

# Deaf-Blind Perspectives

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## The Helen Keller International Art Show An Annual Event

Gail Leslie  
DB-LINK

Art shows are full of surprises. Beauty is captured in a combination of colors, images, textures, and objects. The 2001 Helen Keller International Art Show offered many such marvels. Bulging yellow eyes and black handles extending from a sculpted head. A large textured blue tree that dominates the serenity of a collage of grandpa's farm. Kangaroos standing under a large sun in a black and white drawing of the Australian outback. A photograph that captures the distortion of images layered in a mirrored reflection. One of the show's more surprising elements, however, was not obvious. The artists were children who are visually impaired, blind, or deaf-blind.

The Helen Keller International Art Show is a yearly event sponsored by the Council for Exceptional Children's Division on Visual Impairments (DVI). Under the guidance of Dr. Mary Jean Sanspree, a professor at the University of Alabama Vision Science Research Center and director of the Alabama Deafblind Project, the show has moved from an annual event in Alabama to an international celebration of children's art that travels to galleries and conferences throughout the country.

The show began in 1984 as a project of the Alabama state chapter of DVI. In 1996, Dr. Roseanna Davidson, a professor at Texas Tech University College of Education, became president of the national chapter of DVI. She had seen the show a number of times in Alabama and suggested that the division develop the show as a national project. Since 1996, the invitation to participate has been open to children from all corners of the world who are under 22 years of age and are visually impaired, blind, or deaf-blind. More than 150 pieces of artwork were submitted for the 2001 show. Thirty pieces are selected each year.

The show includes all types of visual art, such as sculpture, collage, and photography. Throughout the year, art fans (families, teachers, professionals, and even members of Congress) have the opportunity to place bids for individual pieces of art that they would like to purchase. During the seven years that the show has traveled, nearly every piece has sold. Dollars generated from those sales go into the budget for the following year's exhibition.

Families and professionals know about the marvelous accomplishments of children who are blind or deaf-blind. The art show gives the rest of the world an opportunity to experience their talents and expressive abilities. Students are able to demonstrate their formidable talents so that others can share in their unique perceptions of the world.

Many people assume that children who have vision loss can only use art forms that are tactual, such as sculpture. In reality, these children can use a variety of media to express their perceptions and experiences through art. One child takes apart toy trucks to feel the shapes of wheels and fenders and reproduces these shapes in a collage. Another student, who is in a wheelchair with head supports, manages to position himself to create detailed artistic strokes that result in a magnificent tiger portrait. "I have seen a child be one inch from the paper and draw the most perfect Ninja turtle," says Roseanna Davidson.

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“You just don’t know what they can do until they do it.”

Jeff Pruett, a 17-year-old student from Texas, is one of the 30 artists whose work was chosen for the 2001 show. His luminescent portrait of a tiger is entitled *Eyes in the Night*. “Over the years,” says Dr. Davidson, “it is hard to imagine all of the things the show has done for families and students. It gives them a chance to participate in a different realm, to participate in art.” Dr. Sanspree agrees. “I have known entire families who have flown across the country to see their child’s art displayed in the National Cathedral,” she says. “This is a group of kids who often don’t get recognized or get the rewards.” But with participation in the show, they are often featured in their local news and get recognition from their state senators.

The philosophy of the show is that each child is a winner. Each artist who submits a work of art for the show receives a certificate of participation. Those whose work is selected to tour receive artist certificates and a show catalog. To ensure that most of the students get recognized on a local level, U.S. Senators are notified that children in their states have been selected for the show and local newspapers receive press releases.

Dr. Sanspree is the first to express surprise at the show’s success and the extent to which it has taken on a life of its own. General enthusiasm for the show



Craig Axelrod, Texas School for the Blind and Visually Impaired (L) and Jeff Pruett (R)

and a willingness to improvise landed the organizers a grand opening for the first national show at the National Cathedral in Washington, DC. Coincidentally, the ashes of both Helen Keller and Anne Sullivan were placed in the National Cathedral. With very short notice, the group built packing crates, organized shipping, and set up the show. Keller Johnson, an Alabama resident and niece of Helen Keller, went along as a volunteer. Another volunteer printed postcards of the artwork to sell to raise money for shipping costs. Suddenly, an event was born. Six years later, the cost of framing and shipping the show is between \$5,000 and \$10,000 an-

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nually. This covers the regular events that are scheduled each year. Other agencies that would like to have the show displayed at their own locations are asked to cover shipping costs.

Each year the show debuts at the annual Council for Exceptional Children conference. The next six months, from April to September, are typically reserved for touring opportunities. The show has been to galleries at Florida State University, Columbia University, and Texas Tech University. It has been displayed at the National Eye Institute, BellSouth's Corporate Tower in Atlanta, Duke University, and every two years, at the National Cathedral. Each fall it travels to Washington, DC, and is displayed at United States senate and congressional offices until the following July. Usually, the artwork goes to the office housing the senator or representative from the artist's home state. "It's really fun," Dr. Sanspree says of the congressional show. "They are used to having our artwork and they love it. We don't use it as lobbying, we just use it for the kids to have a prominent place to show their work."

Besides the energy and commitment of the DVI committee, the show has benefitted from many dedicated volunteers. Chris Tant runs the Framin' Shoppe in Hoover, Alabama. For a number of years, Dr. Sanspree and others who worked with the Helen Keller Annual Festival were her regular customers. Today, Chris supports their work by supplying materials and expertise. During the year that precedes the show, Chris puts aside miscut or mismeasured frames and mats and saves frames that customers have left behind when reframing their artwork. After she receives the 30 pieces of work for the show, she chooses and cuts the mats and frames for each piece. Then, early one morning, in February, she opens her shop to Dr. Sanspree and a group of volunteers, who mat the work and assemble the frames. By the end of the day the artwork is ready for display. Tant likens this annual event to a mini Santa's workshop but also describes it as something that renews and restores her after the consumer frenzy of the holidays. "It is just something I need every February," she says. "For me, the show is a truly inspirational thing."

People who are involved with children with sensory losses often forget that most people have little experience or understanding of people who have disabilities. The Helen Keller International Art Show creates an opportunity for understanding and sharing the accomplishments of children that one might otherwise never have the opportunity to know. It is an invitation to the unknown. "You can't write off a group of kids because they have sensory deficits," says Roseanna Davidson. "They have to have op-

portunities and what they produce can really surprise us."

