

Deaf-Blind Perspectives

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Cochlear Implants for Young Children Who Are Deaf-Blind

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Should we consider a cochlear implant for our young child who is deaf-blind?

Is he eligible?

At what age might he receive an implant?

What should our expectations be?

How many children with deaf-blindness are being implanted?

Is it effective for children who are deaf-blind?

These are questions that state deaf-blind projects are being asked by parents as more children with multiple disabilities, including deaf-blindness, are being considered for cochlear implantation. The opportunity for cochlear implantation now extends beyond children who are only deaf or hard of hearing. Children who are deaf-blind from birth or early in life before developing language are receiving implants, but very little research has been done for this population, and this raises important issues. How will it be determined which children are likely to benefit? What specialized therapies and educational strategies will be necessary following implantation? It is essential that research be performed and practices developed that address these questions so that parents can make informed choices for their children.

What Is Cochlear Implantation?

Cochlear implants are electronic devices that are surgically placed under the skin behind the ear and consist of four basic parts: a *microphone* to pick up sounds from the environment; a *speech processor* that selects and arranges those sounds; a *transmitter* and *receiver/stimulator* that receives signals from the speech processor and converts them into electrical impulses; and *electrodes* that collect the impulses and send them to the brain. A cochlear implant does not restore normal hearing, but it may provide a sense of sound to people with severe-to-profound hearing loss by compensating for damaged or nonhearing parts of the inner ear (NIDCD, 2002).

Cochlear implants were first approved by the Food and Drug Administration in 1985. In 1990, approval was granted for implantation in children age 2 and older with profound sensorineural deafness (Spencer, 2002a, p. 39). By 2000, approval had been extended for children age 2 and older with severe-to-profound deafness and for children of 12 to 23 months of age with profound deafness (ASHA, 2004). Some implant

In This Issue

Cochlear Implants for Young Children Who Are Deaf-Blind	1
Our Experiences (to Date) with Sam's Cochlear Implant	5
Poems	7
Classroom Observation Instrument for Educational Environments	8

Project SPARKLE	10
Coming of Age: 2005 International CHARGE Syndrome Conference	11
Research Update	12
National Task Force on Deaf-Blind Interpreting	13
For Your Library	13
Conferences and Events	14

centers are working with infants prior to 12 months of age, and the risk and benefits are being studied (Nussbaum, 2003; Waltzman & Roland, 2005). The FDA makes recommendations, but they are not legal requirements (however, insurance reimbursement may be more difficult if a center does not follow FDA-approved recommendations) (Nussbaum, 2003).

Deaf communities throughout the world have expressed strong concerns about cochlear implants for deaf children (Spencer, 2002a, p. 41). In a position statement, the National Association of the Deaf challenges the view that deafness is a disability that needs to be "fixed" by cochlear implants and calls for better understanding of the diversity, heritage, language, and culture of the deaf community. It recognizes the right of parents to make informed choices for their children and respects the choice of cochlear implants, while emphasizing that parents should also understand options other than cochlear implants that promote deaf children's development, language, and literacy. The NAD statement refers only to deaf children, however, and does not address the needs of children who are deaf and also have a visual impairment or other disabilities (NAD Cochlear Implant Committee, 2000).

Criteria for Implantation

One of the challenges for researchers and for centers that perform cochlear implantation is determining which children will benefit from a cochlear implant. They try to identify characteristics—candidacy criteria—that indicate that an implant may be successful and helpful for a particular child. Although there is very little information available about cochlear implants for

children who are deaf-blind, over time, criteria have been identified for children who are only deaf or hard of hearing. Some criteria have been identified as being more important than others, but questions remain about why some cochlear implant users receive more benefit than others. Following are three basic questions that are considered when determining candidacy (ASHA, 2004):

- ◆ Is the physical implantation of the device possible and advisable given the medical status of the individual?
- ◆ Is it likely that the individual will receive more communication benefit from a cochlear implant than from a hearing aid?
- ◆ Do the necessary family, educational, and rehabilitation supports exist or can they be developed?

Implant center teams conduct extensive assessments in order to decide whether a child is a good candidate. In general, centers will include children with bilateral severe-to-profound sensorineural hearing loss; who are 12 months or older; who are failing to progress in speech, language, and auditory development; and who have a motivated family with appropriate expectations (Nussbaum, 2003).

The American Speech-Language-Hearing Association (ASHA) recommends that deaf children with additional disabilities be considered as candidates for implantation (ASHA, 2004). State deaf-blind projects report that eligibility criteria vary for different implant centers. Some centers are hesitant to implant children who are deaf-blind.

