Remarks in Honor of the Retirement of Charlie Freeman

Michael Collins, Director
Hilton/Perkins Program, Perkins School for the Blind

Editor’s note: Charlie Freeman, the officer overseeing deaf-blind projects under the U.S. Department of Education’s Office of Special Education Programs (OSEP), retired in May 2006 after many years of service. A celebration was held in his honor at the National Consortium on Deaf-Blindness topical conference in San Antonio last May. At the event, his colleagues shared memories and thanked Charlie for his leadership and support over the years. The following remarks by Mike Collins were delivered by telephone since he was unable to attend the conference.

Hello Charlie, and everyone! A very big congratulations to you on your well-deserved retirement. I offer my sincere apologies for my inability to be present this evening.

I first would like to offer a few thoughts to consider. Charlie came to OSEP after the departure of Bob Dantona, who oversaw the deafblind program in more favorable and financially generous times. At the time, there was a movement in place for the program to be absorbed into the umbrella program for all children with severe handicaps, and for it to be eliminated as a separate category of service. This was way back in the 1980s! Many of you have been around long enough to remember that the deafblind field revolted, created the National Coalition on Deafblindness to protect the program, and pressured the Congress to retain specific services for the deafblind. As you can imagine, you-know-who was in the crossfire of this action! Yet he handled it diplomatically, patiently, and with the usual “Charlie” polish and reserve. You all know the outcome; the deafblind field has survived and flourished for two and a half decades. Charlie and Shirley Freeman

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half more decades. So, Charlie, you have proven yourself to be both a survivor and a guardian!

Now, everyone, please consider this list:
- James Earl Carter
- Ronald Wilson Reagan
- George Herbert Walker Bush
- William Jefferson Clinton
- George Walker Bush

They all had the honor of serving over Charlie Freeman during his deafblind tenure at OSEP! Now, consider all of their political appointees with all of their strange ideas of education and the various OMB people and their stranger ideas of what services should exist; then tell me that Charlie Freeman is not a survivor!

Another list for you to consider: 48 to 50 state projects, 4 to 5 teacher training projects, dozens of model and demonstration projects, pilot projects, the TASH technical assistance project, research projects, the National Symposium on Deaf-Blindness, the Helen Keller National Center transitional project, TRACES (Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments), NTAC (National Technical Assistance Consortium on Children and Young Adults Who Are Deaf-Blind, DB-LINK (National Information Clearinghouse on Children Who Are Deaf-Blind), the National Consortium on Deafblindness, and the American Foundation for the Blind’s Hand in Hand Project. Now consider the thousands of opinions these hundreds of projects have represented over 25 years! Enough to drive a man home to Missouri or away to Wyoming, I should think! And Charlie, you have survived them all, mentored them all, and aided their purpose hugely.

It is with a great sense of gratitude that we wish you the happiest of retirements and congratulate you on a job well done! You have not only helped us to survive but helped us to accomplish our purposes throughout your years of service. All our best to you!

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New OSEP Project Officers

Following Charlie Freeman’s retirement, the Office of Special Education Program’s deaf-blind project assignments were distributed among four project officers who are part of a new Deaf-Blind Portfolio Workgroup. *Deaf-Blind Perspectives* asked each of the project officers—Anne Smith, Ernest Hairston, Louise Tripoli, and Glinda Hill—to tell us about their current work and interests.

**Anne Smith, Deaf-Blind Portfolio Workgroup Manager**

When Charlie Freeman retired, OSEP determined that it was necessary to shift from a “one-project-officer-does-it-all” management approach to a “distributed leadership” structure in order to actively involve a number of OSEP staff members in managing the $12.8 million annual expenditures that are allocated for projects related to infants, toddlers, children, and youth who are deaf-blind. Distributed leadership ensures that all OSEP teams are aware of and will become increasingly familiar with the deaf-blind projects.

Personnel serving on the Deaf-Blind Portfolio Workgroup all have expertise working with people who are deaf or hard of hearing or people who are blind or visually impaired. There are repre-
sentation from both the Research to Practice Division (Ernie Hairston, Glinda Hill, Louise Tripoli, and myself) and the Monitoring and State Improvement Division (Angela McCaskill). In addition, the workgroup meets regularly with JoAnn McCann regarding captioning and media services and Maryann McDermott regarding the low-incidence disabilities personnel preparation programs.

In addition to working with the deaf-blind workgroup, I serve as project officer for an array of projects including field-initiated research, technical assistance, personnel preparation, and technology efforts. I am a third-generation educator and have degrees from Syracuse, Gallaudet, and Johns Hopkins universities. Becoming the lead for the Deaf-Blind Portfolio Workgroup is very much like “coming home.” I am delighted to be working with the deaf-blind projects.

I graduated from Gallaudet College (now University) with a bachelor’s degree in education. I received a master’s degree in administration and supervision from California State University at Northridge, and a doctoral degree in special education administration from Gallaudet.

As an education research analyst within the Office of Special Education’s Research to Practice Division, I serve as the agency’s expert in educational media and media technology for individuals with disabilities, including those who are deaf, hard of hearing, blind, or print-disabled. In addition to working with a number of deaf-blind projects, I am the project officer for the Described and Captioned Educational Media Program, the National Center for the Study of Supported Text in Electronic Learning Environments, the Center for ASL/Bilingual Education and Research, and the Minority Outreach and Technical Assistance Center.