For information about the 2002 Helen Keller International Art Show contact:

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## It's Never Too Early Collaborating With State Early Childhood Programs

Kathleen Stremel  
Diane Haynes  
John Killoran

Tremaine was born prematurely and weighed just 21 ounces at birth. He spent two months in the hospital. At the time he left the hospital, hearing and vision loss as well as additional medical problems had been identified and he was referred to his state's early intervention program for infants and toddlers. Fortunately, early intervention program staff worked with the state's deaf-blind project and together they were able to develop a program to meet his complex needs.

Early intervention services during infancy and early childhood provide a tremendous opportunity to influence the development of children with disabilities, including those who are deaf-blind like Tremaine. Research over the past 25 years has found that infants have a great capacity to learn at a very young age and that social and environmental factors during the early years play a significant role in child development (Sameroff, 1993). In 1986, as part of the Education of the Handicapped Act Amendments (Public Law 99-457), Congress added Part H, a comprehensive program for infants and toddlers, to the Education of All Handicapped Children Act. The act was reauthorized in 1991 as the Individuals with Disabilities Education Act (IDEA). The goal of Part H was to develop and expand state early intervention services for infants and toddlers with disabilities (birth through age two) and their families. In the IDEA Amendments of 1997, Part H was renamed Part C and as of today all states participate in Part C.

Under Part C, each state has a designated lead agency whose purpose is to establish and coordinate a statewide system of early intervention. These agencies are required to provide early intervention

services to all eligible infants and toddlers. It is crucial for state deaf-blind projects, families, and other advocates for children and youth who are deaf-blind to be knowledgeable about the specific early intervention systems in their states in order to both benefit from and influence available services. This article describes many of the important features of early intervention services and makes suggestions for expanding and improving these services for infants and toddlers who are deaf-blind.

## Resources for Early Intervention

Although all states have systems in place to provide early intervention for children with disabilities, the participation in these systems of people with expertise in deaf-blindness is essential to ensure that infants and toddlers who are deaf-blind receive services that meet their unique needs and learning styles. Their needs are complex. In addition to hearing and vision loss, many also have additional physical, medical, and cognitive disabilities. Many professionals who work in early intervention programs do not have the knowledge and skills necessary to address the needs of these children in such areas as mobility, learning, communication, socialization, and development. Families, state deaf-blind projects, and other service providers working in the field of deaf-blindness can provide the assistance that early intervention programs in their states need to ensure that these young children have:

- the multiple and diverse services they require;
- services that are well coordinated;
- appropriate adaptations to help them access their environments;
- early communication systems; and
- intervention that is included as a part of caregiving routines and family activities.

Many state agencies responsible for early intervention services and training may not be aware of all of the helpful resources available to them through agencies such as the state deaf-blind projects, the National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC), and DB-LINK, The National Information Clearinghouse on Children Who Are Deaf-Blind.

## Characteristics of Early Intervention Services

The Office of Special Education Programs (OSEP), U.S. Department of Education, has funded numerous grants throughout the past 20 years to deter-

mine the effectiveness of early intervention services. Guralnick (1997), analyzed these services and found that, in general, successful early intervention programs:

- center on family needs;
- are based in the local community;
- integrate multiple disciplines; and
- plan and coordinate supports and services from numerous agencies.

Although, the systems that provide early childhood services vary from state to state, there are federally established, minimum components that are required under IDEA. These are as follows:

1. Definition of developmental delay;
2. Timetable for ensuring appropriate services to all eligible children;
3. Timely and comprehensive multidisciplinary evaluation of needs of children and family-directed identification of the needs of each family;
4. Individualized family service plan and service coordination;
5. Comprehensive child find and referral system;
6. Public awareness program;
7. Central directory of services, resources, and research and demonstration projects;
8. Comprehensive system of personnel development;
9. Policies and procedures for personnel standards;
10. Single line of authority in a lead agency designated or established by the governor;
11. Policy pertaining to contracting or otherwise arranging for services;
12. Procedure for securing timely reimbursement of funds;
13. Procedural safeguards;
14. System for compiling data on the early intervention system;
15. State interagency coordinating council;
16. Policies and procedures to ensure that to the maximum extent appropriate, early intervention services are provided in natural environments.

(NECTAS)

State deaf-blind projects and other advocates can improve services for infants and toddlers who are deaf-blind, by collaborating with state lead agencies on a number of these components. Because service characteristics are not uniform for all states, it is important to be knowledgeable about your own individual state system. Some key features of effective early intervention services are described below.

**Early identification and referral.** It is critical that infants with combined vision and hearing loss be identified and referred for services as early as possible. If infants are not identified, they can not be served. If they are not served, their risk for developmental delay is increased. Many are born very prematurely or have syndromes associated with serious medical issues. Health care professionals often concentrate on the medical issues rather than on the impact of sensory loss on development.

Census data collected on infants and toddlers who have combined vision and hearing loss indicate that few infants are identified and referred for early intervention services prior to one year of age. It is important that infants who are at risk for vision and hearing loss, such as very low-birth-weight infants, receive vision and hearing screenings before leaving the hospital.

All states are required to have comprehensive child find services in place to identify, locate, and evaluate children with disabilities. State deaf-blind projects should be knowledgeable about how child find systems operate in their states and they should establish linkages with involved agencies to assist in the early identification of infants who are deaf-blind.

**Natural environments.** IDEA requires that “to the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate” (Code of Federal Regulations, 1999, §303.12(b)). A justification must be made for the “extent, if any, to which the services will not be provided in a natural environment” (§303.344(d)(ii)). Provision of services in the natural environment alone, however, is not enough. The techniques used must be effective ones. These include making use of typical events, activities, and routines in a variety of settings to teach a range of skills; providing interactions that focus on the child’s engagement and interests; and using strategies that are nonintrusive and are appropriate for each child’s developmental stage and unique abilities (Warger, 1999).

