

# Deaf-Blind Perspectives

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## Oregon Deafblind Project Intervener Training Program

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Children who are deafblind have unique learning needs. Unlike hearing-sighted children who obtain information by observing and listening to activities that occur around them every day, children who are deafblind require special educational interventions and trained personnel to help them communicate and access information about the world. Interveners—paraprofessionals with special training and skills in the area of deafblindness—can provide the specialized help that children who are deafblind need. Interveners are an important part of the educational team and work under the supervision and direction of classroom teachers.

Although the usefulness of interveners is increasingly recognized in the United States, there are few available training programs to provide the specialized training that they need. The Oregon Deafblind Project has responded to this need in Oregon by developing an intervener training program, which is currently in its pilot phase.

## Oregon's Regional Service Delivery Program

In order to understand the structure of the intervener training program, it is helpful to have some background information about Oregon's system of delivering services to children who have low-incidence disabilities—deafblindness, autism spectrum disorder, orthopedic impairments, other health impairments, deafness/hearing impairment, and blindness/vision impairment—and the Oregon Deafblind Project. Oregon uses a regionally based model of service delivery. In each of eight regions, consulting teachers provide technical assistance to educators to help them gain the information and skills that they need to effectively educate children who have low-incidence disabilities.

Consulting teachers who have received extensive training in educational methods for children who are deafblind work with the Oregon Deafblind Project in each of the eight regions and at the Oregon School for the Blind. Every year the project contracts with each regional program to purchase a specified number of days for the consulting teacher to work on behalf of the project. The number of days contracted is based on the number of students with deafblindness in each region and on identified technical assistance needs. Four days are reserved for training specific to deafblindness, for the discussion of needs in each region, and for networking and resource sharing among the Oregon Deafblind Project, the Oregon Department of Education, the regional consulting teachers, the Oregon Commission for the Blind transition specialist, and the National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC) technical assistance specialist.

### In This Issue

Oregon Deafblind Project Intervener Training Program . . . . .	1	Personal Perspectives. . . . .	11
Mississippi's Deaf-Blind Focus. . . . .	3	Report from the 2003 Texas Symposium on Deafblindness . . . . .	12
Interview with Jamie McNamara, Executive Director, American Association of the Deaf-Blind . . .	6	For Your Library . . . . .	13
Improving Systems: An NTAC Initiative . . . . .	8	Conferences and Events. . . . .	14
New NTAC Activity: Development of a Classroom Observation Instrument. . . . .	10	Announcements . . . . .	15

The regional program model of service delivery was cited as a significant strength of the Oregon Deafblind Project in a federal site review in 2002. This model and the exceptional knowledge and skills of the regional consulting teachers were major factors in the project's decision to develop the intervener training program. By utilizing the strengths of the Oregon system, the program uses personnel already in place and ensures cost-efficient services and ongoing supports.

## The Intervener Training Program

The intervener training program provides teachers and interveners with the knowledge and skills they need to work together to effectively use educational strategies for students who are deafblind. It was created by a task force that worked for a year to design a program that takes advantage of the regional model in Oregon and allows preexisting educational teams for specific students to focus on the needs of those students. The program is being field tested during the 2002–2004 school years. Teachers and interveners who are already working with students who are deafblind enroll in the program as teams. Three teacher/intervener teams are currently participating.

The training program consists of nine sessions based on modules that cover a variety of subject areas. The goal of each modular training session is to improve participants' understanding of the subject area and enable them to successfully apply the skills that they have learned with their students. The nine units cover the following topics:

- Module 1: Overview of Deafblindness; Overview of the Intervener Training; The Role of the Intervener; Teacher and Intervener Teaming; and Sensory Motor Learning in the Classroom
- Module 2: Every Child is a Communicator
- Module 3: Teaching in Routines
- Module 4: Calendar Systems
- Module 5: Observation and Interpretation in the Classroom
- Module 6: Movement in Different Environments
- Module 7: Student Progress, Program Development, and Adapting Routines
- Module 8: Success in School and in the Home
- Module 9: Planning Ahead: Preparing for the Next School Year

Parents are welcome to attend any training session but are specifically encouraged to participate in Modules 1 and 8.

### Off-Site Training

Three of the modules provide combined training for each of the three participating teacher/intervener teams at a location away from their schools. These are scheduled at the beginning, middle, and end of the training year and give the teams an opportunity to network and share strengths, challenges, ideas, and resources.

Outside consultants with expertise in deafblindness have served as presenters at these events. Their expertise is useful not only for meeting the present learning needs of the participants but also for improving the

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capacity of in-state program trainers to take on this teaching role in the future.

### On-Site Training

Six modules are designed to provide individualized training to each teacher/intervener team at their schools. Instruction and support is provided by Sylvia Carnes, Oregon Deafblind Project coordinator; by the regional consulting teachers in the participants' regions; and by Shawn Barnard, NTAC technical assistance specialist. The modules consist of a one-hour presentation followed by a two-hour block of time for team planning. Planning allows teams time to apply their new knowledge and to make decisions about how to best incorporate new skills as they work with their students.

The two weeks following the presentation of each unit are used for practice time when interveners can apply their new knowledge and skills with their students. The regional consulting teacher visits the classroom once during this time to observe, provide feedback, and offer any additional needed instruction. The consulting teacher also completes an "Implementation Checklist" to provide the program trainers with feedback on the intervener's use of the new skills. Although the field test is not yet complete, we have already observed that teachers and interveners utilize the skills they have learned to benefit not only the student who is deafblind, but also other students in the classroom.

### Future Plans

During the pilot phase, all training is occurring in a predetermined curriculum sequence, and a manual outlining the curriculum is being developed. In future years the training sequence and unit selection will likely continue to be predetermined in most cases, but in some situations additional material may be added to meet the needs of a specific student and intervener.

During the 2003–2004 school year, five new sites will be selected to receive training. Each new site will participate in a training program similar to the one described above. In future years, regional consulting teachers will take on more extensive teaching roles in their regions. By the 2004–2005 school year, all regional consulting teachers will have the knowledge and skills to implement the intervener training program in their respective regions.

The Oregon Deafblind Project looks forward to the expansion of the intervener training program and to the positive impact that it will have for children who are deafblind in the state of Oregon. Evaluation of the program will continue on an ongoing basis. The evaluations will be used to identify what is successful

about the current program and what needs to be modified. We consider the program to be a "work in progress" and will continually take steps to improve its effectiveness.