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Outcomes of Implantation

Research about the effectiveness of cochlear implantation has been based primarily on children who are congenitally deaf without additional disabilities and has focused on spoken communication, particularly speech perception and production. As Patricia Spencer (2002b, p. 226) writes,

Cochlear implants provide many, but not all, deaf children with access to information that can help them develop understanding and production of spoken language. However, the range of benefits experienced is large and the factors that influence the benefits received by an individual child are still being investigated.

Overall, research shows that deaf children who have cochlear implants have significantly greater rates of growth in spoken language than deaf children who do not have implants. Specific findings include the following:

- ◆ Children implanted at younger ages (12–23 months) do better on auditory skill development than those at even slightly older ages (24–36 months) (Robbins, Koch, Osberger, Zimmerman-Phillips & Kishon-Rabin, 2004).
- ◆ Early implantation is associated with better speech production (Conner, Hieber, Arts, & Zwolan, 2000).
- ◆ Speech perception consistently improves with the length of time the child has been using the device (Tyler et al., 2000).
- ◆ A child's preverbal communication, cognitive, and attending skills all play a critical role (Spencer, 2002b, p. 249), as does nonverbal intelligence (Geers, 2002).

Increase in Implantation for Children Who Are Deaf-Blind

A survey was conducted in September 2005 of state and multistate deaf-blind projects to determine (a) the number of states that collect information about children with deaf-blindness who have received cochlear implants, (b) the number of children with deaf-blindness who have received implants, and (c) whether there has been an increase in the number who have been implanted over the past five years. Forty-seven of the projects responded.

Nineteen percent of the state deaf-blind projects formally collect information about cochlear implantation. Many other states do not formally

collect information but are aware of children who have received implants. Overall, states report that more than 225 children with deaf-blindness have a cochlear implant. Seventy percent of states have seen an increase in the number of children with implants, and in some, this increase has been significant. In Texas, for example, the number has increased from 5 receiving implants in 2002 to 32 in 2005 (figure 1). Fourteen percent of states do not believe there are any children with deaf-blindness in their state who have cochlear implants, and an additional 14% don't know.

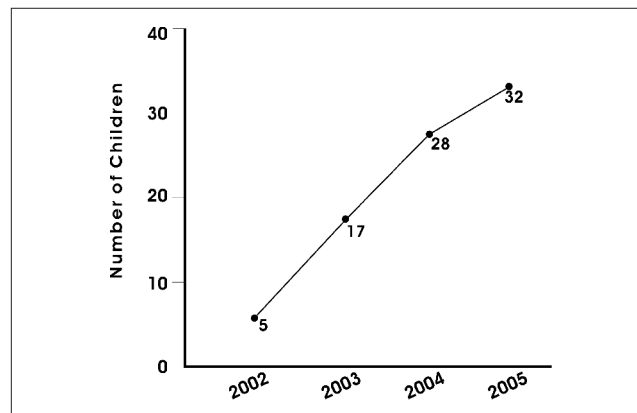


Figure 1. Rate of increase of cochlear implantation in children with deaf-blindness in Texas.

It is clear that the number of children with deaf-blindness who are receiving cochlear implants is increasing, and it is likely that an increasing number of children will be considered for cochlear implants in the next five years. Despite this, however, research to determine the effectiveness of cochlear implants for these children is limited. Several small studies of children with multiple disabilities, primarily CHARGE Syndrome, have included children with visual impairments (Bauer, Wippold, Goldin, & Lusk, 2002; El-Kashlan, Boerst, & Telian, 2001; MacArdle et al., 2002; Stjernholm, Muren, & Bredberg, 2001). All combined, the studies included ten children, all over the age of 3, and their outcomes were mixed. Some did not benefit, but most showed increased detection of environmental sounds and improved speech perception. More research with larger numbers of children is clearly needed. Recently, Teaching Research Institute at Western Oregon University was awarded a grant from the U.S. Department of Education to study the outcomes of cochlear implantation for children who are deaf-blind. The three-year research project will be carried out in collaboration with the University of Kansas, the Midwest Ear Institute/St. Luke's Hospital, and approximately ten state deaf-blind projects.

Tools used to assess speech and language in children who are deaf may not be appropriate for children who are deaf-blind if they rely on miniature objects or pictures. Many of these types of assessments are used to determine whether a deaf child is benefiting from an implant. Assessments for children who are deaf-blind may also need to measure skills such as social interactions, prelinguistic communication, cognitive development, and behavior.