**Individualized family service plans.** The individualized family service plan (IFSP) is the process by which a family and an IFSP team determine the outcomes that they would like to see for the child and the family. The IFSP must address service coordination, natural environments, and transition to preschool. IDEA regulations outline 16 different services (e.g., assistive technology, physical therapy, audiology, vision services) that may be included under early intervention services, but these services are not exhaustive (Code of Federal Regulations, 1999, §303.12). Each child and

family eligible for services must be provided with a service coordinator.

**Central directory.** Each state must have a central directory of information about state early intervention resources and services, that is accessible to families and service providers. State deaf-blind projects and other agencies providing services to children who are deaf-blind should make sure that they are listed as resources in this directory. They should also make sure that they have access to the central directory and use it as a resource.

**State early childhood technical assistance systems.** Many states have developed early childhood technical assistance programs to provide training and support to early childhood providers (NECTAS). Technical assistance is essential because teacher-training programs in colleges and universities do not adequately prepare teachers to provide effective early intervention services (Kilgo and Bruder, 1997).

## Suggestions for Participating in Statewide Early Intervention Systems

There are many ways that state deaf-blind projects and other advocates can participate in statewide early intervention systems and work to improve outcomes for infants and children who are deaf-blind.

- Become a part of your state lead agency’s public awareness program. These programs focus on raising awareness about the importance of early identification of infants and toddlers with disabilities and the availability of early intervention services.
- Attend Interagency Coordinating Council (ICC) meetings. State ICCs are comprised of a variety of individuals and agencies appointed by the governor, including parents and service providers. Their purpose is to advise and assist lead agencies regarding aspects of early intervention services.
- Invite a member of your state’s lead agency to be a member of your advisory committee.
- Share materials about deaf-blindness with your state’s lead agency and parent training and information center.
- Be aware of the knowledge and skills that are most needed by direct service providers and parents and inform them about the needs of children who are deaf-blind.
- Be aware of your state’s Comprehensive System of Personnel Development (CSPD) plan and serve as a resource to state early intervention training programs.

- Network with families. State deaf-blind project family specialists can provide information and support or serve as mentors to families.

## Summary

There is strong support for a connection between early intervention and learning experiences and later school and work performance (Sandall, McLean, and Smith, 2000). Identifying children who are deaf-blind and starting services as early in life as possible are crucial in order to give each child the best possible opportunity to learn and develop. State deaf-blind projects and others involved in the lives of children who are deaf-blind can play an important role by assisting state early intervention systems to meet the unique needs of infants and toddlers who are deaf-blind.

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## Technical Assistance to Early Childhood Providers in Kentucky

The following are examples of technical assistance activities used by Kentucky Services for Children and Young Adults Who Are Deafblind:

- Various local, state, and regional training opportunities (topics determined based on evaluation of participants' needs).
- Printed information (topical papers, brochures, newsletter) to update families and service providers about resources, upcoming events, and best practices.
- Regular, ongoing contact with families by telephone to find out how they are doing and determine whether they have a particular need that might be addressed by the project.
- Reach for the Stars, a specific training initiative designed to help families and service providers use a person-centered approach to plan a young child's transition from early intervention to preschool and from preschool to primary school.
- Close collaboration with the state's lead agency and other major service providers in the state to improve early identification of children who are deaf-blind (this has resulted in a significant rise in the number of referrals of children, from birth to age two, who have been referred to the project).
- Training of service providers to teach receptive and expressive communication skills to persons who have severe and/or multiple disabilities including deaf-blindness (the project received Comprehensive System of Personnel Development (CSPD) funds to develop and provide this training).
- Development and coordination of a university course, Severe Handicaps Integrated Preschool Programming, funded by a grant to the project from CSPD and Part B 619 funds (individuals serving children on the state deaf-blind project census are given first priority to attend the course).
- Development and teaching of other university and distance-learning courses as part of Kentucky's State Improvement Grant activities on the topic of natural environments.
- The use of project staff as trainers on four statewide early childhood training teams, giving them an opportunity to share valuable information about deaf-blindness and to conduct child find activities.



## Update on the IDEA Reauthorization Process

Joe McNulty

Director, Helen Keller National Center  
Co-Chair, National Coalition on Deaf-Blindness

Over the past few months, the U.S. Department of Education, along with interested parties within the disability and general education communities, has begun to plan for the reauthorization of the Individuals with Disabilities Education Act (IDEA). Active involvement in the process by people in the field of deaf-blindness will be important in order to ensure that services addressing the needs of deaf-blind children are included in the new law. This article discusses provisions specific to deaf-blindness currently included in IDEA as well as some of the issues that will be important for the reauthorization.

### IDEA 1997

Educational services for deaf-blind children have been part of the Department of Education's special education programs for more than 20 years. Prior to the reauthorization of IDEA in 1997, a deaf-blind program was one of fourteen discretionary programs found in the Act. The program received \$12.86 million per year to support deaf-blind projects including NTAC, DB-LINK, and several demonstration projects. During the 1997 reauthorization, however, those fourteen discretionary programs were collapsed into five broad categories and placed in Part D, National Activities to Improve Education of Children with Disabilities, of the new Act. The five categories are coordinated research, personnel preparation, technical assistance, support, and dissemination of information.

Although services previously provided under the deaf-blind program could easily fit into the technical assistance category found in Part D, there was no guarantee that the existing projects in deaf-blindness would continue to be funded, nor was there a provision to ensure that money would be made available for deaf-blind specific programs. Fortunately, the National Coalition on Deaf-Blindness was able to secure language in several sections of the Act to protect both the structure of the deaf-blind program and its funding. Of greatest significance was Sec. 661, Administrative Provisions, which includes a minimum funding requirement to ensure that at least \$12,832,000 be provided to "address the educational, related ser-

vices, transitional, and early intervention needs of children with deaf-blindness."

While the minimum funding language mandated that the Department of Education spend \$12.8 million on deaf-blind children, how they spent the money remained a major concern. Here again, specific references to deaf-blindness within the Act helped shape the services. The definition of a "low incidence disability" found in Sec. 673, Personnel Preparation, includes "a visual or hearing impairment or simultaneous visual and hearing impairments." Sec. 685, Coordinated Technical Assistance and Dissemination, lists examples of the types of activities that may be carried out under national information dissemination, including "services for populations of children with low-incidence disabilities, including deaf-blind children, and targeted age groupings." In the same section, under Specialized Technical Assistance, authorized activities include those that "focus on needs and issues that are specific to a population of children with disabilities, such as the provision of single State and multi-State technical assistance and in-service training . . . to schools and agencies serving deaf-blind children and their families."

