Deaf-Blind Perspectives

Improving Education for Children with Deaf-Blindness Following Hurricane Katrina

A Technical Assistance Initiative

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This article describes an intensive technical assistance initiative in which the Louisiana Deaf-Blind Project (LADB) and the National Consortium on Deaf-Blindness (NCDB) collaborated with local personnel of the school district serving New Orleans over a period of two-and-a-half years, to help rebuild its capacity to provide services for students with deaf-blindness and other significant disabilities following Hurricanes Katrina and Rita.

Shortly after the school year began in August and September 2005, Hurricanes Katrina and Rita hit the state of Louisiana, causing devastation so far reaching that schools in a seven-parish area were closed for all or part of the remaining school year. The New Orleans area was one of those hardest hit, with most of the infrastructure of the city being heavily damaged or destroyed. Many of the city's school buildings, already in a state of disrepair, were damaged beyond use. Academic records, birth certificates, court documents, and banking records were destroyed or damaged in much of the southern part of the state.

Because of this unprecedented catastrophe, the Louisiana Department of Education decided to designate a large number of the public schools in Orleans Parish as part of the state's Recovery School District (RSD). The RSD is a special school district administered by the Louisiana Department of Education. It was created by a legislative act in 2003 and designed to transform underperforming schools throughout the state into successful places for children to learn (Recovery School District, n.d.). Following Hurricane Katrina in 2005, its scope was enlarged to include numerous schools in New Orleans.

The Recovery School District in New Orleans opened the doors to three schools in the Fall of 2006. It began its first full school year during the fall of 2007 as residents who had fled the city began to slowly return. Trying to rebuild a school system under conditions where there was little or no infrastructure presented numerous challenges. One of the most daunting was how to provide services to students with disabilities, especially those with very significant disabilities like deaf-blindness. For help meeting this challenge, the RSD requested technical assistance from the Louisiana Department of Education based in Baton Rouge.

Technical assistance (TA) can be thought of as a way to help an agency, organization, or even an entire system obtain the skills and resources it needs to solve specific problems. It is useful in situations in which

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the entity needing help lacks the internal means to solve the problems on its own, and it involves outside participation by individuals or agencies with expertise in finding solutions to the types of difficulties presented. In response to the RSD's request for assistance, Joyce Russo, the director of the Louisiana Deaf-Blind Project, and Nanette Olivier, program consultant for significant disabilities at the Louisiana Department of Education, met with Margaret Lang, the director of the RSD's Office of Intervention Services, which oversees special education services, to discuss the district's concerns and explore technical assistance options. Following this meeting, a request for additional assistance was made to NCDB, and in October 2007 Joyce Russo and Nancy Steele, a Tennessee-based NCDB TA specialist, met with Margaret Lang and other special education administrators in New Orleans for a strategic planning meeting. The goal of the meeting was to discuss how the combined resources of LADB and NCDB might assist the district in resolving the major problems it faced. Not surprisingly, the problems were extensive:

◆ There was a severe teacher shortage, and few of the available teachers had certification or experience teaching students with significant disabilities.

◆ Principals and other school administrators had limited understanding of this population of children.

◆ Most of the district's five special education cluster leaders, who were responsible for providing expertise and support to teachers and principals regarding students with disabilities, had limited knowledge or expertise in significant disabilities.

◆ The whereabouts of many children with deaf-blindness who had previously been on the Louisiana Deaf-Blind Project (LADB) Census were unknown, and district administrators were unfamiliar with procedures that could be used to identify them.

Working together, the LADB/NCDB TA providers and members of the RSD's special education administrative team developed a technical assistance plan to address the multilayered, complex needs of the district. Its primary goal was to build the capacity of the school district to identify and educate children who are deaf-blind, but educational personnel working with children with other types of significant disabilities were also included in many of the TA activities.

The TA initiative was conducted from October 2007 to April 2010, and its activities were designed to build on one another from year to year. The first year focused on building relationships with administrators, finding and correctly classifying children with deaf-blindness, and providing training to large numbers of personnel. The second year focused on in-depth coaching for school teams working with students with deaf-blindness. The third year emphasized building the capacity of the administrative team to take over the role of technical assistance to teachers and schools.

Year 1: Getting Started

When the initiative first began, many residents were living in trailers throughout the metro New Orleans area and the homeless resided in tents under the I-10 overpass that runs through the heart of the city. The RSD's earliest-opened schools were concentrated in parts of the city where buildings

could be repaired quickly. Children were allowed to attend any school regardless of where they lived. The RSD's central office was housed at a former social service agency near the Lower Ninth Ward, a section of the city that had been almost totally destroyed, and a number of RSD staff members were living in FEMA trailers. Despite these adverse conditions and even though they themselves had been profoundly affected both personally and professionally, the school personnel of the RSD were dedicated and resilient in their efforts to rebuild the devastated system. Helping the administration learn how to find and assess children who are deaf-blind and conducting workshops and other personnel training events were the primary activities during the first year.

Finding Children with Deaf-Blindness

LADB, like deaf-blind projects in other states, maintains a census of children and youth who are deaf-blind. However, as a result of the confusion following Katrina, previously collected information was no longer accurate. The RSD needed to determine which students with deaf-blindness had returned to the city, where they lived, and if they were attending school. Because the district's assistive technology specialist was the person on the administrative team who was most familiar with where students with significant disabilities were located, she was assigned to lead efforts to find children with deaf-blindness. She enlisted two teachers of the visually impaired to assist her. LADB and NCDB provided training and guidance to the group to help them understand and implement the assessment process for new children in the district suspected of having hearing and vision loss and also in applying criteria for including them on the Louisiana Deaf-Blind Census.

Training Personnel

In response to a critical need for professional development on evidence-based practices for children with significant disabilities and deaf-blindness, a series of training events were conducted in April and May of 2008 for educational personnel in New Orleans and the surrounding parishes. These included introductory workshops on deaf-blindness for teachers; for related service providers such as occupational therapists, physical therapists, and speech-language pathologists; and for paraprofessionals. A separate workshop was held for 25 school principals, during which a "Toolkit for Administrators" was distributed, which described effective classroom environments for students who are deaf-blind and instructional strategies that should be used by their teachers.

Because the RSD was committed to raising awareness of educational strategies for children with significant disabilities and to expanding the inclusion of this population of children in regular classrooms, the events were open to both general and special educators.

The last large training event of the year was a 3-day summer institute on communication for children who are deaf-blind, attended by approximately 75 teachers and related service providers. This large professional development event, hosted by the RSD at the University of New Orleans, was an essential component of the overall TA plan. All subsequent coaching, consultation, and training activities provided in Years 2 and 3 of the initiative built on specific communication practices and strategies taught during this institute.

Targeted Training for Cluster Leaders

Special education cluster leaders who work for the RSD provide TA and training to principals and school personnel who work with special education students. Because of their key role in providing support to schools, the cluster leaders received targeted technical assistance during the initiative. The goal was to improve their ability to provide TA related to deaf-blind education once LADB and NCDB were no longer closely involved in the district. This was essential to sustaining achievements gained during the initiative.

During the first year, training and coaching were provided to five cluster leaders and other central office administrators, including the coordinator of speech and related services, on how to promote effective teamwork and facilitate conversations with school administrators. This helped to prepare them for one of the biggest challenges they face, getting teams of teachers and related service providers who work with students with significant disabilities to collaborate in ways that result in consistent and effective instruction for students.