I am coauthor of Black and Deaf in America: Are We that Different?, and I am involved in a number of organizations including National Black Deaf Advocates, National Association of the Deaf, and Mabuhay Dance Troupe (a Filipino-American organization). I am also a sign master for some of the Washington, DC, area theaters, including the Kennedy Center, Arena Stage, and Smithsonian Institution, and for Center Stage in Baltimore.

In addition to serving as project officer for five state deaf-blind projects, I am the project officer for four regional technical assistance and dissemination centers that address transitional and postsecondary educational programs for students who are deaf or hard of hearing, and I monitor a number of grants in personnel preparation, technology and media, and research programs. It gives me great pleasure to be working with the deaf-blind projects. My passion is to learn about the challenges and opportunities facing students who are deaf, hard of hearing, or deaf-blind as they transition from secondary school into postsecondary educational settings or employment. I am interested in the development of a stronger partnership between secondary education and postsecondary education programs.

I received a bachelor’s degree from the University of North Texas and a master’s degree in deaf education from Columbia University. I have served as the project officer for the Described and Captioned Educational Media Program (DCMP) and the National Center for the Study of Supported Text in Electronic Learning Environments (NCST). I have also worked with the Center for ASL/Bilingual Education and Research and the Minority Outreach and Technical Assistance Center.
Glinda Hill

I’ve worked at OSEP as an Education Research Analyst since 1997 on a variety of projects in the areas of early childhood, visual impairment and blindness, technology, and parent training. I am also a member of an OSEP policy workgroup focusing on implementing the IDEA amendments related to the National Instructional Materials Accessibility Standard and serve on a number of interagency workgroups concerned with child abuse and neglect, early identification and screening of visual problems in infants and young children, and other issues in visual impairment and blindness. Prior to joining OSEP, I worked as a special education teacher, a technical assistance provider, and a Part C district office director.

I have a bachelor’s degree in special education from the University of Alabama and a master’s degree in special education and visual impairments from Vanderbilt University, and I have completed doctoral coursework in human development and learning at Vanderbilt University. I am married to Rod Hill, a musician and teacher, and have three sons, two daughters-in-law, and one beautiful granddaughter (Rosalie Coretta Hill, age 4 months). All live in Nashville. I have commuted to Washington, DC, for the past 10 years!

My primary interests are planning and developing new programs and initiatives and improving existing programs. My professional experiences and interests both at OSEP and prior to OSEP make working with the deaf-blind program and its individual projects a good match for me. I look forward to working with the deaf-blind projects in the coming months.

Deaf-Blind Interpreting News

Susanne Morgan Morrow

A national spotlight is being placed on the important topic of deaf-blind interpreting. The National Task Force on Deaf-Blind Interpreting (NTFDBI) was established to remedy the lack of training in the field of deaf-blind interpreting. The task force resulted from the passing of a motion written by the American Association of the Deaf-Blind and the Registry of Interpreters for the Deaf, Deaf-Blind Member Section (RID DBMS) during the 2005 RID National Conference. Over time, the initial collaborative effort grew to include three national entities: the Registry of Interpreters for the Deaf, the American Association of the Deaf-Blind (AADB), and the National Consortium of Interpreter Education Centers. The first face-to-face meeting of the task force, facilitated by Cathy Kirscher (a regional representative for the Helen Keller National Center), was held during the RID National Conference in San Francisco in August 2007. The purpose of the meeting was to develop the mission statement and scope of work for the task force. Rhonda Jacobs (jacobs_rhonda@yahoo.com) and I (morgansusie@att.net), as co-chairs, welcome input and questions regarding the task force.

The RID subsection that focuses on deaf-blind interpreting has made the official transition from the Deaf-Blind Special Interest Group (DB SIG) to the Deaf-Blind Member Section (DBMS). In order to make the transition, RID required a formal request, endorsements from RID members, and a member section purpose and profile. The new entity, RID DBMS, held a social and fundraising event during the RID National Conference in August. The master of ceremonies was AADB Executive Director Jamie Pope, and the event included entertainment, raffle drawings, and prizes. Raffle ticket sales totaled $1,012, and donations in the amount of $3,295 were collected. Generous fundraiser cosponsors included Sorenson Communications; Northeastern University Regional Interpreter Education Center; Northern California Association of the Deaf-Blind; SignTalk, LLC; Seattle Lighthouse for the Blind; Deaf-Blind Explorers; and DB-TIP (Deaf-Blind Training, Interpreting, and Professional Development). All proceeds will go to the RID DBMS to support deaf-blind interpreting training initiatives. Questions or suggestions for the Deaf-Blind Member Section may be sent to RIDDBMS@hotmail.com.

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Harmonious Interactions: A New NCDB Publication

The National Consortium on Deaf-Blindness (NCDB) has a new 4-page publication called Harmonious Interactions. It describes the importance of teaching families and educators to create and maintain high-quality interactions with children who are deaf-blind. This is the first of series of publications, called Practice Perspectives, designed to expand and broaden the use of current information resources by developing easily understandable products with accessible formats.

When people interact harmoniously, their attitudes and actions toward one another are comfortable and reassuring. These types of interactions form the basis for meaningful, secure relationships that are essential for learning, development, and communication. Harmonious Interactions is based on publications by Marleen Janssen, a researcher in the Netherlands, and her colleagues, who found that although interactions with children who are deaf-blind can be difficult, family members and educators can learn to create and maintain harmonious interactions.


