. Alice was just four-years old. She was several years younger than the age at which most girls were admitted to the school and three years younger than the age at which Helen Keller was approached by teacher Anne Sullivan. She returned with her mother to her home near Maitland in the Hunter Valley and was finally admitted to the school when she was seven.

This was the beginning of a remarkable relationship between Berta and Alice. Because of the school's teacher-student ratio, Alice was educated in a class with the other children, unlike Helen's education, which was generally undertaken by Anne on a one-to-one basis.

Readers familiar with the Helen Keller story will recall that the major breakthrough in Helen's education occurred when Anne ran water over her hands. With Alice, it was when a shoe was one day presented to her, after many years of repetition, and a pattern tapped onto her hand. Repetition had made the pattern recognizable. She first tapped the pattern onto her own hand, then reached to touch the shoe. The all-important connection between pattern and shoe had been made.

Alice's education was a triumph. She became an avid reader. Her range of interests widened, and she eventually graduated from the school in 1920 as its Dux (top student of the year). The gold medal she received is still in the possession of her family. Those who knew Alice testified that she was extremely well informed on current affairs. She was rarely idle and was highly independent. She kept her room and its possessions tidy and also helped with household chores. She learned to type and won prizes for her work in open competition. In 1930 she left Darlinghurst and moved back to her family's farm at the small township of Denman. Little is known about her life there.

In 1939, Alice married a Victorian (a resident of the neighboring state of Victoria) named Will Chapman, a man who had been deafblind since the age of 21. She moved with Will from New South Wales to Victoria, where they lived happily for several years. In 1948, Helen Keller visited Australia and met Alice and Berta at what was then called "The Blind School" at Wahroonga, one of Sydney's most affluent suburbs. Three weeks after the historic meeting, Alice's husband, Will, died.

In 1966, Alice herself died at Helen Keller House in the Sydney suburb of Woolahra, aged 65. One of the few journalists who had interviewed her during her latter years described her as "a fine woman of marked intellect." According to the matron of Hellen Keller House, she was "the most unusual woman I ever met." Valerie Thompson, her biographer (1990), stated that without exception all who knew Alice found her "a happy well-adjusted person and a joy to be with" (p. 134). In 1990 the Royal Institute named its special school for children with multisensory disabilities The Alice Betteridge School.

## The Legacy

The Royal Institute's Alice Betteridge School (ABS) is now a leading special school for children (aged 3 to 18) who have a sensory disability as well as, in some instances, an intellectual or a physical disability. It is located on the Institute's campus at North Rocks and provides a wide range of educational, specialist, and therapy services to approximately 80 students with high support needs. The school is recognized nationally and internationally for the high quality of its curriculum and staff. Each student at ABS receives a highly individualized educational program through which families and staff work in partnership. Those who visit the school are invariably impressed with what they see and hear. Its excellence is a fitting tribute to the memory of a truly remarkable Australian.

## Reference

Thompson, V. (1990). *A girl like Alice: The story of the Australian Helen Keller.* Sydney: North Rocks Press.

*Special thanks to Alan Baynham, manager of the Royal Institute's VisionEd Department for advice in writing this article.*

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NTAC

## NTAC Update

NTAC, 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. This column describes some recent state and regional activities, a national workshop for state deaf-blind project staff, and the National Deaf-Blind Census.

### State and Regional Activities

**Arizona (Shawn Barnard)**

In 1999, the Arizona Deafblind Project staff began a statewide intervener initiative. Under this initiative, students who are deaf-blind will have access to skilled and knowledgeable interveners as determined by his or her IEP team. In 2001, the first group of trained interveners and a group of trainers will receive certificates of completion. A second group of interveners will complete the first phase of training. In October 2000, a strategic planning meeting was held between NTAC, Arizona project staff, and project consultants. The meeting resulted in a three-year activity plan to establish further state and local support, recruit additional groups of interveners, and create a statewide network to support interveners who currently work with deaf-blind students.

**Maine (Susanne Morgan)**

Educators at Baxter School for the Deaf and other professionals throughout Maine have indicated a growing need for information about Usher Syndrome. To meet this need, an Usher Syndrome awareness workshop co-sponsored by NTAC is scheduled for April 10, 2001. The workshop will provide introductory information to educators and service providers. Additionally, an interdisciplinary team will be created to establish a statewide screening process for children at risk for Usher Syndrome. Charlotte Cushman with Catholic Charities and the New England Center for Deaf-Blind Services will lead in coordinating these events.