Year 2: Building Expertise

Technical assistance during the second year was designed to raise the skill level of teams of teachers and other educational personnel by offering on-site coaching in classrooms and other types of training. The goal was to create a pool of expertise in deaf-blind education that would be available in the district once the TA initiative was completed. The Recovery School District also hired two additional cluster leaders with backgrounds in speech and communication and in significant disabilities.

Coaching Educational Teams

The classroom-based TA involved intensive coaching for educational teams responsible for children with deaf-blindness. It built on knowledge that team members acquired at the summer institute on communication development. Although essential learning can result from large-group training events like the institute, research indicates that unless training is followed by on-site coaching, any acquired knowledge and skills are unlikely to be effectively implemented with children in classrooms (Joyce & Showers, 2002, p. 78).

Five teams serving a total of seven students were selected to receive coaching during Year 2 (a sixth team was added during Year 3). The teams typically included the school principal, a special education teacher, a regular education teacher, a paraprofessional, an occupational therapist, a physical therapist, a speech-language pathologist, and a teacher of the visually impaired. Classroom visits were scheduled monthly.

Coaching provided to team members while they were engaged with their student in the classroom included the following:

- demonstrating ways to interact with children and then offering guidance while team members tried the same things,

- facilitating discussions and helping resolve problems concerning students,

- giving assignments and providing feedback, and

- providing emotional support.

Throughout the process, the TA providers and team members worked together as partners, with the team members taking the lead. The content of the coaching sessions focused on specific strategies that teams could employ to promote their students' communication development, such as the use of calendar boxes and routine-based instruction. A team for a student who was fully included in a pre-kindergarten classroom also worked on how to help the child participate in classroom activities.

In January of 2009, all of the teams, a total of 75 participants, came together for an in-service training on how to assess children's communication skills and develop strategies to teach communication based on assessment findings. As with the summer institute, the information provided at this event was used as a basis for further coaching during classroom visits.

A Core Group of Experts

As noted above, the primary purpose of on-site TA was to help the RSD develop a core group of educational personnel with expertise in the education of children who are deaf-blind. These personnel, who work in different schools and represent a variety of roles and specialty areas, can serve as resources to other educators. Examples of this occurred when several related-services team members, independently of coaching or training sessions, assisted teachers to set up classrooms for two young children with deaf-blindness, one of whom had been recently enrolled in an inclusive pre-kindergarten classroom.

Year 3: Planning for the Future

The 2009 to 2010 school year was the last year of the initiative. The main goal for the year was to move the administrative team at the RSD's Office of Intervention Services into the lead role in providing technical assistance and, thus, sustain the procedures that had been put in place during the first two years. Preparation for the administrative team to take over began in the first year of the initiative, when procedures were established to ensure shared decision making and regular high-quality communication between the LADB/NCDB TA providers and the administrative team. Over the course of the initiative, regular meetings were held to evaluate progress, discuss what had been accomplished, identify where improvement was needed, and go over, in detail, the plans for each step of the initiative. In addition, every classroom visit during the second year was attended by the district's assistive technology specialist, the significant disabilities specialist, and the augmentative communication speech-language pathologist, all of whom represented the administrative team.

A New Strategy

During the third year, classroom visits to coach educational teams continued, but their frequency decreased to once every 6 weeks. During this time, a new strategy was introduced to help the teams become more comfortable developing instructional routines for their students. The lead teachers on each team were given video cameras to tape their students engaged in key routines. The video clips were sent to the LADB/NCDB TA providers and were used for discussion during the next classroom visit. The clips were also reviewed with the administrative team members so they could learn to identify and analyze instructional strategies and student interactions. By the end of the

year, the administrative team members were able to review the clips and give solid recommendations to educational teams. The use of video clips was an effective strategy to maximize the limited time available to spend with teachers and other team members and increase the ability of administrators to do classroom coaching.

Creating Sustainability

In January 2010, the administrative team and the LADB/NCDB TA providers met to discuss the progress of the initiative that had been made up to that point and to begin work on a sustainability plan. The plan detailed professional development and coaching activities that would occur in the year following the completion of the TA initiative and indicated who would be responsible for the activities and for providing support to schools and educational personnel.

Conclusion

A great deal was achieved over the two-and-a-half years of this initiative. The RSD developed the infrastructure necessary to provide support and training to classroom teachers and educational teams for students with deaf-blindness. Occupational therapists, physical therapists, and speech-language pathologists increased their leadership capacity to support students in inclusive settings, and more than 200 teachers and other educational personnel developed knowledge and skills in areas essential to improving educational outcomes for students who are deaf-blind or have other significant disabilities.

A final training event in April 2010 showcased the accomplishments of educational personnel to reestablish services for students with significant disabilities and their resilience in working under incredibly difficult circumstances. The scope of this initiative was unusually extensive, but it was necessary given the catastrophic conditions that were present in the aftermath of Hurricanes Katrina and Rita. It illustrates how an educational system and external technical assistance experts can work together to resolve major challenges and improve services for children who are deaf-blind.

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Remembering Charlie Freeman

It is with great sadness that we acknowledge the passing of Charlie Freeman, who died of leukemia at age 70 on June 6, 2010 in North Carolina. All of us at NCDB extend our deepest sympathies to his family.

As OSEP's project officer for the deaf-blind projects from the early 1980s until his retirement in 2006, Charlie was enormously influential in developing and sustaining educational services for children who are deaf-blind and he touched the hearts of all who knew him. Over the more than two decades that he was at OSEP, Charlie worked with all of the state deaf-blind projects, the national projects (TRACES, NTAC, DB-LINK, and NCDB), dozens of model demonstration projects, and many teacher training programs. Following his death, professionals in this network of deaf-blind projects shared their memories of Charlie via an e-mail discussion group. He had been a friend and mentor to many and his unwavering support and encouragement helped those who worked on the projects develop strong services and supports for children who are deaf-blind and their families. He made everyone feel welcome in the community of deaf-blind projects and is remembered as an intelligent, sincere, humorous man who cared deeply about his work and treated everyone with kindness and respect.

Charlie was a strong champion and advocate for children who are deaf-blind. His commitment to improving their lives and his skill as a project officer left an indelible mark on services for children with deaf-blindness in the United States. He will be greatly missed, but his work lives on through the projects he led and the many people he inspired. He made the world a better place, and we will be forever grateful.

Shaping Collective Wisdom in the Field of Deaf-Blindness

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Many readers may be aware that NCDB is working closely with the Department of Education's Office of Special Education Programs to implement a technology initiative to enhance and systematize the national deaf-blind project network and expand opportunities for technical assistance at state, local, and classroom levels. As this exciting initiative moves forward, I find myself reflecting on the current and future value of *Deaf-Blind Perspectives* (DBP), as well as on ways that information about deaf-blindness and the broader field of special education can best be shared among families, consumers, educators, and other service providers within our field. That reflection leads me to a conclusion that a "dual reality" exists relative to information infrastructures that the deaf-blind network can and should exploit to make information and content available. While recognizing and very much supporting that information dissemination efforts are increasingly influenced by the technical, dynamic world of web-based information and resources, as well as by increasingly popular blogs and tweets that deliver "sound-bites" of information, I believe it's important that we not lose sight of the inordinate value and purpose of more traditional publications like *Deaf-Blind Perspectives.*

DBP provides to its audience a dedicated mechanism to highlight current issues in and explore content about deaf-blind education. It focuses deeply on the specialized instructional strategies and methodologies required by students who are deaf-blind and provides families and schools a means to maximize this specialized knowledge by helping to integrate it with other information and resources within the broader field of special education. That's important. We should all offer our thanks for the significant time and dedication each contributing author gives to ensure that readers are provided with valuable information, and we should acknowledge and applaud the significant time and talent of DBP's editorial staff. It's extraordinary how much behind-the-scenes work is required to produce each issue in a way that meets consistently high standards. The high quality of content and the expert articulation of "message" are evident, and we are grateful.