Special Issues for Children Who Are Deaf-Blind and Their Families

The potential benefits of cochlear implantation early in life for children who are deaf-blind range from helping children to better experience their physical and social environments to understanding and using some level of speech. How much a child benefits often seems to depend upon the severity of any additional disabilities (ASHA, 2004). Consequently, controversy continues to exist about implanting children who are deaf and have additional disabilities (Bauer et al., 2002, p. 1013). The success of a cochlear implant depends not just on characteristics of a child prior to implantation but also on the follow-up intervention and training the child receives afterwards. The follow-up period requires good support from service providers and a strong commitment by the family.

The Texas Deafblind Project has found that a number of children who received implants are no longer wearing their external headpiece or sound processor, thus deactivating the implant. It is unclear why the families elected to deactivate the implants, but the following are some possible reasons (C. Miller, personal communication, October 2005):

- ◆ The mapping (programming) for the device may not have been effective.
- ◆ The families may have lacked access to appropriate follow-up intervention and education.
- ◆ They may have been unaware of the potential time that it might take to observe benefits.
- ◆ They may have had high expectations that were not met.

These possibilities emphasize two very important points: the need for parents to be well-informed prior to implantation and the need for children to receive intensive follow-up interven-

tion and training—“habilitation”—after implantation.

Information for Parents

Additional research must be conducted for larger numbers of children who are deaf-blind so that families will have access to the accurate information they need to make informed decisions. Since the degree of benefit can vary widely, it is critical that parents are counseled to have appropriate expectations (Bauer et al., 2002, p. 1017). At present, implant centers may not apply anticipated outcomes for deaf children who do not have vision impairments to children who are deaf-blind. They must let parents know that evidence about the outcomes for children who are deaf-blind are extremely limited overall and non-existent for children under the age of three. It is also imperative for centers to inform families about medical risks and the need for intensive, long-term habilitation following implantation. Habilitation for children with special needs can take twice as long as that of children who are only deaf (MacArdle et al., 2002, p. 347).

Habilitation

Habilitation is the process following implantation by which a child receives intensive training to learn to use the cochlear implant and to develop listening and speech skills. State deaf-blind projects report that the amount of habilitation children receive varies widely, ranging from no auditory training or educational strategies to intensive auditory and verbal therapy from qualified providers.

There are a number of major considerations for providing habilitation to children with deaf-blindness that differ from those for deaf children without additional disabilities. Many young children with deaf-blindness do not yet know that people, things, and locations have names or that other people have knowledge of the world. It isn't simply a matter of applying speech to an existing language system. Children who are deaf-blind need an opportunity to learn during meaningful social interactions in optimal environments. Children who are totally blind may need habilitation techniques that include tactile, movement, and sensorimotor strategies.

Habilitation curricula that have been developed for deaf children rely on good visual skills and cognitive skills beyond 24 months of development. There is a great need for effective and appropriate auditory, speech, and language techniques and curricula to support habilitation

for children who are deaf-blind. Also critical are parent training materials and service providers with the skills to provide habilitation training.

Summary

There is tremendous promise for the use of cochlear implants for children who are deaf-blind, but research to determine the long-term impact and to guide decision-making and follow-up strategies is essential, as is the development of effective habilitation strategies and skilled personnel to provide those strategies. We must make sure that the technology does not outdistance effective support and practices provided by early intervention providers, schools, and families.

For more information about cochlear implants, go to "Selected Topics" at the DB-LINK Web site (<http://www.dblink.org>) or contact DB-LINK (800-438-9376; 800-854-7013 TTY; dblink@tr.wou.edu).

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Our Experiences (to Date) with Sam's Cochlear Implant

Shannon Butalla

On November 19, 2002, my husband and I received devastating news, news unimaginable to most parents. "I regret to inform you, but your son has a rare condition with no good outcomes. His condition causes hearing and vision loss, mental retardation, and neuromuscular problems. . . . It is a childhood disease. . . . We just don't know what to tell you."

My son, Sam, has a rare disease called a Peroxisomal Biogenesis Disorder (Zellweger's



Spectrum of Disorders, Infantile Refsum's Disease). Sam was born with vision and hearing, but both senses deteriorated over the first nine months of life. At four months of age, he had mild loss in both ears. At nine months of age, his auditory brainstem response showed that his hearing loss was severe (between 70 and 90 decibels).

At the same time, Sam's vision deteriorated. His eyes started shaking (nystagmus). His optic nerve appeared dusky and gray, and there seemed to be a waxy pallor to his retina. The best medical guess was that Sam could see somewhere between 20/200 and 20/800.