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## State Snapshot



### Mississippi's Deaf-Blind Focus

Cassandra Holly, Deaf-Blind Specialist  
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In recent years, the state of Mississippi has made great improvements in its services for adults who are deaf-blind. One and one-half years ago, the Mississippi Department of Rehabilitation Services (MDRS) began providing specialized services for deaf-blind adults at two locations in different areas of the state. Although the program is still in the early stages, it had been on the drawing board for years. This article describes the development and structure of the program as well as ongoing challenges and future plans.

### Program Development

The development of the deaf-blind program was no small task. When planning began, MDRS provided services for only a small number of deaf-blind adults at one location, the Ellisville State School. These individuals received services along with other consumers who had different types of disabilities and different needs. MDRS recognized the need for a specific program for deaf-blind individuals. They contacted the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) for guidance and received information and support from the center during the planning and implementation phases of the program.

The new program is based on the MDRS Deaf-Blind State Service Delivery Plan developed by MDRS with input from Mississippi Services for Children and Young Adults with Deaf-Blindness and the Helen Keller National Center. Susan Lascek, HKNC Southeast Regional Representative, played a large role in

helping to write the plan. Thanks to the hard work of these organizations and to funding provided by the state and federal governments, MDRS began providing services to deaf-blind individuals in the new locations in June 2001.

## Program Structure

MDRS decided to offer services at two locations in order to serve consumers with different types of needs. The sites chosen were the Addie McBryde Center for the Blind in Jackson, in the southern region of the state, and the Allied Personal Adjustment Center in Tupelo, in the northern region of the state. For over 30 years the Addie McBryde Center (AMC) has provided services for individuals with vision loss, including some who are deaf-blind. Because of this experience, it was decided that AMC would be a good place to establish an advanced program with a focus on providing services to improve communication and socialization skills and to provide personal adjustment training, vocational training, and job development.

The past experience of the Allied Personal Adjustment Center, on the other hand, was with individuals with traumatic brain injuries or multiple disabilities. MDRS felt that this site would be a beneficial location for services modeled after the Helen Keller National Center's PATH program, with a focus on helping consumers with limited language to build communication skills.

In order to accommodate deaf-blind clients at each location, MDRS created four deaf-blind specialist positions, two at each site. Each specialist facilitates communication and instruction, supports consumers and instructors, identifies deaf-blind individuals in the state, and provides community outreach services. Required qualifications for the deaf-blind specialists include a bachelor's degree in education or a related field and fluency in American Sign Language. Currently three of the four deaf-blind specialist positions are filled.

Additionally, after-hours support service provider (SSP) assistance is available at the Addie McBryde Center. Karen Brown, director of AMC and other staff members realized that there was a need for more extensive deaf-blind services in the residential setting after hours. She discussed the issue with H.S. McMillan, executive director of MDRS and he responded to this need by finding funds to support the SSP service for 20 hours per week.

## Personnel Training

### Training for Adult Service Personnel

The MDRS deaf-blind service plan not only included establishing the two-tract service provision system, it also included providing more intensive training for its service providers. After evaluating its existing deaf-blind services, MDRS and its supporting agencies realized that extensive training in deaf-blindness for its deaf-blind specialists and other vocational rehabilitation personnel was necessary. Once the need for training was recognized, MDRS contracted with the Helen Keller National Center to provide five week-long training sessions over the course of one year. Each session focused on different aspects of deaf-blindness.

The training program, provided by the HKNC National Training Team, began in June 2001 and ended in May 2002. Topics included causes of deaf-blindness, communication strategies, person-centered plans, orientation and mobility, sighted-guide techniques, functional language training, behavior management, working with sign language interpreters, self-determination skills, self-advocacy skills, support service providers, interveners, careers, and employment.

At the end of each session, Sister Bernadette Wynne, coordinator for the HKNC National Training Team, gave participants homework assignments to be completed before the next training. Each participant was also required to complete an action plan identifying ways to integrate new knowledge gained from the training into their teaching strategies and professional work. For example, an action plan might be designed to identify opportunities for improving sign language skills or to help find work experiences for deaf-blind clients.

The HKNC training program was so successful that other Mississippi agencies decided to use the same program to train their service providers, in order to enable them to work more effectively with deaf-blind adults and transition-age youth. Mississippi Services for Children and Young Adults with Deaf-Blindness, South Mississippi Regional Center, and the Mississippi Council on Developmental Disabilities contracted with HKNC to repeat the series of workshops for a new audience. This training began in January 2003 and took place at the University of Southern Mississippi Conference Center in Gulfport. The second session was held in March, and three more will occur before the end of the year. Participants are personnel from the Mississippi Department of Mental Health and several private rehabilitation agencies.

MDRS, Mississippi Services for Children and Young Adults with Deaf-Blindness, and the Mississippi Council on Developmental Disabilities place a great deal of emphasis on providing training on the person-centered plan (PCP) approach. Ed Butler, executive director for the Mississippi Council on Developmental Disabilities, is a strong supporter of the deaf-blind program in Mississippi and has facilitated several of the PCP meetings for our deaf-blind consumers. The Mississippi Council on Developmental Disabilities has played an enormous role in securing funding for the training that our staff has received over the last year and a half. The council's mission statement is "To provide community integration and inclusion for individuals with significant disabilities and to help make their lives better, while providing support for their families." This pledge from the council has been demonstrated to our deaf-blind programs time and time again over the past year and a half.

### Parent and Teacher Training

In addition to increased training for adult service providers, providing more educational opportunities for parents and teachers who work with deaf-blind children and youth is an important goal in Mississippi. Dr. Linda McDowell, director of Mississippi Services for Children and Young Adults with Deaf-Blindness, has applied for a personnel preparation grant in hopes of receiving funding for a special education master's degree in severe disabilities, with an emphasis on deaf-blindness. This program would provide increased training opportunities for educators who work with deaf-blind children and youth in the state. It would be offered through the University of Southern Mississippi in conjunction with Texas Tech University and would include six online courses and two practical teaching experiences, one in state and one out of state. The funding would cover tuition, books, fees, and travel for forty individuals over a 5-year period.