In July of 1998, approximately one year after IDEA '97 was signed into law, several dozen representatives from national, state, multi-state, and university or demonstration projects in the field of deaf-blindness, as well as consumers, parents, and state education agency staff, met in Alexandria, Virginia. The goals of the group were to identify key issues in the education of children and youth who are deaf-blind and to provide the Department of Education's Office of Special Education Programs (OSEP) with input from the field on directions for federal support. Taking into consideration the recommendations from the focus group and following the language found in IDEA '97, the OSEP staff kept the structure of the old deaf-blind program and has since held competitions and awarded grants to provide national technical assistance, state and multi-state technical assistance, and personnel preparation.

### IDEA 2002

The Department of Education recently completed a series of seven public forums to solicit comments on the upcoming reauthorization to be considered during the administration's drafting of the new bill. Although the National Coalition on Deaf-Blindness (NCDB) has not developed a formal position statement at this time, testimony provided by parents, professionals, and students on behalf of the

deaf-blind programs focused on several key issues including the following:

**Maintain the minimum funding language in Sec. 661.** In my opinion, this is the linchpin of the entire network. Without this requirement, I do not believe the Department of Education would continue to place the same financial resources into the education of deaf-blind children and, consequently, services at the state and local level would be dramatically reduced, if not eliminated entirely.

A second, but very important, part of this particular issue is to get the minimum-funding amount increased significantly. In 1976, there were 4,600 children with deaf-blindness who benefited from the services provided by ten regional centers. At that time children were educated primarily at state schools for the blind or another type of residential program. The funding level was \$16 million. Over 10,000 youngsters are currently being served, primarily by local education agencies (LEAs). The need for the technical assistance provided by the deaf-blind projects has never been greater but the funding has remained at \$12.8 million for the last ten years.

**Maintain the thirteen existing disability categories, including deaf-blindness.** During the 1997 reauthorization process, there was some discussion about eliminating the categories. Those in the field of sensory impairment felt, and continue to feel, that the identification of the disability (deaf-blindness, deafness, hearing impairment, visual impairment including blindness) was, and is, an important factor in securing proper educational services for children.

**Improve the definition of a child with deaf-blindness.** As it's currently written, the definition is extremely limiting and excludes nearly 85% of children being served by the state projects.

**Full funding for all parts of IDEA.** In an attempt to fulfill its pledge to pay for 40% of the cost of special education, the federal government has approved large increases in the funding of IDEA over the past few years. Unfortunately, none of the additional money has gone into Part D. While it's imperative that the LEAs receive adequate financial support from Washington, the additional money will do the children little good without the coordinated research, personnel preparation, technical assistance, support, and dissemination of information provided by the projects funded through Part D. This recommendation is tied directly to the request to increase the minimum funding level found in Sec. 661.

It is expected that Congress will pass a one year extension of IDEA, which means that it will come up

for reauthorization in the fall of 2003. During the next 18 months, the National Coalition on Deaf-Blindness will continue to be actively involved with a number of other groups, including the Consortium for Citizens with Disabilities, as it advocates for improvements in educational services for all children with disabilities.



## Strategies for Postsecondary Educational and Support Service Personnel Serving College Students With Usher Syndrome

Patricia Lago-Avery

Usher Syndrome is a genetic disorder characterized by congenital hearing loss and gradually developing retinitis pigmentosa that leads to loss of vision. It is estimated that the syndrome occurs in 4.4 of every 100,000 people in the United States (Boughman, Vernon, & Shaver, 1983). The two most common types of Usher Syndrome are type I and type II. Type I Usher Syndrome is characterized by congenital deafness, vision problems beginning in early childhood, and balance problems. Type II is characterized by moderate-to-severe hearing loss and night blindness that typically begins during childhood. Historically, most students with Usher Syndrome type I attended residential schools and colleges for the deaf, while those with type II attended regular public schools and universities. With the mainstreaming of deaf and hard of hearing students brought about by Public Law 94-142, the Americans with Disabilities Act, and Section 504 of the Rehabilitation Act, students with Usher Syndrome now attend school in all types of educational settings. It is critical for support service personnel and counselors in college and university environments, who provide career, personal, and mental health counseling to students with Usher Syndrome, to have a good understanding of special issues that arise for these students and to be aware of strategies that will be of benefit when working with this population.

College age students who have Usher Syndrome face the same developmental issues encountered by most adolescents and young adults. However, they also have educational, personal, and social concerns that are not encountered by students who have normal hearing and vision or even by their deaf and hard of hearing peers with normal vision. Orientation and mobility skills to negotiate travel around campus, communication in the classroom and with

peers, career considerations, and the ongoing process of adjustment to changes in hearing and vision loss are some of the Usher-specific challenges faced by these students.

The first priority in a postsecondary educational environment should be to conduct an interview to complete an educational needs assessment. Do not assume that the student is already knowledgeable about Usher Syndrome. Assess his or her knowledge about the medical aspects of Usher Syndrome as well as about services available to people who have Usher Syndrome. Questions you may wish to ask include:

- Do you have trouble finding your way around in new places? Can you hear or see the fire alarm in your dorm room? Can you see in dimly lit places?
- Do you have trouble reading the blackboard? Is it easier for you to read whiteboards with black markers?
- Do you have a problem with glare from overhead projectors or in the classroom?
- Do you have difficulty reading regular printed materials? Does it help to have a larger font size such as 18- or 24-point? (Show the student examples of different font sizes.)
- Are you able to visually follow your interpreter in the classroom? Is his or her use of space outside of your vision range?
- Are you having difficulty hearing in the classroom or in situations where there is a lot of background noise?
- Can you follow group discussions?
- Do you have any concerns about your chosen career and your future?

Once you have completed the needs assessment, you can begin to help the student address issues related to optimizing the educational environment. You are also establishing a foundation on which subsequent personal and social issues can be considered.

## Educational Issues

**Orientation and mobility.** Some students may need orientation and mobility training. Many, for example, will have a difficult time finding their way around campus or the surrounding community at night because of night blindness. Locate orientation and mobility services in your community by contacting your state commission for the blind. If there are no services available in your community, find out if they are available in the student's hometown.