Print and Braille copies are available from:
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New National Consortium on Deaf-Blindness Website

Nationaldb.org  Nationaldb.org  Nationaldb.org

- Comprehensive source of information and resources on deaf-blindness, technical assistance, and personnel training
- Easy access to full text materials on more than 70 subjects in Selected Topics
- Announcements of upcoming events and new publications
- Resources for families and teachers
Selecting an Intervener for a Student Who Is Deafblind

Cindi Robinson
Deafblind Specialist and Intervener Training Coordinator
Arizona Deafblind Project

In this day and age, most special education programs use instructional aides (paraprofessionals) to assist teachers in the classroom. Some special education students are assigned a one-to-one paraprofessional based on needs identified in their individualized education programs (IEPs). An increasing number of students who are deafblind are assigned an interveners, who also works one-to-one. However, there is a significant difference between an interveners and a typical one-to-one special education paraprofessional. The primary difference is that the interveners works with a student who is deafblind, and is expected to receive specialized, in-depth training in deafblindness and deafblind educational strategies. Therefore the term "intervener" is used only for individuals working with students who are deafblind. A key role of interveners is to provide continual access to both information and communication for their students (Alsop, Blaha, & Kloos, 2000).

Finding the right person to be an interveners for a child who is deafblind is essential. The Arizona Deafblind Project has been supporting and training interveners for 10 years, and during that time we have learned a great deal about the qualities, characteristics, and training needs of effective interveners. An understanding of these is important when interviewing candidates for interveners positions. This article addresses important issues and strategies and suggests potential interview questions to help interview teams identify the best candidates.

The Arizona Deafblind Project’s Experience

The Arizona Deafblind Project began its journey into the world of interveners training and support in 1997. At that time, only three other states (Utah, Texas, and Minnesota) were using interveners. As we began to develop an interveners training program, Arizona Deafblind Project staff members collaborated with professionals in these other states. Over the past 10 years, our program has expanded in both size and vision. It is currently a 2-year team-training program that includes six workshops of two or three days each, ongoing support, and onsite classroom follow-up for entire educational teams. Each team that attends the training program works with a student who has been identified as deafblind, and team members participate in assignments and activities that focus on their student. During the past 10 years, over 250 people have been trained.

Arizona interveners trainers include specialists in deafblindness, communication, vision, hearing, neurodevelopmental therapy, orientation and mobility, and occupational therapy. Trainers meet regularly to plan and review training components and to continually improve the program. Arizona trainers have developed a two-year training plan, several teaching units on specific topics, and a document entitled “Enduring Understandings for Deafblindness,” which details the core beliefs and mission of the interveners initiative in Arizona.

Suggestions for Interview Teams: Overview of the Issues

Much of the decision about whom to hire as an interveners for a specific student is based on the instincts of the interview team members and their direct knowledge of the student. It is also important for the interviewers to have a clear understanding of the skills and abilities required of interveners before beginning the interview process. Because of the specialized skills and qualities that are required, questions asked in an interview with an interveners candidate should be more comprehensive than those asked of typical paraprofessional candidates. Additionally, the interview team must glean information about a candidate that they may not be able to ask for directly.

It is essential that an interveners have a strong interest in working with children who are deafblind. The team must ascertain a candidate’s level of experience with children (both with and without disabilities). However, it is possible that an individual with little or no experience, but a high degree of interest and a willingness to learn, may be the best candidate. The candidate should also have realistic expectations about working with a student who is deafblind or deafblind with additional disabilities. The work can be very intense and demanding, and interveners must be able to handle the pace and intensity of the work.

An interveners should sincerely like the child with whom he or she works. The bond between an interveners and a student is critical for success be-
cause it is the foundation for a student’s learning, development, and socialization. A good match between a student and an intervener in terms of personality and energy level is important. An intervener must be aware of the importance of touch and movement and cannot have difficulties with personal space or touching that would interfere with his or her ability to work with a student. Even if a student has some useable vision or hearing, most children identified as deafblind rely on touch to help them gather information and learn. The intervener will have to learn the hand-under-hand method of interacting (a technique of guiding a child’s hands to explore and manipulate items), as well as work in close physical proximity to his or her student, sometimes with their bodies touching.

As stated above, interveners are required to have specific training in deafblindness. Many state deafblind projects offer intervener training and support to educational teams. There is also an intervener training program available online (see announcement, page 8). The classroom teacher and the intervener for a child should attend all intervener and deafblind trainings together. Other related service providers assisting the student should also be trained in deafblindness and encouraged to attend trainings with the teacher and the intervener. This will strengthen the team and provide an understanding of deafblindness and deafblind teaching strategies to the primary decision makers on the educational team.

Interveners need good observation skills and the ability to learn about the child from the child. They must be able to incorporate the strategies demonstrated and modeled by service providers from a wide variety of disciplines. In addition, they must be able to accept feedback from these many service providers.

The ability to collaborate is essential because interveners work closely with teachers and related service providers. They should be comfortable sharing with other members of the educational team the information and techniques that work well with a student. Collaborative teaming skills are addressed in most intervener training programs, so candidates without prior experience working on teams, but who have the ability to learn these skills, can get appropriate training.

### Potential Interview Questions

The following are recommended questions to ask intervener candidates. Agency-specific questions can be added at the end (or beginning) of the questions.