Mississippi Services for Children and Young Adults with Deaf-Blindness is also working with the Mississippi Department of Education to offer workshops for parents and teachers of deaf-blind children. The training covers techniques that teachers can use in the classroom, parental issues and support, and other issues related to deaf-blindness. The training is being led by Janet Salek, project coordinator, and Jennifer Baker, support coordinator, both from the Mississippi Services for Children and Young Adults with Deaf-Blindness.

## Ongoing Program Evaluation

At MDRS we plan to revise and improve our deaf-blind services program as necessary on an ongoing basis. After more than a year of operating deaf-blind services under the two-tract system, we have identified a few snags and are taking another look at some aspects of our current deaf-blind services. One issue that we are looking at is how to best evaluate the deaf-blind specialists' fluency in American Sign Language. At present, fluency is determined by passage of the state interpreter certification exam. Because deaf-blind specialists work one-to-one with clients communicating at a conversational level rather than as formal interpreters, MDRS is considering changing the state interpreter exam requirement. The Sign Communication Proficiency Interview (SCPI) is being considered for this purpose, and MDRS is working with the University of Tennessee Knoxville to provide the test to service providers via the Internet.

We are also reevaluating how well the two-tract system of service delivery is working. Currently individuals with formal communication skills are served by the Addie McBryde Center, while those who need to learn formal communication methods are served at the Allied Personal Adjustment Center. However, many deaf-blind consumers and their families have expressed a desire to receive services in their local area regardless of the type of services that they need.

## Summary

Deaf-blind consumers in the state of Mississippi have seen a positive shift in the services being provided to them. The revision of Mississippi's deaf-blind service delivery plan and the state's renewed commitment to serving deaf-blind consumers has resulted in a more community-oriented system of service delivery and has provided increased opportunities for individuals who are deaf-blind. Mississippi has come a long way in serving individuals who are deaf-blind and is continuing to learn from each experience.

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## Interview with Jamie McNamara, Executive Director, American Association of the Deaf-Blind

There have been many changes recently at the American Association of the Deaf-Blind (AADB). At *Deaf-Blind Perspectives*, we decided that this would be a great time to talk to Jamie McNamara about what is going on in the organization and about her new role as executive director. This conversation took place in March.

**DBP:** What is AADB?

**JM:** AADB is a national consumer organization of, for, and by people with dual vision and hearing loss. Our mission is to ensure that all deaf-blind people achieve their maximum potential through increased independence, productivity, and integration into the community. Our membership consists of people who are deaf-blind, supporters who are not deaf-blind, and organizations interested in supporting AADB's mission.

**DBP:** How long have you been involved with AADB?

**JM:** I first became involved in 1994. A friend of mine was scheduled to speak at the AADB national conference in North Carolina that year, but she could not make it and asked me to substitute for her. We were both professional social workers so it was easy for me to take her place. When I got to the conference, I just fell in love with AADB. I immediately became a member. I was elected as a board member in 1997 and served until 2001. I was also editor of AADB's magazine, *The Deaf-Blind American*, from 1997 to 2001. I served as AADB vice president from 2001 until I was hired as executive director in May 2002.

**DBP:** What is your educational and professional background?

**JM:** I have a bachelor's degree in social work from Gallaudet University and a master's degree in social work from Catholic University of America. In the past I worked as a social worker, first in a nonprofit agency serving deaf adults and later with deaf children and youth in mainstreamed public school programs. Prior to becoming AADB's executive director, I worked for 5 years as a technical assistance specialist for NTAC.

**DBP:** It seems that there have been a lot of changes at AADB recently. What has been happening?

**JM:** AADB has been a formal organization since 1984, and since that time it has continued to grow. There has

been a huge increase in the number of contacts to us made by the public, deaf-blind people, professionals, and family members, but there have not been enough resources to handle all of the work. Until I started as executive director, there was only one staff person working full time in the office. It was just impossible to keep up with the workload and do a good job at the same time. In order to keep up with the growth and all of the important issues affecting deaf-blind people, we realized that it was necessary to make some changes. Creating the position of executive director was the first step. This is the first time that AADB has had an executive director.

**DBP:** What will the next steps be?

**JM:** We have a mission statement, but we need to develop a value statement for our organization. Once we have finalized this statement, we hope that we can begin strategic planning for the next five years. So much is happening this year with the upcoming conference in San Diego this July, board elections, and board-meeting activities that it is difficult to do strategic planning at this point.

**DBP:** Sounds pretty busy. What kind of staff do you have helping you?

**JM:** When I first started, I didn't have any permanent office help, but I did have help from temporary workers and volunteers. We contracted with an accounting service to help us put AADB's financial records in order. Volunteers helped us to reorganize and clean the office, to catch up with our e-mail and mail backlog, to improve the membership database, and lots more. I also have several board members assisting me with various projects. I'm very pleased to announce that we hired a full-time office manager just this past January. His name is Greg Eaheart. He is a huge help! He has a wealth of office and computer experience, which is much needed. I am presently preparing to ask the board to approve one or two more positions because the work is still overwhelming for the two of us.

**DBP:** A lot of people are looking forward to the conference this summer. What does it take to prepare for such a big event?

**JM:** It involves working with all of the conference committee chairs to ensure that work is done in a timely manner. There are committees for registration, housing, transportation, tours, exhibits, support service providers and interpreters, technology, and volunteer and local workers. There are many details to consider and many questions to answer. We have contracted with a consultant to assist me with coordinating the details of the conference.

**DBP:** You mentioned that there is an upcoming board member election. What is the structure of the board and what are its activities?

**JM:** The AADB board consists of four officers and eight board members. All of the board seats are up for election this spring, but not the officers. The board is very important to AADB. Board members oversee the whole organization. They make policy and finance decisions. All of the board members are deaf-blind except for the secretary who is hearing-sighted.

**DBP:** What are some examples of long-term or ongoing projects?

**JM:** Our mentoring project is going really well. Its purpose is to train deaf-blind adults to be effective mentors to deaf-blind youths. We are really happy with this project, and so is our cosponsor, DB-LINK. We also have committees that do ongoing work. For example, our multimedia committee is working on ways to improve *The Deaf-Blind American*, to establish a Web site, and to improve our membership form and other AADB public information materials. And our finance committee is working on creating an annual budget, on working with an auditor, and on monitoring our finances.