When Sam's audiologists and speech language pathologists indicated that Sam would likely hear better with a cochlear implant than with hearing aids, we decided to pursue it as an option. Sam had worn hearing aids for almost two years, but his access to speech sounds was still limited. He was experimenting with his voice, making mostly vowel sounds.

After the MRI, CT scan, vestibular tests, and blood work all showed that we could proceed, we met with the cochlear implant team at Boys Town National Research Hospital. We'd had ongoing conversations with this team from the time Sam was nine months old. Sam was not a clear-cut case, but all team members agreed that Sam could receive greater benefit with a CI than with hearing aids. After a long discussion, we decided to go ahead with the surgery.

Sam was implanted on November 22, 2004. The surgeon and audiologist came in three hours later to tell us that the surgery was a success. They had gotten responses from Sam's brain on all of the channels tested.

Sam slept most of the day, but during the night, he was awake and bouncing in the hospital crib. The next day, we were discharged. The initial compression bandage bothered him a little, but he was perky and happy to be back in the comforts of home.

The next day, the surgeon removed his bandage, and Sam was supposed to wear a lighter dressing for a couple of days. He was totally annoyed with the dressing, and it was off in no time. His head healed quickly, and we went back to Boys Town for activation of the implant on December 16, 2004.

Activation day was much like the day that Sam got his hearing aids. It was evident that he could hear through the device, but he seemed a bit bewildered by the sounds coming into his head. The mapping (programming) was broken up into two-hour time blocks over two days, and the audiologists were pleased with the initial map. The first month was a transition phase to help Sam get used to the device. He wore the implant on his left side and his hearing aid in his right ear. Soon he began to prefer the implant to the hearing aid. We tried to get him to wear both, but he continued to take the hearing aid out. Now he will only wear it if the implant is off—and even then we struggle to keep it in.

Habilitation—the process of training a child to use a cochlear implant and to learn listening and speech skills—has not been free from uncertainty. There is no CI habilitation program or curriculum designed specifically for children who are deaf-blind. Sam undergoes mapping once every three months at Boys Town, and we see their speech language pathologist (SLP) twice a year to evaluate his progress. The SLP is in contact with our local school district, sharing what she observes and recommending strategies for speech understanding and acquisition. Sam's teachers use a total communication approach. Sam just began early childhood special education preschool this fall and attends three mornings a week. He spends a minimum of 120 minutes a week with his deafness educator, who carries out his auditory verbal training.



We are very much at the beginning of Sam's auditory training. His teachers are doing the best

they can with the resources available, but the cochlear implant habilitation resources they have were developed for deaf children. I know that Sam and his team would all benefit from a CI curriculum developed especially for children who are deaf-blind.

We have seen an increase in Sam's receptive language, and he is just beginning to make new sounds with his voice. For months after he was implanted, he was very quiet, taking in everything around him. Now he is babbling and saying more consonants, and he is experimenting with his voice. His first word with his hearing aid was "mama," but after he received the implant, he wouldn't say it unless the implant was turned off. Now he will say "mama" with his implant turned on, and he attempts to say "more," especially when Coca Cola is involved!

Sam has made big gains physically and developmentally since his surgery. This could be coincidental, or it could be because Sam now has more consistent hearing and has a reason to seek out new things. It is difficult to know what Sam's outcomes will be from implantation, just as it is difficult to know how his disease will affect him in the years ahead. Regardless of the outcome, one thing is certain—his smile is enough to let us know we made the right decision.



Poems

Fifteen Today

For Kenneth James Johnston, for fathers

by Theresa Vincent

He cradles her in his arms as he offers her
spoonfuls of mashed banana and peaches.

He looks out the window
in between bites.

The old cast iron piss-pot on the patio table
now filled with pale yellow violas.

She opens her mouth for more.
She turned fifteen today.

He looks at me and says,
This makes me happy.

Guardianship

by Theresa Vincent

We've been asking ourselves,
who will be there for her?
We've been asking ourselves,
who will care for her
when we are gone?

Who will live with –
and not just live with,
but with love, also –
seizures,
spasticity,

the risk of aspiration,
the struggle for a breath
and changing diapers
for a 20, 30,
40 year old?

For now, some people stay,
and then – it's too much
for backs, shoulders,
hearts – *one day*
her suffering will be over,

one of them says
as she leaves.
There was a time
when I carried her
everywhere

on my hip,
over my shoulder,
across my arms.
Now, it is more
than I can do.

