

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 Light-

house 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.

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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 Wash-

ington, 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.



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 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: Grannie To Go

Storyline: Little Red Riding Hood has gone to see her Grannie, 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

"I knock on the door."
 "She says 'Who's there?'"
 "Red Riding Hood."
 "And I go IN."

Response

(knock four times)
 "Who's there, who's there?"
 "Red Riding Hood."

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, com-

bined 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.

Email: keith@busheyhillrd.demon.co.uk

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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.



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.



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.



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



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 Pre-school

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>



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 non-

verbal 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>

**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>

**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>

**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>

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).



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
 ness01@doc.mssm.edu

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

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>

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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