**DBP:** How is AADB funded?

**JM:** Primarily through membership dues and donations.

**DBP:** Since you began as executive director, you've been working hard to improve AADB's public visibility. What does this involve?

**JM:** In the past, AADB has not had good visibility on the national level, but this is getting better with the additional staff in the office. I've been very busy promoting AADB since I started this job. I've attended a number of conferences, including the National Association of the Deaf (NAD) conference and the Deaf Way II conference, in Washington, DC, last July. AADB had an exhibit at the NAD conference, and there were good opportunities for networking. At Deaf Way II, an international conference and festival for the Deaf, there were 10,000 participants from around the world. There were many wonderful opportunities for AADB President Harry Anderson and I to promote AADB. I was also a co-presenter with Susanne Morgan and Joyce Houghton at a workshop on deaf-blind interpreting.

I've also been able to participate in and present at a number of other events including the annual Project Directors' Meeting in Washington, DC, a camp for deaf-blind teens in Michigan, a forum considering the service needs of deaf-blind people in Kansas, and a deaf-blind interpreter-training workshop in Nebraska. And I'm on the Maryland Deaf-Blind Project Advisory Board. This has been a great opportunity to

build relationships with the Maryland Deaf-Blind Project and with schools and agencies that serve deaf-blind children in the state.

Recently, I was invited to have dinner with Stig Ohlson, president of the World Federation of the Deaf-Blind (WFDB), and Andre van Deventer, national director of Deafblind South Africa. They were in Washington, DC, for the World Bank Conference on Disabilities. It was a very interesting dinner. English was the main language spoken, although it was accented with Swedish and Afrikaans. There were five support service providers interpreting the respective languages as we conversed over dinner.

I also recently attended a terrific grant-writing workshop, presented in ASL, in San Francisco. So, as you can see, it has been a busy but very interesting beginning in my new position as executive director for AADB!

**DBP:** How do you like being executive director of AADB? Has it been a good experience for you personally and professionally?

**JM:** I love this job! It is a perfect fit with my skills and talents. It has been an awesome growth experience for me both personally and professionally. It is really meaningful to represent deaf-blind Americans in disability-related events, to make AADB more visible, and to make it known that deaf-blind people are out there and part of our society. As a deaf-blind person myself, it is very exciting to grow with this experience and to show that deaf-blind people can succeed regardless of their dual disability.

**DBP:** What are your hopes for AADB in the future?

**JM:** My hopes for AADB are many, but mainly I want to see AADB become a powerhouse and watchdog on deaf-blind issues at the national level and be in a much better position to affect the lives of deaf-blind Americans through advocacy and outreach. AADB is on its way! We are continuing to grow stronger as we face challenges and make positive changes.

If you would like to become a member of AADB or need additional information, contact:

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## Improving Systems: An NTAC Initiative

Paddi Davies, Area Director  
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In recent years, both the national (NTAC) and state deaf-blind projects that are funded by the Office of Special Education and Rehabilitation Services (OSERS) have been given a new charge of facilitating systemic change and school reform. The thinking behind this is that by enhancing the capabilities of the people and systems that provide services to children and youth who are deaf-blind, we will see improved results by children and youth who are deaf-blind and their families.

For many years, NTAC and the state deaf-blind projects have been providing technical assistance to families and providers who work with children and youth who are deaf-blind. A few examples of this technical assistance include consultation to infant programs or school teams, training for families and teachers, and developing written and video resources. When OSERS asked NTAC and the state projects to include a focus on strengthening systems, our technical assistance took on a new look. This charge, though exciting, is a tall order.

Most of NTAC's assistance has traditionally been a collaborative effort between NTAC and the state deaf-blind projects. Successful systems-change initiatives, however, usually require a broad base of support, including a substantial time and funding commitment from those involved. We knew that this intensive assistance could only be accomplished with many new partners and thoughtful planning. Therefore, based on the work of Dr. William Sharpton from the University of New Orleans, NTAC developed six criteria to help define and shape the systems-change work we do with states. These criteria are:

1. There is a substantiated need that is agreed upon by the partners.
2. There is shared leadership and commitment among the identified partners.
3. Partners share resources to support and maintain the initiative.
4. Multiple technical assistance strategies (e.g., strategic planning, training, case studies) are used to improve outcomes for both students and systems.

### Systems Change: A Definition

The term "systems change" is widely used but not always defined. A "system" is a group of people or agencies that work together or mutually support each other's work to achieve a common goal. The following are five different levels of systems identified by NTAC and example of each:

- *Building level system:* a local school with all of the administrators, teachers, related staff, and students;
- *District level system:* a school district with all of the schools, administrators, teachers, related staff, and students;
- *County level system:* all of the preschool programs in a county;
- *Agency level system:* a vocational rehabilitation agency and all of its offices;
- *State level system:* a family support group made up of families from across the state.

"Change" is the act of making something different. Therefore, systems change, in a simple definition, is changing a system, whether in part or in whole, with the expectation of improving the outcomes of the system.

5. The technical assistance strategies used are known to be effective and are based on research.
6. The partners use an ongoing planning process and specific methods to document the progress of the initiative.

For the past two years, NTAC has been working closely with 11 states on systems-change initiatives. These states include Arizona, Oregon, Idaho, Iowa, Nebraska, Indiana, Alabama, Florida, Tennessee, Maryland, and Rhode Island. The initiatives are in different stages of development and focus on a variety of systems. In this article we will share the activities and outcomes of three transition-related initiatives from the states of Florida, Alabama, and Idaho.

### Florida

A need to improve the transition outcomes for students with significant disabilities was identified by the Hillsborough County School District in Tampa. The district has 8,600 transition-age students with disabilities, 500 of whom have significant disabilities. Of these 500 students, 17 are deaf-blind. To demonstrate and measure the effectiveness of the work of the initiative, three students, one with deaf-blindness and two with autism are participating.

This initiative enjoys the benefit of having multiple partners including representatives from the Hillsborough County School District, the Florida Department of Education, the Florida Network on Deaf-Blindness including vocational rehabilitation and developmental disabilities agencies, the Florida Outreach Project for Children and Young Adults Who Are Deaf-Blind, the Center for Autism and Related Disabilities at the University of South Florida, and NTAC. In addition, the Florida Statewide Transition Project has been instrumental in supporting a local community interagency task force with school, business, and state-agency-level representation.