**Classroom visual adaptations.** A variety of techniques can be used to make it easier for students with Usher Syndrome to see visual information presented in the classroom. It is important to find out which adaptations work best for a particular student. Adaptations include the following:

- Good lighting that does not produce glare.
- If blackboards and whiteboards are used, find out which works best for a particular student. Some may need a notetaker to take notes for them.
- When using overhead projectors, use an 18- or 24-point font on transparencies and distinct color combinations for good contrast (e.g., black on white, black on yellow, or white on dark blue). Yellow transparencies may help to reduce glare. Provide the student with paper copies of transparencies.
- Technology has greatly enhanced learning opportunities for individuals who are blind or visually impaired. Investigate the possibility of providing a CCTV (closed circuit television) for reading books and handouts from the instructor. Computers that take advantage of adaptive technology for blind and visually impaired individuals are also of great benefit. If the student needs this type of equipment for success in the classroom, he or she will need it for success in life as well. Work with the student's sponsoring agency to secure necessary funds.

**Communication in the classroom.** The use of an interpreter is very important for students who use sign language. If the student is attending a college where the faculty and students all use sign language, use of a copy interpreter (someone who sits within the visual range of the student and repeats what has been signed or spoken) may be beneficial. If the student is in a setting where sign language is not commonly used, an interpreter notetaker and may be necessary. If the student does not use sign language and depends on lipreading and residual hearing, use of a notetaker is critical. These students may also require an oral interpreter.

## Career Issues

Career choice is an important concern for deaf-blind students. The impact of vision loss may be a consideration for some types of careers, but it is hard to predict how each person's vision might change as he or she ages. Educate yourself about the types of careers that deaf-blind people have and encourage the student to research career options as well. Currently, one can find people with Usher Syndrome

working in the following professions: researcher, professor/author, chef/owner of restaurant, lawyer, certified public accountant, information technology specialist, computer programmer, public health manager, counselor/professor, minister, librarian, veterinarian, health planner, clerk, medical transcriptionist, mental health counselor, high school teacher.

Students with Usher Syndrome study a wide variety of subjects in college. In 1995, research was conducted at the National Technical Institute for the Deaf analyzing data compiled by Dr. Don Johnson (then director of the NTID Eye and Ear Clinic) regarding the number of students with Usher Syndrome who had attended Rochester Institute of Technology/National Technical Institute for the Deaf. RIT was founded in 1829 and is a privately endowed coeducational university that includes seven colleges. One of these colleges is the National Technical Institute for the Deaf. Between the academic years of 1984 and 1995, 62 students with Usher Syndrome entered the colleges. At the end of this period of time, 21 students were currently enrolled, 20 had already graduated, and 21 had either withdrawn or taken a leave of absence. At first glance the number of students who withdrew or took a leave of absence might seem high, but the percentage is actually much lower than the national attrition rate of fifty percent (Brawer, 1996). In comparison, two-thirds of the students with Usher Syndrome who were enrolled at RIT/NTID during the period 1984 to 1995 stayed in college or had already graduated. These numbers speak very highly of the motivation and skill level of students who have Usher Syndrome. Moreover, they suggest that students' educational support and service needs were positively considered.

## Personal and Social Issues

**Adjustment to Usher Syndrome.** The process of adjustment to Usher Syndrome is ongoing. For students who are struggling academically and/or emotionally, it is important to gently try to help the student understand that changes in vision and hearing may be impacting his or her ability to function in the classroom or with peers. If a student is unwilling to talk about these issues or is depressed, angry, and afraid, he or she may need more in-depth mental health counseling. If you feel you are not qualified to work with students who have these types of problems, locate a qualified therapist to whom you can refer the student. If a student is resistant to your assistance or to assistance from others, it is important to understand that this type of student might fail. Professionals are trained to try to prevent failure,

but sometimes failure is needed before a student is willing to make changes in his or her life.

**Communication with peers.** If a student is having problems communicating in group settings or dark places, encourage the student to be more open about having Usher Syndrome, to talk about communication needs with close friends, and to learn alternative communication strategies.

**Role models.** If possible, try to find a person who has Usher Syndrome who can function as a role model and mentor for the student. Encourage students to meet other people who have Usher Syndrome, especially adults who have learned how to adapt and make modifications in their lives that enable them to function well and independently. There are also e-mail discussion groups available where people with Usher Syndrome can share their experiences (see resource list).

## Working with Students Who Are Unaware They Have Usher Syndrome

Although professionals who work in the field of deaf education are becoming more aware of Usher Syndrome, there are still a number of students who arrive at the doors of colleges and universities unaware that they have Usher Syndrome. Some students have already lost a significant amount of vision while others have not yet experienced enough vision loss to warrant their attention. You may notice that a student misses some of your signs, doesn't seem to understand what you are saying, or may not respond when you try to catch his or her attention. If you suspect a student might have Usher Syndrome, tread with caution. How you handle this situation could either enhance your relationship with the student or cause harm. If you are not comfortable dealing with this type of situation, then consult with other professionals and bring in someone to assist you. The following suggestions are based on my professional experience working with several students who did not know they had Usher Syndrome when arriving as freshmen in college.

Ask if the student has a vision problem. If the response is yes, ask what he or she knows about the vision problem. It might be a great deal. If the response is no, then you might share your observations. For example, "I noticed that you do not always see me when I am trying to get your attention," or "When I am signing, I notice that you miss some of my signs." Sometimes a student does not know that he or she is missing things in the environment or the classroom. That is why your observations are

important. If the student seems unsure of your examples you might want to ask if he or she has trouble seeing in the dark or in dimly lit places or bumping into objects. If the response is yes to any of these questions, then it is important to strongly recommend an evaluation by an ophthalmologist who specializes in retinal diseases. Do not tell the student that you think he or she has Usher Syndrome. That is not your role. The student might not even have a vision problem or might have a different type of vision loss. Your role is to help facilitate the process and to encourage the student to have a thorough vision evaluation.