1. Tell us about your experience with children, including those with disabilities.
2. Do you have experience with children who have sensory impairments—blind or visually impaired, deaf or hard of hearing, or deafblind?
3. What is your educational background? Have you taken classes at the community college or university level? If so, what topics did you study?
4. Why are you applying for this position? What is your interest in deafblindness?
5. Do you have sign language skills? If not, would you be willing to learn? (Probe whether candidates

### Qualities needed in an Intervener

- Creativity
- Flexibility
- Ability to multitask
- Organizational skills
- Realistic expectations
- Good observational skills
- Willingness to attend trainings
- Good collaborative teaming skills
- Willingness to accept input and feedback
- Comfort with advocating on behalf of a child
- Comfort with touch and close physical proximity
- Willingness to learn and apply knowledge and skills
- Willingness and ability to learn about the child from the child
- Ability to wait, wait, wait for a student to process and respond
- Ability to show rather than describe, or to show and describe simultaneously
- Comfort with sharing and modeling effective student strategies with professionals
- High degree of interest in working with a child with a combined vision and hearing loss
would be willing to take classes outside of work hours at a community college or at your agency. It is recommended that the intervener learn sign language before beginning to work with a student. Learning sign language along with a child is usually not advised.

6. Children who are deafblind use touch to learn, communicate, and move. (Provide the candidate with a scenario to explore how he or she feels about personal space and touching and his or her comfort level to work in close proximity with a tactile learner.) Here are two sample scenarios:

**Sample scenario 1:** A 12-year-old girl who is profoundly deaf and totally blind is learning to make a peanut butter and jelly sandwich in a home economics class. She is sitting at a table, and her intervener is sitting beside her. The student has placed her hands on top of the intervener’s hands to tactiley observe the process of making a sandwich. What are your feelings about engaging in this type of activity with constant touching?

**Sample scenario 2:** The teacher of an 8-year-old boy with cognitive challenges and very limited vision and hearing is trying to establish reciprocal communication with the student. The student is sitting on the teacher’s lap facing the teacher, and the teacher’s hands are on the student’s shoulders. The teacher begins rocking gently forward and backward with the student. She then stops and waits for the student to somehow indicate he wants to continue rocking. The teacher resumes the rocking, then stops again and waits for a response, then starts and stops again and waits. She repeats the process a number of times. What are your feelings about working in such close physical contact with a student?

7. What are your hobbies? What types of activities do you enjoy? (Probe the energy level of the candidate and assess the goodness of fit with the student.)

8. If you were selected for this position, you would need to attend an in-depth intervener training program. Would you be willing to commit to participating in training, completing all of the assignments, and possibly being gone overnight for training? (Describe the training that is available.)

9. This position requires ongoing collaboration and teamwork with both the student’s teacher and other members of the child’s educational team. Have you ever worked on a team before? Describe your experiences in this area.

10. What are your long-term goals? Where do you see yourself in five years? (Probe whether the intervener plans to stay in the position for some length of time. Continual staff changes are extremely difficult for children who are deafblind.)

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**References**


For more information about interveners go to the National Consortium on Deaf-Blindness Web site Selected Topics page: www.nationaldb.org/ISSelectedTopics.php.

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**Online Intervener Training Program in Deafblindness at Utah State University**

An online intervener training program in deafblindness will be available through Utah State University beginning in the spring of 2008. The courses are designed to prepare paraprofessionals to work as interveners with children and youth who are deafblind. They may also be useful to teachers, parents, administrators, and adult service providers. The courses may be taken on a credit or non-credit basis and participants will receive a certificate upon completion. There is also an option to take the coursework as part of an associate degree program in general studies with a focus in deafblindness. For more information contact:

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The National Center for Leadership in Visual Impairment (NCLVI)

Shawn Sweet-Barnard
NCLVI Fellow and Coordinator of the National Center on Sensory and Severe Disabilities

Professionals in the fields of visual impairment and deaf-blindness recognize that, despite our best efforts, the delivery of educational services by educators who have the specialized skills necessary to address the complex and unique learning needs of children with sensory disabilities continues to be limited (Corn & Spungin, 2003). There are simply not enough professionals to cover the needs of the children we are entrusted to serve (Ludlow, Conner, & Schechter, 2005).

In a survey of faculty in the field of visual impairments conducted by Silberman, Ambrose-Zaken, Corn, and Trief (2004), more than 60% of respondents indicated being over the age of 50. This suggests that over the next 10 to 15 years, there will likely be an increase in retirement among the few faculty members currently training educators to work with children with visual impairments or deaf-blindness. Many of these individuals are the sole program directors or instructors at their universities. A diminishing supply of qualified higher education faculty will worsen an already weakened capacity to train new faculty, administrators, and educators (Ferrell, 2007).

To help alleviate this growing shortage, faculty at the Pennsylvania College of Optometry established the National Center for Leadership in Visual Impairment (NCLVI), funded by the U.S. Department of Education’s Office of Special Education Programs (OSEP). NCLVI’s mission is “to increase, through specialized doctoral training, the number of quality leadership personnel competent in the areas of research, public policy, advocacy, administration, and higher education, to improve services for individuals with visual impairments from birth through age 21” (NCLVI, 2004).