The long-term goals of the initiative are:

1. the placement of three students with significant disabilities, including autism and deaf-blindness, in community work;
2. that at least one local agency that provides supported employment services to individuals with disabilities will have staff who are better trained to provide employment services for students with autism and deaf-blindness;
3. the establishment of a community interagency partnership or council to assist with the transition process for all students with significant disabilities.

Activities to date have included conducting workshops, providing on-site follow-up assistance, strategic planning, team meetings, and attendance at national and state conferences. All of the partners have provided financial and logistical support for these activities. The research-based practices outlined in the *NTA Transition Practices Framework* (1998) are used to guide and direct the initiative.

Short-term outcomes accomplished so far include state funding for the formation of a Hillsborough Transition Interagency Council by May 2003, the development of career profiles and person-centered plans, IEP goals and objectives that reflect career or work preferences, increased opportunities for community based-instruction, and paid summer work.

## Alabama

The NTAC initiative in Alabama also focuses on the need for effective transition planning and programs. From 1998 to 2000, the Helen Keller School, a residential program that provides educational programs for Alabama students who are deaf-blind, provided training to parents on the transition process and the potential for successful transitions to the community. Parents began to realize that their children could accomplish a great deal but that successful transitions probably would not occur without early and systematic planning, effective

transition programs, and strong collaboration between the educational system and the adult services system. The Alabama Deafblind Project responded to these concerns by developing a long-term plan to improve transition services for students who are deaf-blind.

The primary partners in this initiative are the Helen Keller School, four public schools (Calera High School, Calera; Hillcrest High School, Tuscaloosa; Crossville Elementary, Crossville; and Phillips Elementary, Bear Creek), the PATH team (a statewide resource group of parents and professionals with training in deaf-blindness), and NTAC. Each partner plays a unique role. Leadership and coordination is provided by transition specialists at the Alabama Deafblind Project and the Helen Keller School. The Alabama Deafblind Project and NTAC provide consultation and training to families, school teams, and adult service providers. PATH team members provide facilitation and problem solving on behalf of the focus students.

The initiative focuses on six students and two different system levels: the building level, including four public schools and the Helen Keller School, and the agency level, which includes the statewide system of adult service agencies. The long-term goal for the students is for each to have an effective educational program that includes a plan for transition into his or her community of choice. The long-term goal for the systems is to have in place an effective process to facilitate the planning and implementation of successful transitions for all students leaving the Helen Keller School or the public schools.

In addition to strategic planning and training, intensive technical assistance is being delivered to the families and educational staff of the six students. A team has been developed for each student that consists of representatives from the Alabama Deafblind Project, the school administrator, the student's educational team, and representatives from vocational rehabilitation and developmental disabilities agencies, and the PATH team.

The teams have accomplished a number of things for the students so far. Person-centered planning has been completed for four of the students. Transition plans that incorporate work, community, self-determination, and independent living goals have also been developed for four students. Families have reported that they are now more able to fully participate in transition planning and to advocate for their children.

Positive results for the systems involved in the initiative have also already occurred. Members of the PATH team have facilitated the transition process for three students and have provided training in additional public schools in order to improve transition services for students who are not involved in the initiative. And a vocational rehabilitation coordinator position, funded by the Division

of Vocational Rehabilitation, was added to the Alabama Deafblind Project to provide services to all of Alabama's transition-age students who are deaf-blind.

## Idaho

Five years ago representatives from several of Idaho's educational and adult services agencies met in Boise to discuss the transition of Idaho students who are deaf-blind. NTAC and the Helen Keller National Center regional director were also involved. The participants all agreed that the current outlook was bleak for these students as they became adults. A crucial need was identified for training adult service providers within the vocational rehabilitation and developmental disabilities systems to help them provide basic services to adults who are deaf-blind. The initial focus of the transition initiative in Idaho was to provide this training, and this has been occurring for several years. Now, the focus of the initiative is on improving the transition process in order to increase opportunities for young adults as they move from the educational system to adult lives. This new focus, which is in the beginning stages of development, will center on transition to competitive community employment.

The Idaho Deaf-Blind Project, the Idaho State Department of Education, and NTAC are spearheading the transition initiative. Each contributes time and financial resources. In year one, a pilot study is being conducted with a young woman who recently graduated from high school. Her family, local adult service agencies including vocational rehabilitation and developmental disabilities agencies, and community members are also involved. In subsequent years, additional students, families, and service providers will be added to the initiative activities.

The goal for the young woman is a paid job within her local community. The job will be customized to fit her skills and employment interests and will include the supports that help her perform at her best. The desired outcome for the local adult service agencies is that service providers will become skilled at developing individualized employment opportunities by using person-centered methods that focus on the contributions an individual can make within his or her community. The long-term goal for the statewide system of adult services agencies is that the model used for the pilot be adopted as a viable method of vocational evaluation and job development and be used for young adults who are interested in a job in the community.

This initiative is using an innovative model of employment planning that promotes:

1. customized job development, including the possibility of self-employment;
2. collaborative cross-agency funding;
3. the use of underutilized resources such as Workforce Investment Act Individual Training Accounts, SSA Work Incentives, and SSA Tickets to Work.

## Summary

Three states and three different initiatives focus on transition for students who are deaf-blind. Each is unique, but they have common characteristics. Each requires a high degree of planning by committed partners, a substantial dedication of resources, a constant and intense level of technical assistance using a variety of strategies, and ongoing evaluation to ensure achievement of the desired results. Although the intensity of this type of technical assistance precludes NTAC from working on an initiative in each of the fifty states, we are excited to engage in additional initiatives in the coming years. The results so far indicate that the additional resources needed for this level of technical assistance will definitely result in positive outcomes for students, as well as in long-term systems change that will benefit more students in the future.

## Reference

National Transition Alliance. (1998). *NTA transition practices framework*. Champaign, IL: Transition Research Institute, University of Illinois at Urbana-Champaign.



## New NTAC Activity: Development of a Classroom Observation Instrument

Kat Stremel, Director

NTAC has recently begun activities that will result in the development of a classroom observation instrument that can be used as a needs assessment tool in classrooms and other learning environments. The major purpose of this instrument will be to efficiently and objectively determine the overall quality of learning environments for students with deaf-blindness and severe disabilities. This type of information will help technical assistance (TA) providers to more effectively design and deliver TA to local programs and direct service providers. The tool will also be used to identify classrooms that may serve as model sites where effective educational strategies can be demonstrated and where opportunities for practical training can be provided to students in personnel preparation programs.