All of us in the deaf-blind network should be cognizant of the opportunities that this publication provides and take advantage of them. To that end, I'd like to highlight the importance of DBP readers' direct participation in the published content. While most articles published in DBP address specific content from the field of deaf-blind education, some offer more personalized perspectives on service delivery models, theories, and approaches that may or may not be familiar to or supported by all readers. While readers all share a personal or professional focus on striving for improved outcomes for and achievement by infants, children, and youth who are deaf-blind, we also have different backgrounds and points of view and can increase our knowledge base by learning from each other. Exposure to and reflection on differing perspectives help to shape our own. Such reflection should be encouraged because the sharing of views and wisdom gained through experience strengthens the accumulated knowledge of our field.

As noted above, there are a variety of ways in which we can share our perspectives and experiential wisdom, and I challenge our readers to take advantage of them, whether in traditional publications like DBP or through newer technology-driven options such as discussion blogs or social media sites. This sharing of information is particularly important during these times in which the United States is engaged in significant educational reform efforts. For example, many readers are aware of pending efforts to reauthorize federal legislation, the Elementary and Secondary Education Act (or No Child Left Behind Act), and presumably to reauthorize the Individuals with Disabilities Education Act. Concurrently within the field of special education, a number of initiatives in the overall design and delivery of both general and special education services are becoming increasingly important, including Response to Intervention (RTI) and Universal Design for Learning (UDL). It is critical that we in the fields of deaf-blindness and other low-incidence disabilities engage actively in conversations about these and other educational reform efforts to ensure that they reflect the needs of children who are deaf-blind and their families, as well as the systemic needs of the field of deaf-blindness. We each have a responsibility to help with the clear articulation of these interests.

In summary, I encourage you to recognize the value of *Deaf-Blind Perspectives* and take advantage of opportunities to contribute to the literature of the field. In the coming months, as NCDB moves forward with its technology initiative, other opportunities for active contribution will become available. Taking advantage of them will allow us

to use the collective wisdom of professionals, families, and consumers to increase our knowledge base and our ability to serve infants, children, and youth who are deaf-blind.

Contributing to Deaf-Blind Perspectives

If you would like to submit an item to be considered for publication in a future issue or if you have ideas and suggestions for future issues, contact Peggy Malloy at NCDB (malloyp@wou.edu; 503-838-8598 or 800-438-9376 Voice; 800-854-7012 TTY).

Deaf-Blind Perspectives publishes articles, essays, poems, and announcements about topics related to deaf-blindness. Its primary focus is on educational issues for children and youth who are deaf-blind.

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Intervener Competencies Training Program in Virginia

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Providing a child with deaf-blindness access to his or her educational environment requires thoughtful planning as well as the involvement of educational team members who understand the impact of dual sensory impairment on learning. Most special educators have never had a student with a combined vision and hearing loss in their classroom, and many states, including Virginia, struggle to recruit and retain teachers who have the knowledge and skills to provide educational services to these students.

The Virginia Project for Children and Young Adults with Deaf-Blindness (VADB) and the Virginia Department of Education (VDOE) are working to address the need for trained individuals to work with students who are deaf-blind. They have created a program designed to provide training and build local expertise in intervention strategies for teams that consist of one paraprofessional and one teacher who work together with a student who is deaf-blind. After completing a year of online coursework through the program, teams re-

ceive an additional year of support that includes on-site coaching.

Interveners

The term intervener refers to a person who has received training to learn specialized skills related to deaf-blindness and who works consistently with an individual who is deaf-blind (Alsop, Blaha, & Kloos, 2000). Core competencies have been established in the field of deaf-blindness that describe the knowledge and skills that a highly qualified intervener should possess (Alsop, 2004; Council for Exceptional Children, 2009, p. 195).

Federal and state special education regulations currently do not recognize interveners as related service providers, and this lack of regulatory recognition has led many states, including Virginia, to seek alternative ways of ensuring that students who are deaf-blind get the supports they need to access their educational environments. One alternative has been for local education agencies to hire staff to serve in the role of dedicated one-on-one teacher aides or paraprofessionals. While this meets the "consistency" part of the intervener definition, it does not necessarily ensure that the person has received training or has the skills to meet the needs of a student with deaf-blindness. Intensive training is necessary for the acquisition of sufficient skills to assist students to gain access to educational and environmental information and, at the same time, promote their independence. Intervener training is one of the main focus areas of the National Intervener Task Force, which was formed in 2002 to work toward a common understanding of the issues, needs, and goals related to interveners (Alsop, Killoran, Robinson, Durkel, & Prouty, 2004). A member of VADB has been on the task force since it began.

Development of the Training Program

Mark Campano, the VADB director at the time the training program was developed, and Deborah Nickerson, president of Dreamcatchers, a statewide deaf-blind family support group, worked in partnership with Dr. Debbie Pfeiffer, the VDOE educational specialist in sensory impairments, to create the Professional Training Program in Deaf-Blindness (PTPDB). The program provides teachers and interveners with the knowledge and skills needed to encourage communication and create access to educational environments for their students. PTPDB uses existing resources to implement a train-the-trainers model that relies on research-based training principles, which includes the elements outlined below.

Trainee Selection

In 2008, VADB staff members selected the first group of trainees from professionals and paraprofessionals who were known to the project. These individuals already had some experience working with children who are deaf-blind and were interested in sharpening their skills and understanding of deaf-blindness. In both 2009 and 2010, applicants were recruited through the VADB's project newsletter, electronic mailing lists, and announcements at professional conferences. To be eligible for the program, applicants had to be currently working with a child on the state's deaf-blind census.

Although individual applicants have been accepted, preference has been given to those who apply as teacher/paraprofessional teams. This promotes teamwork and mutual understanding of the needs of each student and gives participating teachers, who may eventually serve as deaf-blind educational consultants upon completion of the program, a deeper understanding of deaf-blindness and the role of interveners.

Effective Training

Rather than develop a new training program, VADB decided to use a nationally accredited online training program for deaf-blindness offered by Utah State University, which is based on recommended core intervener competencies (Alsop, 2004; Council for Exceptional Children, 2009, p. 195). Trainees take courses in their homes or schools at times that are convenient for them. They complete two four-credit online courses at the undergraduate or graduate level. In addition to covering the full cost of tuition, VDOE provides participants with all course materials.

On-Site Coaching

Once the trainees are enrolled in the training program, a staff member from VADB visits each trainee's classroom to observe their implementation of the intervener competencies and provide suggestions to further improve their skills. Each trainee receives an average of four coaching visits during the program. VDOE pays the travel expenses for these visits, a portion of VADB staff salaries, and the costs of monthly conference calls to facilitate networking among the trainees and to provide support while they are completing their coursework.

Evaluation of Trainees

After the trainees pass both online courses and receive a certificate of completion from Utah State University, VADB personnel assess their skills based on the previously mentioned intervener competencies.