To date, there are 19 scholars (referred to as Fellows) enrolled in full-time doctoral study. Each of the 19 Fellows is enrolled in one of 14 universities in the US that offer doctoral degrees in the education of children with visual impairments, including those with multiple disabilities. These 14 universities, in collaboration with the Pennsylvania College of Optometry, where NCLVI is housed and managed, make up the NCLVI University Consortium.

Four of the nineteen fellows have ties to the field of education for children who are deaf-blind. Julie Durando and Martin Monson entered NCLVI after working for state deaf-blind projects. Amy Parker and I were technical assistance specialists with the National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC), now known as the National Consortium on Deaf-Blindness (NCDB). Julie, Martin, and I are studying at the University of Northern Colorado, and Amy is at Texas Tech University.

In addition to the consortium universities, a Public Advisory Council (PAC) representing 15 national organizations provides guidance and support to the Fellows. The council organizations include advocacy groups for individuals who are visually impaired or blind, national organizations, and state and federal agencies.

Beyond the required programs of study offered by the universities, the NCLVI leadership team, consortium universities, and PAC representatives have designed a value-added enrichment program. The program can be likened to a community of learning with a strong mentorship component. Its purpose is to keep the Fellows in touch and engaged with one another and with other professionals. Enrichment program activities include online discussion boards and LISTSERVs, attendance at conferences, and face-to-face seminars. As a result, a strong camaraderie has developed among the Fellows that will likely continue long after graduation.

The first year of enrichment activities occurred during the 2005–2006 academic year. It focused on public policy topics and included online seminars about current policy issues, such as federal and state legislation, the vocational rehabilitation system, and parent and consumer partnerships. Members of the consortium, PAC, and guest speakers led the discussions on these important topics. Fellows also attended the American Printing House for the Blind’s annual conference in Louisville, Kentucky, where they participated in a special training event that addressed a number of topics related to public policy and systems change.

A highlight of the NCLVI enrichment program occurred in February 2006 when the Fellows met in Washington, DC, for meetings with members of Congress and Department of Education officials. Prior to arriving in Washington, the Fellows worked in small groups with other doctoral stu-
students to write a series of policy briefs (published in the October 2006 issue of the Journal of Visual Impairment and Blindness) on important issues and challenges facing educators of students who are visually impaired. Mentored by experienced advocates from the National Federation of the Blind, the American Foundation for the Blind, and the American Council of the Blind, the Fellows presented the briefs to members of Congress.

In addition to the Congressional visits, the Fellows were welcomed at the Department of Education’s Office of Special Education Programs where they met the Assistant Secretary of Education, John Hagar, and other officials. They also participated in two days of intensive advocacy training conducted by the American Foundation for the Blind’s Public Policy Center and by leaders from the National Federation of the Blind. Following these experiences, many of the Fellows have made return visits to Congress and are committed to participating in policy change activities.

For the 2006–2007 academic year, the focus of NCLVI’s enrichment activities shifted to research. The Fellows received training on how to conduct effective research at the Research Summit on Low-Incidence Disabilities in Vail, Colorado. This conference was hosted by the National Center on Low Incidence Disabilities (now the National Center on Sensory and Severe Disabilities) and by the University of Northern Colorado’s Bresnahan Halstead Center. Researchers from across the United States attended the summit to discuss the unique challenges of conducting rigorous, valid research related to low-incidence populations. At the conclusion of the summit, the NCLVI Fellows were introduced to a new task: conducting systematic reviews and analyses of literature on important topics such as literacy and transition for students with visual impairments and deaf-blindness.

The 2007–2008 enrichment activities will begin in October 2007 in Washington, DC. The Fellows will meet at OSEP to further their knowledge about the higher education system, including existing issues, trends, and challenges. Activities will include interacting with higher education faculty and administrators from throughout the United States.

The activities highlighted here provide just a few examples of how the NCLVI Fellows are moving ahead in their programs. Many are working diligently on research topics of their own. Learn more about the Fellows and their research interests at www.pco.edu/nclvi/fellows.htm. For more information about NCLVI or to become involved, visit the Web site at www.pco.edu/nclvi/news.htm, or contact NCLVI co-directors Kathleen M. Huebner, (kathyh@pco.edu) or Missy Garber, (mgarber@pco.edu).

References

Hunting with Dad
Sue Shaffer

Daniel Shaffer turned 12 last summer, an age when most boys, at least where we live, start hunting with dad. Daniel’s dad Steve loves to hunt. He counts the days each year until the season starts. Last fall Steve was a little depressed when hunting season approached. Daniel was born with CHARGE Syndrome, is deafblind, and has autism. Although Steve had known all along that Daniel would probably not be a hunter, many of his friends had sons who were also turning 12 and getting their hunting permits and it really hit home when he realized his son wouldn’t be joining him out in the woods.
Christmas came with a huge surprise. Friends Chaz Finkenbinder and Shawn Frick presented Steve and Daniel with a very special gift, an adapted hunting trip for children with special needs. The hunt would be during the spring gobbler season. What a wonderful and thoughtful gift! We knew that Daniel really didn’t understand hunting or what it was about, but the fact that someone had seen the importance to Steve of being able to hunt with his son was wonderful.

Steve started taking Daniel to a friend’s house to practice holding a gun, loading it, and pulling the trigger. Steve sat on a chair and had Daniel sit in front of him. They put a camera tripod in front of Daniel to stabilize the barrel of the gun. Steve was able to look over Daniel’s shoulder to aim for the target. They also sat in a “blind” because turkeys are very visually perceptive to any type of movement. Daniel became familiar with the sound of the gun and the feel of the gun when he pulled the trigger.