**Area 2 (Jon Harding, Jamie McNamara)**
*Area 2 states: IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, SD, WI*

In the past, state deaf-blind project personnel have expressed a desire to share information about technical assistance (TA) issues with neighboring or regional state projects. Interest in holding a regional meeting was again expressed at the Project Director's Meeting last October in Washington, DC. As a result, NTAC offered to assist in arranging regional meetings during 2001. Interest from Area 2 states has been strong. A planning committee with representatives from seven states is currently developing desired outcomes and selecting topics for a regional meeting to be held this summer.

The meeting will consist of facilitated discussions on topics including sharing resources across state lines, improving technical assistance delivery to families, and meeting the needs of an increasing deaf-blind population with limited resources. States will have an opportunity to share successes as well as obstacles to delivering effective TA. The hope is that by coming together, state projects in Area 2 can learn how to strengthen their ability to better serve deaf-blind individuals and families. All project staff, regardless of geographic size or political structure, have the same desire to improve the lives of those whom they serve. Perhaps by sharing ideas and strategies in an Area 2 regional meeting, NTAC can assist state projects to utilize existing resources more efficiently.

## National Activity

**Accessing the General Education Curriculum Workshop**

This past February, NTAC sponsored a workshop on how to make general education curricula accessible to deaf-blind children and youth. The workshop, held in San Diego, was attended by state deaf-blind project personnel and other colleagues from approximately 20 states. Mike Burdge from the University of Kentucky gave the keynote presentation. The main part of the workshop was led by Kathy Gee of St. Mary's College in California. Dr. Gee presented specific strategies to adapt local educational curricula to meet the needs and capabilities of individual deaf-blind children. Participants had an opportunity to practice using this information and to share their own expertise while working in groups on sample case studies.

## Annual Deaf-Blind Census is a Great Tool and Resource

Robbin Hembree

The submission date for the National Deaf-Blind Census is May 1st, 2001. Each state and multi-state deaf-blind project will submit specified data giving a "snapshot" of the deaf-blind population (birth through age 21) in its service area as of December 1, 2000. Information reported will include such items as degree of vision loss, degree of hearing loss, educational setting, age, and other data. The census will compile data into a national summary, which can be used to identify national and regional areas of need. Technical assistance can then be geared toward providing improved services based on these needs.

Because of the unique issues faced by individuals experiencing combined hearing and vision loss, organizations must provide services that take the special developmental and educational needs of deaf-blind children and young adults into account. When individuals are not identified appropriately, they often will not get services that meet their specific needs. The state and multi-state projects work very hard to identify children and youth who are deaf-blind. They reported a total of 10,198 on the December 1, 1999, National Deaf-Blind Census. This compares to 1,609 identified as deaf-blind age 6 through 21 (data are not available for ages birth through 5 years) on the Part B Special Education count that was reported in the Twenty-second Annual Report to Congress (U.S. Department of Education, 2000, p. II-20).

Not only does the National Deaf-Blind Census provide a nationwide picture of children and young adults who are deaf-blind in the United States, it is also useful for analyzing such things as the impact of Universal Newborn Hearing Screenings on early identification, trends in etiologies resulting in deaf-blindness across the years, and disabilities in addition to hearing and vision losses that individuals who are deaf-blind, their families, and their service providers must address.

Our leap into the 21st century finds us continuously seeing significant changes that have an impact on this population. Changes in such things as technology, medicine, and transportation systems all influence types of services and how services are provided. Data reported for the National Deaf-Blind Census are imperative to help us keep up with the changing needs of this population and to provide information about the potential impact of current and past services.

### Reference

U.S. Department of Education. (2000). *Twenty-second Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act.* Jessup, MD: Editorial Publications Center.

Note: For more information on the National Deaf-Blind Census contact Robbin Hembree, Deaf-Blind Census Coordinator, (503) 838-8806 or hembrr@wou.edu.

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## Access to Multimedia on the Web

Andrew Kirkpatrick
Technical Project Coordinator
WGBH National Center for Accessible Media

Alternative ways of presenting information using video, audio, animation, and interactive content are becoming much more common on the Web. Much of the technology used to create and play these types of media, however, present significant barriers to people with disabilities. A new project that will address these barriers was recently started at The Corporation for Public Broadcasting/WGBH National Center for Accessible Media (NCAM). The project, NCAM's Access Solutions for Rich Media: Tools, Pathways, and Resources, is funded by a three-year grant from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education. NCAM will work with researchers, technology developers, Web designers, and consumers to find solutions that enable deaf, blind, deaf-blind, hard-of-hearing, and low vision Web users to benefit from Web sites that use multimedia.