To begin development of the tool, NTAC brought together a focus group of family members, instructors from personnel preparation projects, and state deaf-blind project staff in Chicago in February. The Council on Exceptional Children's *Standards for Beginning Special Education Teachers of Students in Independence Curriculums* was used as a basis for the focus group to begin identifying important classroom characteristics to include in the new tool. Other instruments that emphasize quality program indicators and research studies that have demonstrated effective education techniques will also be critical as development of the instrument progresses.



## Personal Perspectives

Peggy Malloy

This issue of "Personal Perspectives" features Ron Relaford, a musician, massage therapist, and music teacher who lives in Salem, Oregon. Ron has had severe vision loss since childhood and became hard of hearing in his thirties. He talked to me about his varied career, his interests and accomplishments, and the impact that growing up with vision loss has had on his development as a person.

Ron's vision loss, caused by juvenile glaucoma, was diagnosed at age 7 at which time he had already lost half of his vision. Because his father was in the military, Ron was admitted to Walter Reed Army Hospital in Washington, DC, where he stayed for more than 6 months for numerous surgeries and treatments (altogether he has had 19 eye surgeries). His family lived in New Jersey, and he saw them on weekends when his parents and sometimes his brothers and sisters were able to make short visits. At the hospital he stayed on an adult ward and was the only child on that ward. "My best friend there was a four-star general named McCann," he says, describing this experience. "It was not a totally unpleasant time for me. The worst parts were the loneliness and the pain and fear of the surgeries. Eye surgery in the 1950s was not as elegant as it is now. I think that those early experiences really helped me to develop the qualities of resourcefulness and self-sufficiency that have helped me so much in my life. They also taught me the value of family."

Ron had already lost half of the retinas in both eyes at the time of diagnosis, and he progressively lost the rest except for 2 to 3% in his right eye. His vision stabilized approximately 20 years ago. He has essentially no vision in his left eye but has a small amount of central vision in the right eye. Because of this his field of vision is narrow and he can only see small parts of

things at one time. For example, when he looks at another person he can see one feature at a time (e.g., an eye or the nose). He is able to read large print in bright light, but can only see one letter at a time.

Ron also has a mixed (sensorineural and conductive) hearing loss of 50 to 55% in both ears. The hearing loss began when he was in his thirties. Although he is not certain of the exact cause he believes that it may have been caused, in part, by exposure to loud noise when he played rock and roll music in college. Other members of his family are also hard of hearing. With hearing aids he can hear fairly well in quiet environments, but he has difficulty hearing in other types of situations.

Despite his hearing loss music is a central part of Ron's life. He is an accomplished musician and plays a number of instruments, including guitar and mandolin. He is the mandolin player in an innovative bluegrass band called Molly Bloom and teaches private music lessons one day a week. He has a wonderfully open, inclusive philosophy about music. "There is a structure and analytical basis to music that anyone can develop," he says. "It's not a mysterious gift." Ron and his wife Janet love to travel, and he has enjoyed learning about different types of music and instruments during his visits to other countries such as Egypt, Pakistan, and Japan. He has found the sharing of music to be a wonderful way to make connections with people in other cultures.

Although music has been an important part of Ron's working life, he has also worked in very different types of occupations. He said that his philosophy has always been to take risks and try new things. After teaching private music lessons full-time for 18 years, he worked for several years as a computer programmer. Although he really enjoyed the analytical aspects of this work and the thought, concentration, and creativity it required, he found that it was very socially isolating. He describes himself as an outgoing and gregarious person, and he wanted to be more involved with people.

This led to his decision 11 years ago to become a massage therapist. He attended a year-long training program and then opened his own business in Salem. He clearly enjoys and is dedicated to his work. He says that he loves the contact that he has with people ("Everybody leaves with a smile on his or her face"), the physical activity and sense of movement it involves, and the knowledge that he is contributing to a lifestyle of wellness for his clients. He also still teaches private music lessons one day per week just for the enjoyment of it. He teaches a variety of stringed instruments, including the mandolin, guitar, and banjo and also some brass instruments (trumpet and euphonium).

Throughout his life, Ron has developed his own ways of adapting to his limited vision and hearing. He says that he feels very comfortable in his own environments. For example, he says that he walks all over Salem and that he is so familiar with even the smallest details of the areas that he frequents that he doesn't feel the need to use a cane.

Playing music has required some creative adaptations. His most severe hearing loss is in the lower frequencies. This can be a problem when playing in a band because, "In many kinds of music it is the bass that ties everyone together rhythmically and harmonically." Taking this into consideration, he says that when performing with Molly Bloom, "We always place the speaker that the bass plays through close behind me on stage. This is necessary so that I know where we are rhythmically. We always play a lot better when I can clearly hear the bass."



Ron Relaford with his mandolin

Ron believes that his family has contributed to his success in life. He has two brothers and two sisters. Because his father was in the Air Force, his family moved often and lived in numerous places in both the United States and Europe. He never went to the same school for more than a year. He says that he has been very lucky to have the family that he has. "Because of the frequent moves we were a very close and stable family, and we drew a lot of strength from one another."

Even though he had severe vision loss from a young age Ron never received any special educational or rehabilitative services. "When my eye problem developed," he says, "my parents treated me as if I was entirely normal. They didn't do anything special to compensate for my vision loss and never discouraged

me from trying things that I wanted to do. Because of this I've had bad failures but also good successes."

Ron says that he had a difficult adolescence because he felt so different from his peers. He never told his teachers or his peers about his vision loss and instead pretended not to have a problem. Most people outside of his family didn't know that he couldn't see because he kept it a secret. He says that he didn't want it to be a part of his identity when he was an adolescent and that this inability to accept blindness as part of his identity made that time of his life very difficult.

Now, however, he says that he is very comfortable with blindness as a part of his identity. In part, he says, this is due to the influence of his wife who is very forthright and has encouraged him to use the word "blind." But he believes that self-acceptance has also come about as part of the process of maturing that every person has to go through. "It's about how you come to accept your identity and get to like yourself." And while his vision has been the same for many years, he says, "My attitude has changed." Now, he feels that hearing loss is more of a difficulty for him than vision loss. He says that he finds hearing loss to be more socially isolating than blindness.