Administrative Support

Prior to entering the program, all trainees are required to obtain permission from their administrator to participate in the coursework and other training activities. The administrators must also agree to allow VADB project staff to provide coaching in the classroom and to allow their personnel to use professional development time to provide coaching to others serving children with deaf-blindness.

Self-Perpetuating

Teachers who complete the program and meet the competencies are eligible to be added to Virginia's Network of Consultants (VNOC) as trained consultants in deaf-blindness and are considered qualified to share with others the intervention strategies they have learned. VNOC is a VDOE program that reimburses school divisions who hire consultants from an approved network of professionals with expertise in the education of children who are deaf and hard of hearing. Prior to the establishment of the Professional Training Program in Deaf-Blindness, the network did not include consultants with expertise in deaf-blind education. When trainees are selected as members of VNOC, additional training on consultation techniques and report writing is provided to them.

Outcomes

During the first year of the program, four paraprofessionals and three teachers completed the coursework. Three paraprofessionals and six teachers completed the coursework in the second year. The effectiveness of the training program was evident to VADB personnel during coaching visits to the first group of trainees. It was obvious that the trainees were competent in ensuring that their students with deaf-blindness were actively engaged in classroom activities. Most remarkable was the quality of their communication with their students.

The trainees themselves also noticed positive outcomes as a result of the PTPDB. In a program evaluation questionnaire, they were asked to anonymously list the changes in their own behaviors and their students' behaviors that occurred as a direct result of the training. The questionnaire was completed by 15 of the 17 trainees, and 100% reported positive outcomes for themselves and their students. The three most frequently reported

outcomes for the trainees were: (a) increased use of objects and/or calendar systems for communication with students (50%), (b) provision to students of more opportunities for choice making (50%), and (c) increased use of strategies to reduce the impact of visual impairments on access to materials and the classroom environment (40%). The three most frequently reported child changes were: (a) increased expressive communication (80%), (b) increased time in a calm, receptive state (decreased frustration) (70%), and (c) increased time spent in exploration (50%). Overall, participants overwhelmingly reported that the coursework was worthwhile because it helped them to better understand their students' needs and behaviors and provided them with strategies to more effectively communicate with them.

Challenges

While the program is already showing positive results, there have been challenges along the way. As stated earlier, the first-year participants were handpicked professionals and paraprofessionals known to VADB. Since then, professionals and paraprofessionals working with children on the deaf-blind census have been openly recruited to apply. Because of the intensity of the training and the time commitment involved, it has not always been easy to recruit and retain enthusiastic participants. The time commitment required to take two four-credit classes seems to be less of a deterrent for teachers and service providers who can use the credits toward recertification. However, finding paraprofessionals who are willing and able to commit to the coursework is challenging. Offering a stipend or credential to paraprofessionals who complete the training may serve as an incentive for participation.

Another difficulty with recruitment is the uncertainty about whether potential participants will be able to work continuously with one student with deaf-blindness for the entire two years of the program. Working closely with school administrators can address this concern to some degree, but there is always a chance that a student will relocate or change schools. Finally, unforeseen events in the participants' personal lives have caused a couple of participants to withdraw from the program. Still, the program has more than an 85% completion rate.

Summary

The positive outcomes reported by participants and observed by VADB staff are the result of significant commitments made by everyone involved.

Trainees spend hours each semester completing coursework and implementing the strategies they learn. The VDOE continues its strong support of the program through its funding of the coursework, training materials, a liaison to oversee the program, and on-site coaching visits from VADB. Local education agencies encourage trainees to participate and to accommodate on-site coaching visits, training activities, and potential work with VNOC. A great deal of time and effort is required from the state deaf-blind project to recruit trainees, coordinate activities, and provide on-site coaching. As we enter the third year, we are planning ways to expand the program further by facilitating opportunities to educate parents and team members who are not in the training program about the strategies that have been implemented successfully by training program participants. While the program continues to be a work in progress, we are pleased to say that in view of the positive outcomes, our efforts have been more than worthwhile.

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Reflections from the Field

"Reflections from the Field" is a column in which we ask experts in the field of deaf-blindness to share their thoughts on important issues. This column features Donna Gilles, Ed.D., associate director of the Partnership for People with Disabilities at Virginia Commonwealth University and the principal investigator for the Virginia Project for Children and Young Adults with Deaf-Blindness, as well as a number of other projects. Throughout her career as a teacher, researcher, and technical assistance provider, Donna has been a strong advocate for people who have significant disabilities, including serving as president of TASH from 2000 to 2003. We asked her to respond to the following questions:

What is your perspective on the availability and quality of services for children who are deaf-blind and their families? How do you think things have changed for better or worse over the past ten years, and what, if anything, do you think needs to be done to improve services in the future?

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Donna Gilles

When I became a teacher a long time ago, my passion was to work with children with significant disabilities—children who were nonverbal, had autism or multiple disabilities, and severe cognitive disabilities. Over time, I moved from teaching to providing technical assistance and training through a variety of projects, including projects for children with deaf-blindness. Since 1995, I have been the director or principal investigator for two state deaf-blind projects, first in Florida and now Virginia. It wasn't until I became a director of a state deaf-blind project that I realized how much need for assistance existed then and continues to exist among families of children who are deaf-blind and schools and community services working with children who are deaf-blind. And although the projects concentrate on a "low-incidence" population, there is enough work for them to last a lifetime.

I am now in my fourth deaf-blind project grant cycle spanning two states, and the Office of Special Education Programs' (OSEP's) message all along, has been, "We want the biggest bang for our buck delivered in the most efficient manner possible." With each iteration of announcements inviting applications for funding for the projects

(1995, 1999, 2003, 2008), the message has been restated, strengthened, and refined. The ever-evolving requirements have included creating and sustaining stakeholder partnerships, using a multifaceted advisory board as a mechanism for needs assessment, building capacity for sustainability, demonstrating impact on other populations, developing communities of practice, reporting effort and effect equally, prioritizing effect over effort, leveraging resources, collaborating with the OSEP Technical Assistance and Dissemination (TA&D) Network (and not just NCDB), improving literacy instruction, and training interveners to enhance child outcomes.

In the 2004 reauthorization of IDEA, the regulatory language authorizing the work of the state and multistate deaf-blind projects (formerly 34 CFR 307.11) was eliminated, and although the funding for the projects was maintained, their vulnerability became salient as they were relegated to equal status with all other Part D programs. This means that their existence is now truly discretionary instead of comfortably authorized. Without specific language in the regulations, the push to prove the worth of the projects has become increasingly important. Those of us who work on the state deaf-blind projects can no longer live in our silos of individual projects; we have had to become active members of the national OSEP TA&D Network. We can no longer just say that we did what we promised; we must demonstrate that what we did worked. We can no longer spend money on activities that are not going to lead to the development of the next generation of knowledgeable professionals; we must make sure that our work will be sustained when we are gone.

A very wise person asked me recently if I thought that the services provided by the deaf-blind projects would be sustained if the funding dried up. The speed with which I said "No" surprised me as much as it did her. There are a myriad of challenges to sustaining the work of the state projects. First, there are very few classrooms in the country that are dedicated to students who are deaf-blind, as we define it. So, one challenge is how to train enough teachers to provide an appropriate education for students who are deaf-blind when students may be in a different classroom every year and/or teachers we have trained may not have eligible students in their classrooms every year. A similar challenge is how to protect students from receiving all of their instruction from a well-trained paraprofessional instead of the majority of it from a certified teacher. A more recently recognized challenge is how to ensure that literacy instruction is delivered to children who are

deaf-blind with equal frequency to that of children without disabilities when so few educators know how to teach literacy skills to children with multiple disabilities, let alone to those needing Braille. Because this is a highly specialized field, meeting these challenges may fuel a false sense of invincibility. That is, the vast need that project staff see everyday can lull us into thinking that the need for targeted services for children who are deaf-blind will always be recognized and funding provided. But, it is important to remember that in the big scheme of all things federal, in an economy that is not likely to recoup to its past level, 10,000 children might one day be viewed as expendable.