For more information about specific resources and technology, visit NCAM's Rich Media Accessibility Website (http://ncam.wgbh.org/webaccess/arm). The purpose of the site is to serve as a centralized source of information and tools for multimedia access issues. It will offer user-friendly tutorials, showcase solutions, and maintain a library of other access solutions to make rich media accessible to blind and deaf Web users.

*Andrew Kirkpatrick can be reached by e-mail at andrew_kirkpatrick@wgbh.org*

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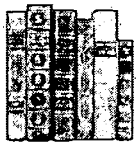

## For Your Library

**Meeting Physical and Health Needs of Children with Disabilities: Teaching Student Participation and Management**
*Heller,K.W. Forney, P.E., Alberto, P.A.., & Goeckel T. Wadsworth Publishing, 2000.*
A text for pre-service special education teachers about how to teach children with physical disabilities and health impairments (e.g., orthopedic impairments, visual impairments, deaf-blindness).

**The Transition Process: Early Intervention to Preschool**
*Alsop, L., Olsen, S., & Risk, T. Logan, UT: HOPE, Inc., 2001.*
Resource materials for service providers and intervention teams involved in transitioning children with special needs from early intervention to preschool settings. Includes a training manual with accompanying video tape, and a DVD to use for self-study. Prices: Training Manual - $50.00, Video Tape - $40.00, Self-Study DVD - $40.00, Complete Set - $110.00. Available from HOPE, INC., 1856 North 1200 East, North Logan, UT 84341. Tel./Fax 435-245-2888, http://www.hopepubl.com

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## Workshops and Conferences

### Workshops on Communication Strategies for Children with Severe and Multiple Disabilities

A two-day workshop presented by Charity Rowland, Ph.D. and Philip Schweigert, M.Ed. from Oregon Health Sciences University will be held at three locations this summer and fall. The workshop, is designed to teach professionals and parents how to help nonverbal children with severe disabilities communicate their needs to care givers and teachers. It addresses Pre-symbolic Communication and Tangible Symbol Systems. A special half-day seminar for parents is also offered, free of charge.

- Charleston, SC, July 26-27, 8:30 a.m. - 5:00 p.m., Registration deadline: **June 25** or until filled **Parent seminar: July 28, 9:00 a.m. - 1:00 p.m.**
- New Orleans, LA, Sept. 13-14, 8:30 a.m. - 5:00 p.m., Registration deadline: **Aug. 15** or until filled. **Parent seminar: Sept. 15, 9:00 a.m. - 1:00 p.m.**
- Baltimore, MD, Oct. 25-26, 8:30 a.m. - 5:00 p.m., Registration deadline: **Sept. 25** or until filled. **Parent Seminar: Oct. 27, 9:00 a.m. - 1:00 p.m.**

Also offered this summer cooperatively with Portland State University is the second annual OHSU Seminar on Communication Intervention, covering similar topics at the following location:

July 9-10, 2001
Mt. Bachelor Village Resort, Bend, OR
8:30 a.m. - 5:00 p.m.,
Registration deadline: **June 15** or until filled.

*Contact*:
Alexandra Dorinson
800-410-7069 ext. 102
dorinson@ohsu.edu
http://www.designtolearn.com

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### 5th DbI European Conference on Deafblindness
### Self determination a life long process
### July 24-29, 2001
### Noordwijkerhout, The Netherlands

*Contact*:
Stichting 5th DbI European Conference on Deafblindness
Anneke Balder,
c/o Unit Deafblindness of sDG
PO Box 222
3500 AE UTRECHT
Tel: + 31 30 2769970
Fax: + 31 30 2712892
sdg@wxs.nl
http://www.deafblindinternational.org

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### 7th Helen Keller World Conference
### What it Means to be Deafblind: Identity, Rights, Unity
### October 7-12, 2001
### Auckland, New Zealand

*Contact*:
Mrs. Jan Scahill
International Conference Committee
Box 7150
Tikipunga
Whangarei
New Zealand
Tel: 0064 9 437-6639
Fax: 0064 9 437-6601
jscahill@ihug.co.nz
http://www.deafblind.org.nz/hkeller.html

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### 5th Annual International CHARGE Syndrome Conference
### July 20-22, 2001
### Indianapolis, Indiana

*Contact*:
CHARGE Syndrome Foundation, Inc.
2004 Parkade Boulevard
Columbia, MO 65202-3121
800-442-7604
marion@chargesyndrome.org
http://www.chargesyndrome.org

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For information about additional conferences and workshops, see the DB-LINK web site: http://www.tr.wou.edu/dblink (click on "Databases" from the home page) or call DB-LINK at 800-438-9376 (voice), 800-854-7013 (TTY).