April 21 was the big day. Steve was nervous the night before with thoughts like “How in the heck will a turkey ever come close enough to shoot with all the noise Daniel makes?” and “I don’t really think the guide understands some of Daniel’s disabilities,” and finally, “Well, I guess we’ll give it a shot.” We set the alarm clock for 3:30 a.m. (who came up with this idea?) and got up and headed to the farm to meet our hunting guide as well as a videographer who would tape the entire hunt. Our local fish and game club had already presented Daniel with a gun and he was dressed in camouflage just like dad. The guide gave Daniel a turkey call to use, a very easy push-button call that Daniel could operate by himself. Daniel was so excited about getting to “hang with the guys” that we didn’t even have to ask him to smile for the photographer! And though he did make noise when we were sitting in the blind, the guide knew just when to use the turkey call to cover the noise. After about an hour or so of watching and waiting (and freezing!), as if on cue, Daniel fell asleep for about 15 minutes, and while all was quiet, three turkeys walked right up to us!

Steve woke Daniel up and said “Okay buddy, time to pull the trigger.” With help aiming the gun, Daniel pulled the trigger and shot a jakey (little male turkey). It was unbelievable! The guide, the photographer, and the videographer went nuts! They were so excited they couldn’t find their way out of the blind! It was a terrific gift and definitely a memory of a lifetime. And a lesson for mom on why she doesn’t hunt (3:30 a.m. in the cold!), but this was one hunt I wouldn’t have missed for anything.

Eighth International CHARGE Syndrome Conference

Betsy McGinnity
National Consortium on Deaf-Blindness, Perkins School for the Blind

The Eighth International CHARGE Syndrome Conference was held in Costa Mesa, California in July 2007. Nearly 625 participants from 35 states, Puerto Rico, and eight foreign countries attended. As always, this was a very busy event. The 3-day conference offered several keynote sessions and numerous concurrent presentations in six categories: education and child development, family support, general interest, medical and genetic aspects of CHARGE, new family information, and transition to adulthood. In addition, breaks and meal times, a carnival, a dance, and a silent auction gave participants ample opportunities to network and socialize. A photographer took portraits, medical researchers enlisted families to participate in genetic studies, and children with cochlear implants were screened for a research project. Some children were also evaluated for a study that is attempting to establish the characteristics of the feet of children with CHARGE Syndrome.

Tina Prochaska of the Tennessee School for the Deaf presented a keynote session on the needs of siblings of children with CHARGE and the role that siblings play in the family. She noted that, in many ways, the issues faced by children who have a sibling with CHARGE are similar to those of children who have siblings with any type of dis-
For their children. Models helped them to think about future options from the very diverse panel and that having role models helped them to think about future options for them during the conference. There were also special sessions for fathers and grandparents.

Another keynote speaker, Joe McNulty, director of the Helen Keller National Center, emphasized how important it is for parents, family members, professionals, and young people with CHARGE to learn from one another. He spoke about the significant increase in knowledge about CHARGE Syndrome that has occurred since the first International CHARGE Syndrome Conference 14 years ago, and how during these years, families, medical professionals, and educators have all been able to learn from each other and improve services. Now, as young adults with CHARGE Syndrome transition from educational settings to the world of rehabilitation and adult services, the information-sharing process needs to expand to include young adults with CHARGE Syndrome and professionals who provide services for adults with disabilities.

The final keynote session was a special presentation by a panel of adults with CHARGE. The panelists included a woman in her forties, whose diagnosis of CHARGE came after her school years, and several recent high school graduates—a young woman who is currently seeking employment, a young man who will become a full-time college student in the fall, and another young man who is a part-time college student and full-time worker. Two mothers were also on the panel, representing their young adult daughters who did not have the ability to represent themselves. After the panel members gave their formal presentations, the session was opened to questions from the audience. It was obvious that families in the audience appreciated the opportunity to learn from the very diverse panel and that having role models helped them to think about future options for their children.

More than 75 new families attended their first CHARGE conference this year. As the group prepared to leave Costa Mesa, many of these newcomers as well as regular attendees were making plans to attend the Ninth International CHARGE Syndrome Conference scheduled for July 2009 in Bloomington, Illinois.

National Consortium on Deaf-Blindness Topical Conference
Peggy Malloy
National Consortium on Deaf-Blindness

NCDB held its annual topical conference in San Antonio, May 15–16, 2007. It was attended by more than 120 people, primarily personnel from state deaf-blind projects throughout the country. The conference covered three topics, representing three of NCDB’s strategic focus areas—early identification, postsecondary transition, and underserved families. For each topic there was a keynote presentation, followed by shorter concurrent sessions.

The keynote speakers were Karl White, Michael Callahan, and Diana Autin. Karl White, the director of the National Center for Hearing Assessment and Management, spoke about the importance of identifying hearing loss in newborns and then providing follow-up and intervention as early as possible during infancy. Michael Callahan, the president of Marc Gold and Associates (a network of disability professionals who specialize in employment and community participation for persons with significant disabilities), described the development of customized employment opportunities for individuals with severe and multiple disabilities. His presentation included numerous examples of clients who have successfully found employment. Diana Autin, executive codirector of the Statewide Parent Advocacy Network in New Jersey, spoke about building cultural reciprocity with families. She described strategies that state deaf-blind projects can use when working with culturally diverse families of children who are deaf-blind.