Looking to the future and recognizing both the vulnerability and the potential collective power of the state deaf-blind projects may help us become more aware of what we need to accomplish our mission to provide quality educational services for children who are deaf-blind. I was at a recent conference in D.C. where several offices of the U.S. Department of Education, including the TA&D projects, collaborated around the topics of leveraging resources and technology. It was my first meeting with national projects, and I was surprised by the number of them that are layers removed from the child level. The deaf-blind projects are the only projects in the OSEP TA&D Network that can come close to producing measurable child change. They are also the only TA&D programs that have a national project (NCDB) that supports state projects, which, in turn, ensure that technical assistance and dissemination is locally relevant and reliably available. For these reasons, the work of NCDB and our state projects is critical to keeping the TA&D Network alive. Yet the deaf-blind projects are vulnerable because they target an extremely low-incidence population. In order to develop a national presence, our projects need social capital—the kind of relationships where the national TA&D projects can go to bat for us because we have connected with them, done something for them, asked them to do something for us. We need to start a dialogue about how individual state projects can be seen, heard, recognized, respected, and accessed. We need to figure out how to make what we have to offer an asset beyond deaf-blindness, recognizing that what we know is relevant to the larger group of infants, toddlers, school-aged children, and young adults with disabilities. The days of being perceived as being important only to children who are deaf-blind have to end. I really believe that the survival of the deaf-blind projects, and the essential services they provide for children who are deaf-blind, depends on it.

With all of that said, one area of expertise we have to offer is the teaching of augmentative and alternative communication methods. The most common characteristic among the students I taught was that adults communicated for them. It was assumed they would never be able to do it for themselves. To this day, I feel that providing people with disabilities a means of communicating a more sophisticated message than requesting food, drink, bathroom, and break is the single most important thing we can do in our field. Deaf-blind projects have led the way on some major strategies. For example, the popular use of visual schedules for children with autism spectrum disorders as a foundation on which to build better communication skills followed the long-established use of calendar systems in the field of deaf-blindness. Another concept that we recognized long before others is that activities have beginnings, middles, and ends and that children need to experience all parts of them to succeed in adding skills to their repertoire. We have expertise to offer others, we just need to figure out the pieces of our expertise that others will value and get the word out that we really do know what to do with children who have complex learning needs. I am not suggesting that we work with other groups on an ongoing basis; we don't have the resources for that. I am just suggesting that power comes from looking as if and behaving as if our work in the field of deaf-blindness can have an impact on more than 10,000 children.

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Our Life in Music

Crystal and Danielle Morales

We are 27-year-old twin musicians from Austin, Texas. We were born three months premature, and since birth we have lived with hearing and vision loss. Our vision impairment is due to a number of conditions—cortical visual impairment (affecting visual processing in the brain), nystagmus, amblyopia, severe myopia, and severe strabismus. We also have sensorineural hearing loss as a result of ototoxic medications that we received at birth, and we use high-power hearing aids. We have been playing and composing music since the age of 6, and this article describes our musical background and interests.

We are self-taught musicians who learned by playing songs we heard on the radio, one note at a time, on a small Casio keyboard with 8-bit sounds and small keys. As we grew older, we progressed

to more advanced keyboards and synthesizers. We used the same process to learn to play other instruments as well, such as the dulcimer and cello. Currently, we create our compositions using the piano, synthesizer, electric bass, cello, violin, and hammered dulcimer.

Crystal, Umbro (Crystal's guide dog), and Danielle

Synthesizers—electronic instruments that are designed to create a variety of sounds—are an important part of our work. Depending on the type of synthesizer, programming is executed by using knobs, sliders, and controls or by entering numbers into the CPU. Programming synthesizers gives us the freedom to create any sound imaginable. We can completely control every aspect of a sound from its beginning to its end. The basic structure of a synthesizer consists of a signal generator, which emits a sound; a filter, which shapes the waveform; and an amplifier, which controls how loud the sound is over time. Our first "real" synthesizer was a Casio CZ-1000 programmable synthesizer. It uses numbers to alter aspects of a waveform to change its overall shape and create a completely new sound.

Our band name is Jumelle, meaning twins in French. This name was given to us by our Grandmother Danielle, who is a native of France. We compose music every day, and our style ranges from jazz, new age, and classical to retro 80s synth-pop and techno. We enjoy experimenting with new ways to create music that is unique and fun. We have two CDs, *All Things Possible*, and *Meditations*. The latter was a collaborative project with our local Baha'i Center. These CDs are our older compositions. Our newer ones can be heard on YouTube, a website that allows users to watch, upload, and share videos worldwide. You can link to our music channels by going to www.youtube.com/user/TheSynthFreq and www.youtube.com/user/MsMotif6. We are also

members of online forums such as the Association of Adult Musicians with Hearing Loss and the Deaf Musicians section of AllDeaf.com. These forums provide opportunities for us to discuss hearing loss issues, such as the most useful kind of hearing aids, with other musicians.

Although performing live gives us great joy, YouTube is our current venue for sharing our music. As every visually impaired person knows, finding adequate transportation is difficult, and this is a major obstacle for us. Although public transportation is wonderful in Austin, it is not possible to transport our equipment and synthesizers from place to place on the city bus. We hope to solve this problem and return to playing live music again in the city we love so much. In the past we performed at local coffee shops, bookstores that sold our CDs, a radio station, a few local colleges, and at the Arts Council in Denton, Texas, which features artists with disabilities. We also made an appearance on a local morning news show.

To play and compose music in our studio, we use a variety of assistive devices. We cannot hear high or low frequencies. On a piano, low notes just sound like noise and we can't hear higher notes at all. Our hearing aids are designed to shift these frequencies into the audio range that we can hear. In order to write a bass line, for instance, we shift lower notes to a higher octave that we can hear better. We then memorize the notes in the higher octave and shift them back to the original octave when making a recording. The Phonak iCom device is very helpful. It streams audio directly from a synthesizer's amplifier to our hearing aids using Bluetooth. We both wear Phonak Naida V UltraPower hearing aids.

To modify our studio for our vision needs, we have arranged our equipment in a way that allows easy access to switches and controls and we try to keep all wires out of the way. Our sequencer is on a music stand so that its screen can be viewed more easily, and a magnification sheet, taped to the screen, is used to minimize eyestrain. We use Braille and large-print reference sheets that have technical information describing how to operate and program the equipment.

Our synthesizers have Braille labels to identify switches, controls, connection ports, and parameter buttons. We have placed the labels for the connection ports upside down so that we can identify them without having to move the keyboard. The light source in a room or on stage is an issue for most visually impaired performers. Braille labels allow us to find switches and controls quickly and

ensure that we can accurately locate important functions. They are the most effective type of labels since large-type ones do not fit on a synthesizer's complex and crowded control panel. Having to put on reading glasses to search for a switch or control would not be ideal during a rehearsal or on stage. We also use bright green packing tape on small items that are difficult to see, such as SD (secure digital) memory cards, small metal jack adapters, and cables.