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## Announcements

## Two Usher Syndrome Research Projects

### Hereditary Hearing Loss Study

This study is evaluating hearing ability in families who have one or more children with hereditary hearing loss. Families of children with hearing loss since birth or Usher syndrome qualify as participants. The project is especially interested in families of Acadian (Louisiana) descent. Testing will be done on normal hearing parents and siblings rather than the affected children.

For more information contact:

Dr. Linda Hood, Principal Investigator, or
Ms. Sonya Tedesco, Audiologist
Kresge Hearing Research Laboratory
Department of Otorhinolaryngology and Biocommunication
Louisiana State University Medical Center
533 Bolivar Street, 5th Floor
New Orleans, LA 70112
Tel. 504-568-4785 Fax 504-568-4460
lhood@lsuhsc.edu or stedes@lsuhsc.edu

### Study to Find Genes Responsible for Usher Syndrome in Ashkenazi Jews

Individuals of Ashkenazic heritage who have Usher syndrome, or both hearing loss and vision loss that has no other known cause, or family members, may be eligible to participate.

For more information contact:

Judith Willner
Department of Human Genetics
Box 1497
Mount Sinai School of Medicine
One Gustave L. Levy Place
New York, NY 10029
212-241-6947
nesss01@doc.mssm.edu

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## New Email Discussion List Regarding Congenital Rubella Syndrome

This discussion list has been established as 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 with congenital rubella syndrome.

If you are already registered with Yahoo-groups you can subscribe by sending a blank email to HKNC_Rubella-subscribe@yahoogroups.com. If you are not registered with Yahoo-groups, go to http://www.yahoogroups.com/register. For assistance, contact the owner HKNC_Rubella-owner@yahoogroups.com

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## Camp Abilities

Camp Abilities is a developmental sports camp for children who are blind, deafblind, or multihandicapped, held at the State University of New York at Brockport. The Summer 2001 session is from June 24-30. The camp serves children from age 9 to 19. Activities include: track and field, swimming, goal ball, beep baseball, tandem cycling, gymnastics, canoeing, judo, archery, bowling, dancing, camping, and horseback-riding. The camp is totally accessible for children who are deaf-blind and all deaf-blind children have 1:1 intervenors. Early registration is encouraged. Camp Abilities will also be held in 2 additional locations this summer, at the Iowa Braille School in July and at the New York Institute of Special Education in August. For information contact:

Lauren Lieberman
SUNY Brockport
Department of Physical Education
Brockport, NY 14420
Tel. 716-395-5361, Fax 716-395-2771
llieberm@brockport.edu
http://www.brockport.edu/campabilities

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## Sense Launches Deafblind Manifesto on National TV

Sense, the UK's leading charity for people who are deafblind, launched Deafblind Vote 2001 - including a manifesto by deafblind people - on a television show called See Hear on Saturday, March 3rd.

Deafblind Vote 2001 is a major national campaign by Sense to make sure prospective parliamentary candidates and political leaders understand the needs of deafblind people and their families.

The campaign follows a Sense report that revealed one in four deafblind people in the UK felt they were prisoners in their own homes as they have such little support.

According to Benedict Lewin-Leigh, Sense's Head of Campaigns and Policy,

> Deafblind people, their families and careers have joined forces to create the first ever Deafblind Manifesto. It's a clear set of aims for the next government and is set to be the focus of Sense's pre-election 'hustings' [a type of political meeting] around the UK.
>
> At the hustings deafblind people and their families will meet and question local candidates, making them aware of deafblind constituents, the problems they face and the changes that would improve their lives. Deafblind Vote 2001 is fantastic for the deafblind community. We see it as a significant step towards making positive changes to the lives of the people we work with. We hope Deafblind Vote 2001 will ultimately lead to equal democracy for everyone—not just the hearing and sighted.

For further media information contact:
Natalie Pritchard
Press & PR Officer
Sense
Tel. 020 7272 7774 After Hours 0370 580 843
npritch@sense.org.uk

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