Although Ron believes that his upbringing helped him to develop self-sufficiency, he feels that he would have benefited from contact with blind adults when he was a child. "I like to talk to blind children myself, as often as I can now, to share my experiences." His advice? "It's important to try things and take chances. Don't assume that you can't do something just because you are blind. Everybody has aptitudes and skills and abilities. I believe that courage is shown, not by doing things that are dangerous or life threatening, but rather by doing things that are difficult or frightening. Even failure can be a success because, if nothing else, you learn something from it."

Editor's note: You can read about Molly Bloom, the band in which Ron plays, and hear some tunes on their Web site at <http://www.mollybloombluegrass.com>.



## Report from the 2003 Texas Symposium on Deafblindness

Nancy O'Donnell, Coordinator of Special Projects  
Helen Keller National Center

Every so often, it's a good idea to attend a conference for professional development. It was this motivation, and not the hope of a reprieve from a brutal New York winter, that landed me in Austin in February. Texas was sponsoring a state symposium, and I was one of the lucky attendees. I had suspected that

the statewide conference would be a small affair, but I should have known better. Texas lived up to its expansive reputation with a forum that rivaled a national conference in quality.

Family therapist Marlyn Minkin set the tone for the conference with her opening presentation. Marlyn has worked with families of children who are deaf and deaf-blind for many years. Along the way, she has surveyed many families and professionals. Because Marlyn's focus is on emotional and mental health, she devised a scale, which she named "The SABOE Factor," a tool for parents and professionals to rate their "Stress, Anxiety, Lack of Balance, Overwhelmed, and Exhausted" levels. Her results show the following:

1. Not surprisingly, the lives of parents of deaf-blind children are consistently more overwhelming and exhausting than those of the professionals who serve them.
2. Mothers are consistently more stressed than fathers, except in the area of "personal life struggles unrelated to deaf-blindness."
3. The one area in which professionals surpassed parents was in "difficulty saying no." Marlyn suggested that many professionals come into this field to help and that saying no is not perceived as being helpful. Mothers, on the other hand, reported the least difficulty saying "no." This is probably an indication of a mother's need to put her child first and to make decisions that are in the child's best interests.

Knowing how stressful life can be, a natural question is, "How can professionals support families through their stressful lives?" Marlyn's first suggestion was to advocate nationally for better respite services. Everyone needs a break! She also emphasized the importance of simply acknowledging feelings. Talking about stress actually provides relief. So many of us want to actively fix situations and people. Marlyn's recommendation was to just listen and affirm. Marlyn administered the SABOE to the conference participants. Although the group's stress level was way above the national average, mine was low. I guess a trip to Texas in the middle of a wicked New York winter can pay off after all.

The next presenter was Barbara McCletchie from Perkins School for the Blind, who provided a refreshing look at teaching concept development and communication to students who are deaf-blind. Communication instruction has historically focused on labeling people, objects, events, and time. Barbara suggested that, although often overlooked, emotions are also critical to concept development. Her formula for success is "People and Emotions + Real Life Learn-

ing Experiences + the Conversational/Interactional Approach + Mutual Trust = Concept Development."

Concurrent sessions offered presentations on an array of topics that were very difficult to choose among. Sessions about sexuality education, cochlear implants, interveners, identification of students who are deaf-blind, technology, and Internet resources were just a few of those available.

The final day of the symposium included an awards luncheon, followed by presentations from a father and two deaf-blind individuals. Presentations by parents always remind me of all the reasons that I love my work. Parents have taught me so much. This gentle man was painfully honest as he generously shared his family's story. His presentation painted a palette of emotions, framed with strength, humor, and love. I wanted to help, to fix something, but I could hear Marlyn's message ringing in my ears. The message, I realized, was to simply listen and affirm. So I sat there, nodding my head in a small but hopefully perceptible sign of affirmation. He closed his presentation with a tribute to his wife to the tune of "Have I Told You Lately That I Love You." I will never think of that song in quite the same way again.

Every so often, it's a good idea to attend a conference. The Texas Symposium on DeafBlindness was a great one.

Nancy O'Donnell, Coordinator of Special Projects, Helen Keller National Center is a DB-LINK information specialist. She also edits *News From Advocates for Deaf-Blind*, the National Family Association for Deaf-Blind (NFADB) newsletter, manages the HKNC National Registry of Persons Who Are Deaf-Blind, and collects and disseminates information about late emerging manifestations of congenital rubella syndrome.



## For Your Library

HomeTalk: A Family Assessment of Children who are Deafblind

*Bringing It All Back Home Project, 2003.*

This is an assessment tool for parents and care providers of children who are deaf-blind and have other disabilities. It is designed to help them participate in their children's education by giving them a way to provide a broad picture of a child's skills, special interests, and personality. *HomeTalk* was developed by the Bringing It

All Back Home project a collaborative effort of Design to Learn Projects at the Oregon Health and Science University and the College of Physicians and Surgeons at Columbia University. It is available for free from DB-LINK. Phone: 800-438-9376. TTY: 800-854-7013. E-mail: [dblink@tr.wou.edu](mailto:dblink@tr.wou.edu).

### PRIIDE DVD

*Logan, UT: HOPE Publishing, Inc. Anticipated publication date is June 1, 2003.*

This DVD is an interactive educational program that addresses sensory loss issues related to deafness, blindness, and deafblindness. The program consists of three curriculum areas: 1) Vision Loss, 2) Hearing Loss, and 3) Combined Vision and Hearing Loss, which are captioned and available in English or Spanish. It provides information and instruction that helps families, teachers, service providers, and medical personnel gain a better understanding of what it means to be deaf, blind, or deaf-blind. Available from HOPE Publishing, Inc. Phone/Fax: 435-245-2888. E-mail: [hope@hopepubl.com](mailto:hope@hopepubl.com) Web: <http://www.hopepubl.com>.

### DeafBlindinfo.org (Web Site)

Links to information and resources for and about people with combined vision and hearing loss. Web: <http://www.deafblindinfo.org>.