To read the LCD displays on our synthesizers during the programming process, we use tinted magnification lenses and high-power reading glasses. Fortunately, all of our synthesizers have high-contrast dot matrix LCD displays, which were very popular in the 1980s (most of our synthesizers are over 20 years old). They are easier to read because they have a 36-point font size and were designed to accommodate performers on stage in low lighting. When naming synthesizer programs, we use all capital letters to make the display easier to read.

Another technological application that we use in our studio is the BrailleNote mPower. This is a small Braille computer that functions like a laptop with a word processor. We use the BrailleNote for concert notes, programming terminology, song ideas, and notes.

Our hearing and vision impairments affect us as musicians in many ways, but we don't let them stop us. We would love more than anything to make music our main career, although we have Bachelor of Arts degrees in vocational rehabilitation counseling/human resources and have that choice of a career as well.

We have been composing music for 20 years and will continue to so. We can't imagine ourselves being truly happy doing anything else. Our goal is to work in the music industry in some capacity. Being musicians and composers means everything to us. We don't know life without writing music, listening to music, and being inspired by other musicians. Being a musician takes you on a personal quest to write new and better music and to challenge yourself to become more skilled at what you do. Performing a successful concert and knowing that your audience enjoyed it with you is the best feeling in the world.

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Striving for Excellence: New Standards for Deafblind Services in Ontario

Jolene Stowell
DeafBlind Ontario Services

In the province of Ontario there is a wide range of services offered to people with deafblindness, including residential programs, community intervenor (the Canadian spelling of the term) programs, accessible housing, and education. Although a variety of agencies and organizations provide these types of services, until recently there were no formal standards to evaluate their consistency and quality. To address this need, in the Fall of 2009 DeafBlind Ontario Services embarked on a project, funded by the Ontario Trillium Foundation, to develop standards to ensure consistent quality of service to people who are deafblind. Standards put organizational values and principles into practice, provide a blueprint for effective and efficient operations, and act as a tool for continually evaluating and improving service.

Development of the Standards

Initially, the plan was to create standards that focused solely on intervenor services. Intervenors facilitate interactions between people who are deafblind and their environments. They are trained in a variety of communication methods and in the use of assistive devices, and they act as sighted guides and communication partners. They provide information using the deafblind person's preferred mode of communication. The goal of intervention services is to promote an individual's independence across his or her lifespan.

In Ontario, the use of intervenors is an essential part of services for people who are deafblind. For example, adults and children who are deafblind may live at home independently or with family and receive assistance from an agency that provides intervenor services in their homes and communities. There are also specialized residential programs exclusively for deafblind adults that provide intervenor services 24 hours a day, 7 days a week. In Toronto, there is a fully accessible, adapted apartment complex that provides people who are deafblind with affordable housing staffed with intervenors available on an as-needed basis. Because intervenor services often occur in the context of these other types of direct services to people who are deafblind, we soon realized that the standards had to be broad enough to cover a range of services, not just intervenor services.

The first step in the development of the standards was to form an advisory committee. The Standards Advisory Committee consisted of representatives from nine organizations that provide intervenor services in a variety of settings, including schools for children who are deafblind, a community college that has an intervenor-training program, a national advocacy organization for people who are deafblind, and several agencies that provide residential or community services. It was crucial to the success of the project that the committee consist of a diverse range of people, agencies, and organizations.

Throughout the process, the committee struggled with the question "How can we ensure that people who are deafblind have services that meet their individual needs?" This was a difficult question to answer. People with deafblindness are not a homogeneous group. Their needs, dreams, and lives are unique and diverse. Our task was complex because no single formula or checklist could be developed to determine what quality intervention looked like.

Everyone on the committee had direct connections with intervenor services, and most had worked as intervenors. However, because none of the committee members had previous experience developing standards, we hired a consultant to provide guidance throughout the process. We decided that our first step should be to conduct a comprehensive literature review to identify existing standards. As the project coordinator, I worked with the consultant to review standards and best practices developed by sister organizations such as Deafblind International (n.d.) and Sense (Lewin-Leigh, n.d.). We also consulted with accreditation bodies around the world to learn how data associated with standards should be measured and reported. Our full committee then used this information as a starting point for developing our own standards.

The committee worked to make standards specific, but also broad enough to apply to a variety of programs and encompass the diverse needs of people who are deafblind. In addition to covering intervenor services and other types of direct services, they cover management characteristics (governance, financial arrangements, and human resource policies) that are an essential part of the functioning of any organization. The result is a set of standards entitled *Standards of Excellence for People Who Are Deafblind.*

The standards document is divided into four sections: (a) governance—assessing the quality of an agency or organization's management prac-

tices; (b) human resources—assessing the quality of human resource policies and procedures for recruitment, retention, and training of employees and volunteers; (c) financial accountability—best practices for the management of finances; and (d) direct services/intervenor services—provision of services in a way that respects the rights of people who are deafblind and meets their needs. Each of these sections contains specific standards. For example, the direct service standards for client rights include the following:

◆ The organization has policies and procedures in place to inform people who are deafblind and/or their family or advocate about their rights.

◆ The organization supports the right of people who are deafblind to have services that are accessible.

◆ The organization respects the right of individuals who are deafblind to have intervenor services.

◆ The organization recognizes the right of the person who is deafblind to develop and express their individuality through choice, freedom, and self-determination.

◆ The organization recognizes that people who are deafblind are at risk of being isolated and supports and/or facilitates community involvement and inclusion.

Quality indicators are provided for each standard, and the document includes space for organizations to indicate whether a standard has been met fully, partially, or not at all and a column to list supporting evidence that elaborates on the extent to which a standard has been met. Examples of possible types and sources of supporting evidence are provided. The quality indicators provide a way to monitor and evaluate progress, but not all will apply to every organization.

The purpose of the standards is to provide a tool to facilitate discussion and inquiry into what an organization does well and identify areas where improvement is needed. The committee resisted creating a template for "cookie cutter" organizations. Organizations are encouraged to adapt the standards to meet their needs and the needs of their clients. They can also use them to compare their practices against those of other agencies in the field, share new ways of doing things, and learn from each other. The standards publication is a living document and will likely change with time as it is adapted to meet the distinctive needs of each agency that uses it.

Pilot Testing and Implementation

It took approximately one year to develop a first draft of the standards. Two 3-month pilot projects—one at an agency representing people with congenital deafblindness and one at an agency representing people with acquired deafblindness—were conducted to test the initial draft. Feedback was gathered from intervenors, management personnel, administrative staff, volunteers, and most importantly, people who are deafblind. The feedback from the pilot projects was very positive, and we found that the standards worked well in both agencies. Not all of the standards applied to both types of agencies, but this had been anticipated. Standards that do not apply to a particular agency can simply be ignored.

Each of the agencies found the pilot-testing process to be an enriching and team-building experience that uncovered many hidden strengths. As a result, they were inspired to share what they know with others. They developed several new policies and put some of their best practices in writing for interagency use.

As a result of feedback from the pilot, the committee made minor changes to the standards and developed a how-to guide that describes the goals and parameters of the standards and tips for their successful use. Resource binders and CD-ROMs containing the standards and the how-to guide have been distributed to all agencies represented on the committee and all other agencies supporting people who are deafblind in Ontario. It is the goal of the Standards Advisory Committee to make these materials available to all agencies that provide services to people who are deafblind, in order to promote consistency in services across the province of Ontario.