The nine concurrent sessions were led by a variety of invited speakers, including the keynote speakers and professionals from state deaf-blind projects, NCDB, the National Early Childhood Technical Assistance Center (NECTAC), and the Department of Education’s Office of Special Education Programs. The early identification strand of topics addressed working with medical professionals to increase early identification of children who are deaf-blind, collaborating with agencies that serve infants and toddlers with disabilities, and identifying the developmental needs of premature infants. The postsecondary transition strand included presentations on the evaluation of students at different stages of transition, planning for work and community involvement, and transition outcomes for young adults with deaf-blindness. Sessions on underserved families included information about the federal perspective on underserved fami-
lies, effective strategies to support Spanish-speaking families of children with deaf-blindness, and the sharing of strategies to meet the needs of underserved populations (a roundtable discussion).

Although the National Technical Assistance Consortium on Children and Young Adults Who Are Deaf-Blind (NTAC) held many topical conferences in the past, this was the first topical conference given by the new National Consortium on Deaf-Blindness. The high attendance rate and a high rate of positive evaluations demonstrated the value of the conference for professionals in the field of deaf-blindness.

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Research Update

The following are updates of four current research projects for children with deaf-blindness. If you have information about research relevant to individuals who are deaf-blind that you would like to have considered for inclusion in future issues, contact Peggy Malloy (503-838-8598; malloyp@wou.edu).

Cochlear Implants for Children With Combined Hearing and Vision Loss (CICDB)

The current work of the CICDB Project is to identify and assess children with deaf-blindness who have or are being considered for a cochlear implant, in order to learn about the impact of cochlear implantation on auditory perception, language acquisition, and communication. The project is a joint effort by the Teaching Research Institute at Western Oregon University, the Beach Center on Disability at the University of Kansas, and the Midwest Ear Institute at St. Luke’s Hospital, in Kansas City, Missouri. Many state deaf-blind projects and other agencies have also been involved in this effort and a number of new partners have recently joined, including the Cincinnati Children’s Hospital, the New England Center Deafblind Project, and the following state deaf-blind projects: DE, GA, MD, NC, and OK.

At the recent Eighth International CHARGE Syndrome Conference, there were many families of children with CHARGE who either already had cochlear implants or for whom an implant was being considered. CICDB personnel had the opportunity to assess a number of these children for inclusion in the study.

For more information, contact CICDB. Phone: 877-660-2432. E-mail: cidb@wou.edu. Web site: www.wou.edu/cidb.

Validation of Evidence-based Assessment Strategies to Promote Achievement in Children Who Are Deafblind

The purpose of this project is to identify and validate tools designed to assess the communication, social, or cognitive development of children who are deaf-blind and between the ages of 2 and 8. The project has conducted a number of surveys to gather information from parents and professionals about the process of assessing the educational needs of children with deaf-blindness and has conducted focus groups on specific aspects of assessment. A “short-list” of 11 assessment tools was developed based on several criteria. Each tool on this list: (a) was designed for use with 2- to 8-year-old children who have significant disabilities including sensory impairments; (b) can be used by professionals in different disciplines; (c) focuses on social/communication and/or cognitive skill development and recognizes that children may have nonsymbolic forms of communication; (d) is designed to involve, or can readily involve, parents and care providers in the assessment process; (e) can elicit data that are directly related to educational goals; and (f) provides qualitative information so that educational progress can be documented.

Many state deaf-blind projects are participating in this project along with the National Family Association for Deaf-Blind. For more information contact Charity Rowland, Ph.D. (503-494-2263; rowlandc@ohsu.edu). An earlier report on this project can be found in Deaf-Blind Perspectives, Fall 2004, pp. 8–9, or on the Web site: www.dblink.org/lib/assess-proj.htm#assess.

Promoting Communication Outcomes Through Adapted Prelinguistic Milieu Teaching for Children Who Are Deaf-Blind

This research project used a single-subject, multiple-baseline design methodology to evaluate the effectiveness of Adapted Prelinguistic Milieu Teaching (PMT) with 11 children with deaf-blindness in Kansas and Missouri. Study results indicate that Adapted PMT is very effective in increasing prelinguistic communication rates in this group of children, as well as broadening the diversity of the forms with which, and the reasons for which, the individual children communicated. The study is currently being replicated with an additional seven children in Indiana.

For more information, contact Susan M. Bashinski, Ed.D. (sbashins@ku.edu; 785-864-2459). For a more detailed description of this project, see Deaf-Blind Perspectives, Fall 2006, p. 11, or go to the Web site: www.dblink.org/lib/assess-proj.htm#preling.
**Functional Hearing Inventory: Project to Identify Criterion-Related Validity and Interrater Reliability**

The goal of this project is to establish the validity and reliability of the Functional Hearing Inventory (FHI). The FHI was developed to obtain information about how deaf-blind children use residual hearing within their natural environments. The researchers are currently collecting data regarding the use of this assessment instrument and are seeking additional children and young adults (age 0–26) to participate in the study. They are also about to begin field-testing a training protocol and instruction manual that will guide the use of the FHI. To participate in the research or in the field-testing of the training protocol, contact the project co-investigators, Pamela Broadston, Ed.D. (501-324-9585; pamelab@asd.k12.ar.us) or Roseanna Davidson, Ed.D. (806-742-1997, extension 246; roseanna.davidson@ttu.edu). For a more detailed description of this project, see *Deaf-Blind Perspectives*, Spring 2005, pp. 7–8, or go to the Web site: www.dblink.org/lib/assess-proj.htm#funhear.