If the student agrees to have a vision evaluation, your next step is to work with the student and perhaps with his or her parents (with the student's permission) to find an ophthalmologist knowledgeable about retinal diseases. If the student is fully independent and prefers to handle the situation independently, then just work with the student. If you do not know where to find a specialist, you can call the Foundation Fighting Blindness (see resource list). Another option is for you to suggest that the student or parents request a referral from the family doctor. The most important role you can play in this type of situation is that of facilitator.

How do you involve the parents? You should not tell the parents that you suspect that their child has Usher Syndrome. But you can say, "In my work with your daughter/son I have noticed several things that lead me to believe that he/she may not have optimal vision use. It seems that your son/daughter might be experiencing some difficulties seeing in the dark or might have some visual field gaps." With this said, then you could strongly encourage the parents to make arrangements for their child to be seen by a retinal specialist.

How do you help the parents/doctor/student once the diagnosis is confirmed? Again, your most important role is as a facilitator. It is critical to help them find people who can clearly explain what is meant by Usher Syndrome, what the implications are, what the future holds, and how the family and student can get assistance. Doctors can give a diagnosis but more often than not, that is where their help stops. The student and parents need much more than a diagnosis. They will have many questions, they may be in shock, they might ignore the diagnosis, or they might seek out second, third, or fourth opinions, which is their right.

## Conclusion

Working with college age students who have Usher Syndrome presents challenges for postsecondary

educators and support personnel. It's possible to feel overwhelmed, but it's important to keep things in perspective and remember that students with Usher Syndrome are more like their peers than they are different. They have the same educational, social, and psychological needs as other adolescents. It is essential to focus on an *individual* student's unique needs in order to help him or her become successful in life. I emphasize the word "individual" because we are all different in our needs and our perspectives on life. We owe students with Usher Syndrome respect for their individualism and need to keep this in mind when providing services.

## Resources

For more information about Usher Syndrome, contact DB-LINK. Additionally, information about Usher Syndrome and links to other websites can be found at the DB-LINK Website.

### *DB-LINK*

The National Information Clearinghouse on Children Who are Deaf-Blind  
Teaching Research Division  
Western Oregon University  
345 N. Monmouth Avenue  
Monmouth, OR 97361  
Phone: 800-438-9376  
TTY: 800-854-7013  
FAX: 503-838-8150  
Email: [dblink@tr.wou.edu](mailto:dblink@tr.wou.edu)  
Web: <http://www.tr.wou.edu/dblink>

### Other Organizations and Agencies

*American Association of the Deaf-Blind*  
814 Thayer Avenue Ste 302  
Silver Spring, MD 20910  
TTY: 301-588-6545  
FAX: 301-588-8705  
E-mail: [aadb@erols.com](mailto:aadb@erols.com)

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

*Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC)*  
111 Middle Neck Road  
Sands Point, NY 11050-1299  
Phone: 516-944-8900  
TTY: 516-944-8637

E-mail: hknctrng@aol.com  
 Web: <http://www.helenkeller.org/national>

*Usher Syndrome Project*  
 Boys Town National Research Hospital  
 555 North 30th Street  
 Omaha, NE 68131-9909  
 Phone & TTY: 800-835-1468  
 E-mail: [genetics@boystown.org](mailto:genetics@boystown.org)

**E-mail discussion groups**

**DBTeens**

An e-mail Internet forum for teens and young adults who have Usher Syndrome or who are deaf-blind, to share information, ideas, and opinions. This is a private list for teens and young adults. To subscribe, contact Randy Klumph at [klumphr@wou.edu](mailto:klumphr@wou.edu). Send the message "subscribe DBTeen."

**Usher Syndrome List**

An Internet forum for people with Usher Syndrome, their parents, friends, spouses, and service providers. To join this list send a blank email to: [Ushers-subscribe-request@tr.wou.edu](mailto:Ushers-subscribe-request@tr.wou.edu), or contact Randy Pope, [ushers-request@tr.wou.edu](mailto:ushers-request@tr.wou.edu)

**References**

Boughman, J. A., Vernon, M., & Shaver, K. A. (1983). Usher Syndrome: Definition and estimate of prevalence from two high-risk populations. *Journal of Chronic Disabilities* 36 (8), 595-603.

Brawer, Florence B. (1996) *Retention-attrition in the nineties*. ERIC Digest. Report No. EDO-JC-96-06. ERIC Document Reproduction Service No. ED 393 510. Los Angeles: ERIC Clearinghouse for Community Colleges.

**Author Information**

Patricia Lago-Avery is a retired counselor and professor from the National Technical Institute for the Deaf/Rochester Institute of Technology. She has worked with deaf and hard of hearing students for over 26 years, 23 of those at NTID. The information in the above article is based on her many years of experience working with college students who have Usher Syndrome as well as her own personal experience with Usher Syndrome type II. She can be contacted at [pllmbu@rit.edu](mailto:pllmbu@rit.edu) or via her Web site, LA Consultants at <http://www.rit.edu/~pllmbu>

Note: Ms. Lago-Avery wrote a longer version of this article that will be published on the PEN International Web site ([www.pen.ntid.rit.edu](http://www.pen.ntid.rit.edu)) at a future date. PEN-International is a program funded by The Nippon Foundation of Japan at the National Technical Institute for the Deaf, Rochester Institute of Technology .



**It Sounds Nice, But Is Inclusion Really Worth It?**

Nancy Hartshorne, Ed.S.  
 Parent and School Psychologist

**A**t a National Technical Assistance Consortium for Children and Youth Who Are Deaf-Blind (NTAC) workshop about inclusive practices held last year in San Diego for the state deaf-blind projects, many people approached me and asked for my "parent" perspective about how inclusive education works for my son. Jacob is 12 years old and is in sixth grade. He has CHARGE syndrome and is deaf-blind. What are the advantages of his inclusive placement? Is it really worth the time and effort? What have been the outcomes? Here is my answer to these questions.

Jacob has a label of Severe Multiple Impairments (SXI). Without our intervention, he would have remained in the local SXI classroom. In this classroom, from age three to age five, Jacob was completely segregated from peers without disabilities. All supports and services were provided right in the classroom. The students even had lunch there although the classroom is housed within a local elementary school. Activities were individualized, but taught to him separately from other children so socialization did not take place even between the students in the classroom. Most were not able to move independently. Jacob's only meaningful contact at school was with adult service providers. Skills were taught in artificial rather than natural contexts. For example, physical therapy consisted of exercises practiced by rote in the classroom. Jacob used a walker to walk five feet across the classroom floor and then was instructed to turn around and walk back. Language was taught in thirty-minute pullout sessions two times per week.