Conclusion

For more than a year, DeafBlind Ontario Services and the Standards Advisory Committee worked to develop and implement holistic standards of practice for organizations that serve people who are deafblind. Along the journey, we confirmed what anyone working with people who are deafblind already knows, that the uniqueness of communication with people who are deafblind cannot be simplified or compartmentalized. What we can do as organizations is create a culture of consistency, responsibility, and accountability to our clients, the people who are deafblind who touch our lives each day. It is our belief that the *Standards of Excellence for People Who Are Deafblind*

is an important contribution to this ongoing process.

For more information about the <u>Standards of Excellence Project</u> or to obtain a copy of the standards, contact DeafBlind Ontario Services: www.deafblindontario.com.

References

Deafblind International. (n.d.). *Guidelines for best practice for service provision to deafblind people.* Retrieved from http://www.deafblindinternational.org/standard/publications.html

Lewin-Leigh, B. (n.d.). *Standards for services for adults who are deafblind or have a dual sensory impairment.* Retrieved from http://www.sense.org.uk/publicationslibrary/allpubs/professionals/rights/RT11.htm

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Conferences and Training Events

We had so much great information in this issue of *Deaf-Blind Perspective*s, that we ran out of room for announcements of upcoming events. For a list of upcoming conferences and trainings, go to nationaldb.org or call DB-LINK Information Services at NCDB. Phone: 800-438-9376. TTY: 800-854-7013. E-mail: info@nationaldb.org.

Research Update

New Evidence Standards for Single-Case Design Studies

The What Works Clearinghouse (WWC) recently released evidence standards for single-case design (SCD) studies. Because the low incidence of deaf-blindness makes it difficult to use traditional research designs that require a large number of participants, this is an important advance for researchers who study interventions for children and adults who are deaf-blind. Like random assignment studies, well-designed single case designs can attain the highest WWC rating, "meets standards." The publication *What Works Clearinghouse: Single Case Design Technical Documentation* (http://ies.ed.gov/ncee/wwc/pdf/wwc_scd.pdf) includes an overview of SCD studies and the types of questions they are designed to answer.

New Research Study: Understanding Sleep Apnea in Children with CHARGE Syndrome

Currently, there is very little information available concerning symptoms or treatment options of sleep apnea in the CHARGE Syndrome population. The principle investigator of this study, Dr. Kim Blake, is hoping to gather information in this area, as well as determine the effects of tonsil and adenoid removal. Participants in the study will be asked to complete a short series of questionnaires regarding their child's sleep habits. The child must be between birth and age 14 and have a confirmed clinical or genetic diagnosis of CHARGE Syndrome. A previous diagnosis of sleep apnea is not necessary. For more information, contact the research assistant Carrie-Lee Trider at cr281800@dal.ca.

New Research Articles

The number of research articles on important topics in deaf-blindness continues to grow, adding to the knowledge base of the field. The following is a selection of research studies published in a variety of peer-reviewed journals over the past year.

Arndt, K. (2010). College students who are deafblind: Perceptions of adjustment and academic supports. *AER Journal: Research and Practice in Visual Impairment and Blindness, 3*(1), 12-19.

Bashinshki, S. M., Durando, J., & Stremel Thomas, K. (2010). Family survey results: Children with deaf-blindness who have cochlear implants. *AER Journal: Research and Practice in Visual Impairment and Blindness, 3*(3), 81-90.

Fellinger, J., Holzinger, D., Dirmhirn, A., van Dijk, J., & Goldberg, D. (2009). Failure to detect deaf-blindness in a population of people with intellectual disability. *Journal of Intellectual Disability Research, 53*(10), 874-881.

Hartmann, E. S. (2010). Understanding teachers' self-efficacy to support children with deaf-blindness. *AER Journal: Research and Practice in Visual Impairment and Blindness, 3*(3), 91-97.

Ingraham, C. L., & Andrews, J. F. (2010). Hands and reading: What deafblind adult readers tell us. *British Journal of Visual Impairment, 28*(2), 130-138.

Janssen, M. J., Riksen-Walraven, J., van Dijk, J. P. M., Ruijssenaars, W. A. J. J. M. (2010). Interaction coaching with mothers of children with congenital deaf-blindness at home: Applying the diagnostic intervention model. *Journal of Visual Impairment and Blindness, 104*(1), 15-29.

Johansson, M., Gillberg, C., & Rastam, M. (2010). Autism spectrum conditions in individuals with Möbius sequence, CHARGE syndrome, and oculo-auriculo-vertebral spectrum: Diagnostic aspects. *Research in Developmental Disabilities, 31*, 9-24.

Johnston, D. R., et al. (2010). Ophthalmologic disorders in children with syndromic and nonsyndromic hearing loss. *Archives of Otolaryngology Head Neck Surgery, 136*(3), 277-280.

Lina-Granade, G., Porot, M., Vesson, J.-F., & Truy, E. (2010). More about cochlear implantation in children with CHARGE Association. *Cochlear Implants International, 11*(1), 187-91.

Narayan, J., Bruce, S. M., Bhandari, R., & Kolli, P. (2010). Cognitive functioning of children with severe intellectual disabilities and children with deafblindness: A study of the perceptions of teachers and parents in the USA and India. *Journal of Applied Research in Intellectual Disabilities, 23*, 263-278.

Nelson, C., Janssen, M., Oster, T., & Jayaraman, G. (2010). Reliability and fidelity of the van Dijk assessment. *AER Journal: Research and Practice in Visual Impairment and Blindness, 3*(3), 71-80.

Pizzo, L., & Bruce, S. M. (2010). Language and play in students with multiple disabilities and visual impairments or deaf-blindness. *Journal of Visual Impairment and Blindness, 104*(5), 287-297.

Prain, M., McVilly, K., Ramcharan, P., Currie, S., & Reece, J. (2010). Observing the behaviour and interactions of adults with congenital deafblindness living in community residences. *Journal of Intellectual and Developmental Disability, 35*(2), 82-91.

Rowland, C., Stillman, R., & Mar, H. (2010). Current assessment practices for young children who are deaf-blind. *AER Journal: Research and Practice in Visual Impairment and Blindness, 3*(3), 63-70.

For Your Library

New Publications and Products

Practice Perspectives: Authentic Assessment
National Consortium on Deaf-Blindness, 2010, 4 pages.
This publication describes an authentic approach
to the assessment of communication and learning
that emphasizes gathering information about chil-
dren in their everyday environments during nor-
mal activities. This is the sixth in series of
publications called *Practice Perspectives*. This and
previous issues of *Practice Perspectives* are avail-
able on the web (standard print, large print, and
Spanish):
nationaldb.org/NCDBProducts.php?prodID=111.
For print or Braille copies, contact NCDB at
800-438-9376 (Voice), 800-854-7013 (TTY), or
info@nationaldb.org.

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Victory and Fragrance: Kai Hsin's Story [DVD]
*The Pacific and Hawai'i Deaf-Blind Projects, 2010, 17
minutes.*
This DVD tells the story of Kai Hsin, a girl who
has CHARGE Syndrome. The video is narrated by
Kai Hsin's mother who describes her daughter's
history of medical problems and surgeries, the ed-
ucational and other special services that helped
her learn and develop, and how she and her hus-
band have cared and advocated for Kai Hsin
throughout her life. At the end of the video, Kai
Hsin (now 11 years old), who communicates via
sign language, tells her own story of her family,
her school, her interests, and what she would like
to be when she grows up. Cost: $10.00. To order
go to www.cds.hawaii.edu/main/store or call
808-956-5861.