**For Your Library**

**CHARGE Syndrome Revisited (2007): A 5 year follow-up of 6 children with Charge Syndrome**

Jan van Dijk, Catherine Nelson, & Arno de Kort, AapNootMuis.

This is an updated version of the following CD-ROMs: *Living With CHARGE: Assessment, Prevention and Intervention of Challenging Behavior* (2002) and *Living With CHARGE: How to Deal with Challenging Behaviors and Enhance Communication* (2005). In this new edition, four of the original children have been recorded again and two new children have been added. Topics include intervention strategies specific to challenging behaviors, feeding problems, depression, cochlear implantation, communication, and literacy. Cost: $35.00. Available from Vision Associates. Phone: 407-352-1200. E-mail: kathleen@visionkits.com. Web: www.visionkits.com.

**Cortical Visual Impairment: An Approach to Assessment and Intervention**


Topics covered in this book include an overview of cortical visual impairment, its causes and behavioral characteristics, assessment, program planning, and intervention. Cost: $49.95. Available from AFB Bookstore. Phone: 800-232-3044.

E-mail: afborder@abdlntl.com.
Web: www.afb.org/store.

**Interveners in the Classroom: Guidelines for Teams Working With Students Who Are Deafblind**


This booklet provides detailed guidelines in a checklist format for interveners, teachers, administrators, and parents to assist in their understanding of the roles and responsibilities of interveners in educational settings. An intervener code of ethics is included. The cost is approximately $10.00. Available from Linda Alsop at Utah State University. Phone: 435-797-5598. E-mail: lalsop@cc.usu.edu.


This report includes the following data about children reported to the National Deaf-Blind Child Count: total number by age group, race/ethnicity, classification of visual and hearing impairments, additional impairments or conditions (physical, cognitive, behavioral, health), primary cause of deaf-blindness, early intervention and educational settings, and living settings. This document is available on the web at: www.nationaldb.org/documents/products/Childcountreview0607Final.pdf.

**Silence with a Touch: Living with Usher Syndrome**

National Technical Institute for the Deaf, 2006, 26 minutes.

This DVD introduces several individuals, from early adolescence to adulthood, who are living with Usher Syndrome. It was produced by the National Technical Institute for the Deaf in cooperation with the New York State Technical Assistance Project Serving Children and Youth Who Are Deafblind. To order, send a check or money order payable to Teachers College for $20.00 (U.S.) or $25.00 (International). The cost includes postage and handling fees. Mail to New York State Technical Assistance Project, Teachers College Columbia University, 525 West 120th Street, Box 223, New York, NY 10027. For further information, call 212-678-8188, e-mail nystap@tc.edu, or go to www.tc.columbia.edu/nystap/detail.asp?id=dvd.
Students Who Are Deafblind Using APH Products  
(DVD or Video)  

This 20-minute presentation features four students who are deafblind, ages 2 to 15 years, using various APH products in home and school settings, including examples of using APH products to support literacy activities. The cost is $10.00 for either the DVD or video. Available from the American Printing House for the Blind. Phone: 800-223-1839. E-mail: info@aph.org. Web: www.aph.org.

Transition Planning for Students who are Deafblind: Coaching from Students, Parents, and Professionals  

This book begins with chapters that provide background about the history of services for people who are deaf-blind in the United States and about the definition and meaning of deaf-blindness. Subsequent chapters address the following topics: aids and devices, mental health counseling, orientation and mobility, independent living, effective transition practices, and emergency preparedness. A significant portion of the book is devoted to personal essays about transition experiences by students and adults who are deaf-blind and by parents, and to commentaries by professionals. It is available online (no charge): http://prcorder.csun.edu/media/1218%20DeafBlind07/deafblind07

Conferences and Events

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Getting Creative with Challenged Communicators  
November 15–17, 2007  
Orlando, Florida

The Florida Outreach Project welcomes Dr. June Downing, a national leader in the field of education for students with severe and multiple disabilities, including deaf-blindness. Dr. Downing will speak about communication development for individuals who are nonverbal or challenged communicators. The third day of the conference will include an opportunity for families with children who have severe communication challenges to meet with Dr. Downing to ask questions. For more information, contact Shelly Voelker (352-846-3474; shelly.voelker@mbi.ufl.edu) or Pam Kissoudyal (352-846-2758; pam.kissoudyal@mbi.ufl.edu).

Getting in Touch with Literacy Conference  
November 29–December 2, 2007  
St. Pete Beach, Florida

This is a national conference that focuses on the literacy needs of individuals with visual impairments. The theme for this hear is “Charting a Course for Literacy,” reflecting that literacy must be explicitly planned and systematically taught. For more information contact Kay Ratzlaff (kratzlaff@fimcv.org) or go to www.gettingintouchwithliteracy.com.

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

The Helen Keller National Center National Training Team was established to increase knowledge and support the development of skills specific to deaf-blindness. Upcoming seminars include:


For more information contact Doris Plansker (516-944-8900, extension 233; 516-944-8637 TTY; ntthknc@aol.com) or go to www.hknc.org/FieldServicesNTTSchedule.htm.
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