Jacob's current program takes place in his neighborhood elementary school. He has attended this school with his same-age peers since kindergarten. His education is individualized and takes place in natural contexts. Physical therapy takes place during P.E., recess, track meets, and Field Day practices. The occupational therapist's oral motor objectives are carried out during lunch in the cafeteria. Language is taught and practiced throughout all activities of his day. With his classmates, he attends his sixth grade classroom, art, music, P.E., library, recess, and lunch, with the help of a one-on-one intervener. He has participated in school plays and music concerts, auditioned for and performed in the

talent show with his friends, and was a cub scout. He has a strong, active circle of friends. At age seven, he walked independently for the first time. He got up from his desk, walked out of his classroom, down the hall, out the school door, and to his bus to go home. Students clapped and cheered. Many of the teaching staff had tears in their eyes. Everyone celebrated Jacob's achievement with him.

If Jacob had spent the past seven years in the SXI classroom, I believe his outcomes would have been vastly different:

- He would not be walking independently. He would have nowhere to go.
- He would not be using his five manual signs. He would have no one to talk to.
- He would not be locating places and using mobility routes independently, based on object-picture cues. He would have no routes to use or locations to find.
- He would not have met nearly every single IEP objective each year. He would have had little motivation to do so.
- He would not be invited to birthday parties. He would have no friends.
- He would not have his annual "Birthday Swimming Bash." He would have no one to invite.
- He would not have earned The Arrow of Light, the highest honor that a cub scout can earn. He would not have attended campouts. He would not have won two second-place trophies for speed and one first-place trophy for design in the pinewood derby because he would not even have made a car.
- He would not have independently carried out the role of The Star of Bethlehem in the church Christmas pageant for the past two years. No one would have expected that he could play a part, and no one would have asked him to.
- He would not have participated in the school talent show with his circle of friends. No one would have recognized that he had any talent.
- He would not have the constant support of 18 friends without disabilities in the sixth grade, his Circle of Friends. He would have no friends. He would have no one to advocate for him in ways such as these:

Sarah, age 10, who explained the importance of inclusion and circles of friends on camera:

**Sarah:** "Our circle is important because we help Jacob participate in everything the other kids do."

**Interviewer:** "And why do you see this as important?"

**Sarah:** "Cause if he didn't participate with his friends, he'd just come to school and be with teachers all day. No one wants to be with teachers all day—that's no fun."

Justin, age 10, who was nominated for and received a district-wide Martin Luther King peacemaker award for assisting Jacob during a music concert at school. He refused to attend the ceremony or to accept the award, saying, "I was just being his friend—I shouldn't get an award for that!"

Creativity, high energy, collaboration, and thinking "out of the box" have been key characteristics of Jacob's team members. Even so, Jacob's inclusive program is far from perfect. His team struggles with making the sixth grade textbook curriculum meaningful for him. He still spends significant time away from his peers as he works toward independence in the bathroom, receives tube feedings, and is pulled out for some auditory training and specific language therapy. However, this program has been well worth the effort and advocacy on our part. Jacob continues to be happy and motivated to learn, to gain skills, to receive and give social support, and to surprise everyone on a daily basis. And the benefits to his friends without disabilities have been too numerous to count.

The alternative—a segregated, lonely, and hopeless educational track—is unthinkable.

Jacob belongs, and he knows it. He has a community, and he knows it. That is quality of life.



## Registry of Interpreters for the Deaf Deaf-Blind Special Interest Group

Susanne Morgan, M.A., C.I., C.T.

**E**xciting events are happening within the Registry of Interpreters for the Deaf (RID). A Deaf-Blind Special Interest Group (DB SIG) that focuses on the interests of interpreters who work in the field of deaf-blindness has been in existence for several years and is now working to expand its membership and activities. Susanne Morgan (NTAC Technical Assistance Specialist) and Angela Lampiris (HKNC Coordinator of Interpreting Services) were chosen as the new chairpersons of the group at a recent RID conference. Carolyn Jolley has been the secretary and will continue in this role. Planning for the upcoming year is currently underway. Goals include the following:

**Membership networking and expansion.** Increase the number of members, encourage demographically diverse representation, and expand leadership.

**RID Views Column.** Post updates and share information in *Views* (RID's monthly magazine).

**DeafWayII.** This is an international event for the Deaf that will be held at Gallaudet University in July 2002. Work with the DeafWayII Deaf-Blind Interpreter Coordinator Team to advertise the event to deaf-blind individuals and to recruit interpreters and support service providers (SSPs).

**Deaf-blind standard practice paper (SPP).** Work with the American Association of the Deaf-Blind (AADB) to complete this document, which has been in development for several years and is nearly ready for distribution. The paper shares some best practices in the field of deaf-blind interpreting and has been revised over the past several years based on input from representatives of the deaf-blind interpreting community and AADB. When finished, it will be available on the RID Web site ([www.rid.org](http://www.rid.org)).

**DB SIG Web page & e-mail discussion group.** Create a DB SIG Web page that can be accessed via the RID Web site. Investigate the level of interest in and possibility of developing an e-mail discussion group for DB SIG members to share information and network.

**Information sharing about interpreter training workshops.** Develop a way for interpreters and interpreter trainers to share information about workshops they are doing related to deaf-blind interpreting.

**Pre-conference at RID national conference in Chicago, 2003.** Host a pre-conference session at the next national RID conference to increase awareness of deaf-blindness and the number of skilled deaf-blind interpreters.

**Mentorship proposal.** Review a proposal by Leslie Foxman (a former DB SIG chairperson) to provide mentorship opportunities for interpreters interested in the field of deaf-blind interpreting. This pilot program will begin at the 2003 American Association of the Deaf-Blind (AADB) National Conference in California. It will provide an opportunity for students currently enrolled in interpreter-training programs to work directly with mentor interpreters and deaf-blind people.

**National Interpreter Education Project.** Promote discussion about the use of a new curriculum designed to train interpreters to work with deaf-blind people, which was recently developed by the National Interpreter Education Project at Northwestern Connecticut Community College.