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CHARGE Syndrome
*Timothy S. Hartshorne, Margaret A. Hefner, Sandra L.
H. Davenport, & James W. Thelin. Plural Publishing,
Inc., 2010, 381 pages.*
This book provides comprehensive information
about the sensory, physical, and psychological chal-
lenges faced by children with CHARGE syndrome
and ways to overcome these challenges. Available

from the publisher (www.pluralpublishing.com)
and through bookstores.

AER Journal Special Issue: Current Practices
with Children Who Are Deaf-Blind
Deborah Chen, Guest Editor.
The Summer 2010 issue of *AER Journal: Research
and Practice in Visual Impairment and Blindness* con-
tains seven articles about the education of children
with deaf-blindness (four original research articles
and three practice or theory-based articles). The
fall issue of the journal will be a special issue on
deaf-blindness in adults. An annual subscription
to the journal costs $109 for institutions in the U.S.
and $135 for institutions outside the U.S. Single is-
sues can be purchased for $30.00 (in the U.S.) and
$40.00 (outside the U.S.). To order call
800-627-0326 (e-mail aerj@allenpress.com).

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Child-Guided Strategies: The van Dijk Approach
to Assessment (Guidebook and DVD)
*Catherine Nelson, Jan van Dijk, Teresa Oster, & Andrea
McDonnell. American Printing House for the Blind,
2009.*
This guidebook describes the assessment of chil-
dren who are deaf-blind using an approach devel-
oped by Dr. Jan van Dijk. Assessment techniques
and general intervention strategies are provided
for a child's behavioral state, orienting response,
learning channels, likes and dislikes, memory, so-
cial interactions, communication, and prob-
lem-solving skills. Video clips of two children
demonstrating the concepts described in the book
are provided on a DVD. Available from the Amer-
ican Printing House for the Blind. Phone:
800-223-1839. E-mail: info@aph.org. Web:
www.aph.org.

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Let's talk Limbic: The Role of the Emotional
Brain in the Well Being of Persons with Multiple
Sensory Impairment [DVD]
*Jan van Dijk, Catherine Nelson, Arno de Kort, Johannus
Fellinger, & Rick van Dijk. Aapnootmuis, 2010.*
This DVD is for professionals and
paraprofessionals who want to understand the
deep emotional motives of a person with multiple
sensory impairment. It describes the functioning
of a major part of the human emotional brain, the
limbic system and illustrates how sensory depri-
vation affects emotional well-being. Available
from Vision Associates: 295 NW Commons Loop,
Suite 115-312, Lake City, FL 32055. Phone:
407-352-1200. Web: www.visionkits.com.

Providing and Receiving Support Services: Comprehensive Training for Deaf-Blind Persons and Their Support Service Providers

Seattle DeafBlind Service Center, 2010.

This curriculum is designed to be used to train support service providers (SSPs) to work with people who are deaf-blind and to train people who are deaf-blind to work with SSPs. Available free of charge at http://seattledbsc.org/visualweb/SSPCurriculum.html.

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Deafblindness: Educational Service Guidelines [Now available online!]

Marianne Riggio & Barbara McLetchie (Eds.). Perkins School for the Blind, 2008.

These guidelines, first published in 2008, are now available for free online at www.perkins.org/resources/educational-publications/deafblindness-educational-service-guidelines. The guidelines offer state and local education agencies a framework from which meaningful, appropriate programming for students who are deafblind can be developed. Bound copies of the guidelines can still be purchased from the Perkins store (www.perkins.org or 617-972-7308).

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Environmental Description for Visually and Dual Sensory Impaired People

Riitta Lahtinen, Russ Palmer, & Merja Lahtinen. A1 Management UK, 2010.

This book presents techniques to provide real-time environmental description of everyday experiences ranging from life activities to artistic interpretations. It focuses on both the describer's and receiver's perspectives and gives practical examples and exercises for professionals who work with people who are deaf-blind or have visual impairments. Available from the Ear Foundation in the UK (www.earfoundation.org.uk/shop).

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Online Media

New Perkins Webcasts

Web: www.perkins.org/resources/webcasts

Perkins School for the Blind has developed a variety of informative webcasts presented by experts in the field of visual impairment and deaf-blindness and more are planned for the future. Recently added presentations include "Reflections on Deafblindness: Hands & Touch," and "CHARGE Syndrome: Teaching Strategies for Sutdents." These and previous webcasts can be viewed free of charge on the Perkins website.

Who's Who on My Child's Team Videos

Web: www.cadbs.org/videos

California Deaf-Blind Services (CDBS) is developing a series of online videos that highlight the roles of specialists often included on educational teams for students who have both hearing and vision problems. Currently two videos ("Teacher of the Deaf/Hard of Hearing" and "Occupational Therapist") have been completed. Six additional videos are planned.

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Announcements

Invitation to Apply to NLCSD Fellows Program

Applications for fellowships for the second and final cohort of the National Leadership Consortium in Sensory Disabilities (NLCSD) are now being accepted. NLCSD Fellows participate in a structured added-value enrichment program in addition to their individual Universities' doctoral programs of study. Sponsored by the U.S. Department of Education, Office of Special Education Programs, the consortium consists of 25 universities with doctoral programs that have an emphasis in one or more of the three sensory impairment areas: blind/visually impaired, deaf/hard of hearing, and deafblindness. Applications will be accepted until December 31, 2010. The cohort will begin their studies in the fall of 2011. Information about the application process and the application are available at www.salus.edu/nlcsd/index.html.

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New Interpreting Task Force Website

The National Task Force on Deaf-Blind Interpreting is pleased to announce their new website! Visit the site at www.deafblindinterpreting.org to learn more about the task force and find links to the recently updated *Annotated Bibliography* on *Deaf-Blind Interpreting* and other resources.

New on the NCDB Website

The NCDB website is an excellent resource for in-depth, high-quality information about deaf-blindness (nationaldb.org) and it is widely used by people in the United States and throughout the world. Last year there were 1,736,266 visits to the site. Listed below are some of our new website features. If you would like more information call 800-438-9376 and we would be happy to give you a tour of the range of resources that are available.

DB 101 (nationaldb.org/DB101.php)

DB 101 is designed to provide an introduction to educational issues for children who are deaf-blind. It provides links to a selection of introductory materials on the nature of deaf-blindness, the impact of combined vision and hearing loss on communication and social interactions, and the importance of individualized educational strategies and supports.

For Families (nationaldb.org/FFStories.php)

This section of our website contains family stories, important information that families need about educating children who are deaf-blind, advocacy resources, and a description of the work of family specialists at state deaf-blind projects.

National Deaf-Blind Child Count Maps (nationaldb.org/MapsViewOptions.php)

These graphic map displays of National Deaf-Blind Child Count data provide a geographical presentation of state data organized and displayed by a variety of criteria including age, race/ethnicity, and educational setting.

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Search National Consortium On Deaf-Blindness

Do you have questions about anything you have read in *Deaf-Blind Perspectives* or need other information about deaf-blindness?

Contact DB-LINK Info Services at the National Consortium on Deaf-Blindness

Call us!
800-438-9376
800-854-7013 TTY

E-mail us!
info@nationaldb.org

Visit our web site!
www.nationaldb.org

Together We Make The Connections

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