## Conferences and Events

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

Contact:  
AADB  
814 Thayer Ave, Suite 302  
Silver Spring, MD 20910-4500  
Phone: 301-495-4403  
TTY: 301-495-4402  
E-mail: [info@aadb.org](mailto:info@aadb.org)  
Web: <http://www.aadb.org>

Pennsylvania Deafblind Summer Institute  
August 4-5, 2003  
August 6, 2003  
Pennsylvania State University

A workshop called "Communication Development and Teaching Strategies for Children with Severe and Multiple Disabilities" will be presented by Charity Rowland and Philip Schweigert on August 4 and 5. On August 6, a complimentary 4-hour summary presentation called "Overview on Presymbolic Communication and Tangible Symbol Systems: Communication Strate-

gies with Severe and Multiple Disabilities, Including Deafblindness" will be offered to parents unable to attend the full two-day workshop.

Contact:  
Juli Baumgarner  
E-mail: [jbaumgarner@pattan.k12.pa.us](mailto:jbaumgarner@pattan.k12.pa.us)  
Phone: 800-446-5607 (PA only) or  
412-826-2336, ext. 6845  
Web: <http://www.pattan.k12.pa.us>

Wyoming Summer Conference  
August 7-8, 2003  
Rawlins, Wyoming

The Wyoming Deaf-Blind Project in conjunction with the Wyoming Department of Education, Services for the Visually Impaired, and the American Printing House for the Blind are holding a workshop called "Cortical Visual Impairments: Critical Thinking-Developing Strategies for Intervention in the Classroom," presented by Dr. Christine Roman.

Contact:  
Joanne Whitson  
Phone: 307-324-5333  
E-mail: [jwhits@educ.state.wy.us](mailto:jwhits@educ.state.wy.us)  
Web: <http://www.k12.wy.us/svi>

Idaho Summer Institute  
August 12-15 & 18-19, 2003  
University of Idaho, Boise

The topic of the Idaho Project for Children and Youth With Deaf-Blindness Summer Institute for the August 12-15 session is "Communication is for All." The content includes community and activity based curriculum-planning, alignment with state standards (Idaho), developing communication systems for pre-symbolic learners, and assistive technology. The topic of the August 18-19 session is "Cortical Visual Impairment," presented by Dr. Christine Roman.

Contact:  
Robin G. Greenfield, Ph.D.  
Phone: 208-364-4012  
E-mail: [rgreen@uidaho.edu](mailto:rgreen@uidaho.edu)

Continuing Education at Renwick College, Royal Institute for Deaf and Blind Children  
Summer and Fall 2003  
New South Wales, Australia

July 31-August 2: "Pathways to Independence: Contemporary Issues in Orientation & Mobility" presented by Sandra Rosen and Dona Sauerburger. August 2: "Street-Crossing for Individuals Who Are Deafblind" presented by Dona Sauerburger. September 29-October 3: "Family Support and Early Intervention in Sensory Disabilities" presented by Deborah Chen.

Contact:  
Renwick College  
Royal Institute for Deaf and Blind Children  
361-365 North Rocks Road  
North Rocks NSW 2151 Australia

Phone: (02) 9872 0207  
 E-mail: renwick@newcastle.edu.au  
 Web: <http://www.ridbc.org/au/services/main.html>

advance order (approximately \$40.00 US) or would like more information, contact Ricard López at [talking3@teleline.es](mailto:talking3@teleline.es).

Helen Keller National Center National Training  
 Team Seminars  
 Fall 2003

Helen Keller National Center,  
 Sands Point, New York

September 29–October 3, 2003 “Developing Strategies  
 for Person Centered Planning”

November 17–21, 2003 “Sensory Loss for the Elderly  
 Population: Confident Living Program”

Contact:  
 Doris Plansker  
 Phone: 516-944-8900 ext. 233  
 TTY: 516-944-8637  
 E-mail: [ntthknc@aol.com](mailto:ntthknc@aol.com)

For a list of additional conferences contact DB-LINK:  
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 or see the conferences listing on the DB-LINK Web site  
 at <http://www.tr.wou.edu/dblink>.



## Announcements

### Deaf-Blind Awareness Week

Every year, Deaf-Blind Awareness Week is celebrated during the week of Helen Keller's birthday, June 27th. Sponsored by the Helen Keller National Center, the week has a different theme every year relating to deaf-blindness. This year's theme is “employment,” especially of young people who are leaving school. Public relations packets, which include a poster, press release, sample proclamation, and public service announcement, are available from HKNC free of charge. For a packet or for more information contact:

HKNC  
 111 Middle Neck Road  
 Sands Point, NY 11050  
 Phone: 516-944-8900 ext. 326  
 Fax: 516-944-7302  
 E-mail: [HKNCINFO@rcn.org](mailto:HKNCINFO@rcn.org)

### Development of a Spanish Version of *Child-guided Strategies for Assessing Children who are Deafblind or have Multiple Disabilities*

*Child-guided Strategies for Assessing Children who are Deafblind or have Multiple Disabilities* is an interactive CD-ROM that uses video clips to demonstrate strategies to determine how to best teach children who are deaf-blind or have multiple disabilities. It was developed by Dr. Jan van Dijk and Catherine Nelson. A plan to produce a Spanish translation is underway but the producers need to know that there is enough interest in this product to cover the costs of production before proceeding. If you are interested in placing an



*Come to Canada  
 in 2003!*  
**13th DBI World  
 Conference Update**

We trust that you are planning to come to Mississauga, Ontario August 5-10, 2003 to experience a week that you won't forget. This will be a great opportunity to meet and mingle with fellow parents, professionals and persons with deafblindness from around the world. It is an opportunity that Canadians associated with deafblindness should not miss.

The Conference Committee is gearing up to present a superb program that will blend the best of current scientific, educational and practical knowledge in the field of deafblindness from Canada and around the world. We want to make sure that Canada will be remembered as a perfect host in blending the serious nature of the conference within an atmosphere of great Canadian hospitality, friendliness, lodging, food and recreation.

**[www.dbiconferencecanada.com](http://www.dbiconferencecanada.com)**

(800) 438-9376 Voice (800) 854-7013 TTY  
[dblink@tr.wou.edu](mailto:dblink@tr.wou.edu)

### Your Information Resource

<http://www.tr.wou.edu/dblink>



The National Information Clearinghouse On  
 Children Who Are Deaf-Blind

Teaching Research Division  
 Western Oregon University  
 345 N. Monmouth Ave.  
 Monmouth, OR 97361

U.S. Department of Education, Office of Special Education Programs,  
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