As time goes by, interest, recognition, and support by national organizations for the needs of individuals who are deaf-blind, their support persons, and interpreters increases. As a community we can achieve

much more, and the Deaf-Blind Special Interest Group wants to be a part of this. Contact us if you have questions or would like additional information.

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516-944-8900, Ext. 338

### Usher Syndrome Research Project

This study is trying to find the genes responsible for Usher syndrome in Ashkenazi Jews. Individuals (or their family members) of Ashkenazic heritage who have Usher syndrome, or both hearing and vision loss that has no other known cause, may be eligible to participate.

For more information contact:  
Dr. Seth Ness  
Department of Human Genetics  
Box 1497  
Mount Sinai School of Medicine  
One Gustave L. Levy Place  
New York, NY 10029  
Phone: 212-241-6947  
E-mail: [nesss01@doc.mssm.edu](mailto:nesss01@doc.mssm.edu)

[hkncterp@aol.com](mailto:hkncterp@aol.com)



### For Your Library

American Association of the Deaf-Blind 2001-2002  
Deaf-Blind Contact Directory

This directory contains listings for AADB members, support service providers, state and local associations for deaf-blind people, services, and distributors, and manufacturers of assistive technology and products. Available from American Association of the Deaf-Blind, 814 Thayer Avenue, Suite 302, Silver Spring, MD 20910-4500, 301-588-6545 (TTY), 301-588-8705 (Fax), [aadb@erols.com](mailto:aadb@erols.com).

Creative Expression: Opportunities for Persons who are Deafblind (Video & Booklet) *Terre Haute, IN: Indiana Deafblind Services Project & Madison, WI: Bailey Video Design, 2001.*

This video, produced by DB-LINK, The Blumberg Center, and VSA Arts of Indiana and a booklet, produced by Indiana Deafblind Services, present ways to involve deaf-blind people in creative arts including music, painting, pottery, weaving, and writing. The video is available for loan from DB-LINK, 800-438-9376, 800-854-7013 (TTY), [dblink@tr.wou.edu](mailto:dblink@tr.wou.edu). The video and booklet are available for purchase from the Indiana Deafblind Services Project, Blumberg Center, Indiana State University, School of Education, Rm 502, Terre Haute, IN 47809, 800-622-3035 or 812-237-7887, 812-237-3022 (TTY). The cost is \$25.00 for the video, \$10.00 for the booklet, or \$30.00 for both.

Usher Syndrome: Identification and Understanding *Poff, Lisa E. & Goehl, Karen S., Terre Haute, IN: Indiana Deafblind Services Project, 2000.*

This set of materials contains a booklet, sample screening forms, and 2 videos. It provides basic information about Usher Syndrome, how to recognize the syndrome, and tests to help determine whether a person should be referred for medical testing. Available from the Indiana Deafblind Services Project, Blumberg Center, Indiana State University, School of Education, Rm 502, Terre Haute, IN 47809, 800-622-3035 or 812-237-7887, 812-237-3022 (TTY). The cost is \$10.00 for the booklet or \$60.00 for the set.



## Conferences

Helen Keller National Center National Training Team  
Professional Training Seminars 2002  
Sands Point, New York

February 25 - March 1 Developing Strategies for Person-Centered Planning

April 8-12 Professional Development for Employment Training Specialists

May 29 - 31 Family Supports

September 9-13 Developing Strategies for Person-Centered Planning

October 21-25 Sensory Loss for the Elderly Population: Confident Living Program

November 18-22 Orientation and Mobility Techniques for Persons Who Are Deaf-Blind

Contact:  
Doris Plansker  
Phone: 516-944-8900 Ext. 233  
TTY: 516-944-8637

E-mail: [ntthknc@aol.com](mailto:ntthknc@aol.com)  
Web: <http://www.helenkeller.org/national>

Deaf Way II  
July 8-13, 2002  
Gallaudet University  
Washington, DC

Deaf Way II is an international conference and festival of the Deaf. Deaf, hard of hearing, and hearing participants from around the world gather to present and discuss issues of language, history, culture, art, technology, and human rights.

Contact:  
Gallaudet University Kellogg Conference Center  
Phone: 202-651-6064  
TTY: 202-651-6112  
E-mail: [info@deafway.org](mailto:info@deafway.org) or [db.team@deafway.org](mailto:db.team@deafway.org)  
Web: <http://www.deafway.org>

Interpreters and support service providers are needed to provide services for people who are deaf-blind at Deaf Way II. If interested, contact [db.team@deafway.org](mailto:db.team@deafway.org).

6th National Australian Deafblind Conference:  
Touching the World  
July 12-15, 2002  
Sydney, New South Wales, Australia

Contact:  
Deafblind Association (NSW), Inc.  
PO Box 1295  
Strathfield  
NSW 2135  
Phone: (02) 4957 2741  
TTY: (02) 9334 3260  
E-mail: [DBConference@gpo.com.au](mailto:DBConference@gpo.com.au)  
<http://www.dbansw.au.com>

### SALUTE Announcement

Please join Deborah Chen, June Downing, and others at <http://www.projectsalute.net> for stimulating discussions on Successful Adaptations for Learning to Use Touch Effectively!

- I enjoyed this issue of *Deaf-Blind Perspectives* but I am not on your mailing list. Please send future issues to the address below.
- I've moved! Please send future issues of *Deaf-Blind Perspectives* to my current address.
- I'm buried in interesting publications! Please remove my name from your mailing list.

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| <input type="checkbox"/> Administration (e.g., Dept. of Ed., project director) | <input type="checkbox"/> Teacher trainer                   |
| <input type="checkbox"/> Service provider (e.g., social worker, group home)    | <input type="checkbox"/> Government personnel              |
| <input type="checkbox"/> Technical assistance provider                         | <input type="checkbox"/> Medical professional              |
| <input type="checkbox"/> Higher education teacher/researcher                   | <input type="checkbox"/> Other _____                       |

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Mail to: Deaf-Blind Perspectives  
 Teaching Research Division  
 345 N. Monmouth Ave. Monmouth, OR 97361  
 or call Randy Klumph (503) 838-8885, TTY (503) 838-8821,  
 Fax: (503) 838-8150, E-mail: dbp@wou.edu

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

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