We've been asking ourselves, who . . .



Classroom Observation Instrument for Educational Environments Serving Students with Deaf-Blindness

Ella L. Taylor
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Meeting the needs of students who are deaf-blind and often have additional disabilities, can be a daunting challenge for many classroom teachers. Designing an engaging curriculum, providing stimulating instruction, and assessing student progress are difficult tasks in any classroom and may seem overwhelming when that classroom includes students with complex communication needs. Compounding the problem are a lack of identified model classrooms where teachers can observe exemplary practice and scant information about deaf-blindness in teacher preparation programs (Taylor, Kelly, & Evans-Luiselli, 2005). This is an issue not only for teachers but also for technical assistance providers, teacher education faculty, and school district personnel.

The *Classroom Observation Instrument for Educational Environments Serving Students with Deaf-Blindness* (Taylor, Donta-Steele, & Stremel, 2005) was designed to identify characteristics of model classrooms for students who are deaf-blind. According to a report completed for the U.S. Department of Education, "prospective teachers' conceptions of teaching and learning . . . can be transformed through their observations and analysis of what goes on in real classrooms. Stereotypical views can shift when student teachers work in classrooms that enable this to happen" (Wilson, Floden, & Ferrini-Mundy, 2001, p. ii). The identification of model classrooms where both student teachers and practicing teachers can learn through observation is critical.

Development of the Instrument

The process of developing the *Classroom Observation Instrument* took several years. It began with a review of four documents:

- ◆ *CEC Knowledge and Skill Base for All Beginning Special Education Teachers of Students in Individualized General Curriculums* (Council for Exceptional Children, 2001a);
- ◆ *CEC Knowledge and Skill Base for All Beginning Special Education Teachers of Students in Indi-*

vidualized Independence Curriculums (Council for Exceptional Children, 2001b);

- ◆ *Competencies for Teachers of Learners Who Are Deaf-Blind* (McLetchie & Riggio, 1997);
- ◆ *Observational Overview for Programs with Students with Deaf-Blindness* (Rhode Island Services to Students with Dual Sensory Impairments, 2003).

These documents helped to guide the second step in the process, the formation of multiple focus groups consisting of individuals who would most likely use and benefit from the instrument. These included researchers from the fields of deaf-blindness and severe and profound disabilities, teacher education faculty, general education teachers, special education teachers, families of students, and technical assistance providers in the field of deaf-blind services. The focus groups worked to identify essential components of model classrooms, which were then ranked by a panel of experts. Multiple field tests were performed by technical assistance providers and other experts in the fields of deaf-blindness and severe disabilities, and the instrument was revised several times based on the results of those tests.

Validity was assessed by having two observers use the final version of the *Classroom Observation Instrument* in elementary and middle-school classrooms nominated as exemplary by state projects for children and youth with deaf-blindness. Classrooms in five states were observed: two in residential facilities, two in neighborhood schools, and one in an inclusive private primary school.

Description of the Instrument

The *Classroom Observation Instrument* has three main parts: (1) a teacher interview, (2) a student folder review, and (3) a chart detailing specific classroom observations. The teacher interview is a series of questions about the teacher's goals for the student, family involvement in the child's educational program, the student's strengths and challenges and how these are used to design educational strategies, the student's involvement in the general education curriculum, and the student's interactions with peers. The purpose of the folder review is to examine the results of previously performed standardized and functional assessments, to consider how the results are being used to plan instruction, to review the student's IEP goals, and to look at the types of corrective measures and instructional modifications currently being used for hearing and vision.

The main part of the instrument, the rubric of classroom observations, includes the following categories: curriculum, data-based assessment, preservation of dignity, communication, social interactions, and assistive technology. Each category contains a number of components that are essential features of classrooms for children who are deaf-blind. A four-point scale is used to rate the extent to which the component has been met. The communication category, for example, includes items about receptive and expressive communication, opportunities for communication, communication functions, and communication partners. See figure 1 for an example of a scale for receptive communication.

A scoring guide is provided, and a final section allows the observer to note special circumstances or additional information. Usually, administration of all components of the instrument takes approximately two hours. Field tests have indicated that while the instrument's components (teacher interview, folder review, classroom observation) can be conducted separately, it is extremely important that they be conducted in the suggested order. It is crucial to have an understanding of the classroom before conducting the observation.

Findings

Field tests of the *Classroom Observation Instrument* found that it can be used by teachers, teacher education faculty, and technical assistance providers to assess both areas of strength and areas requiring improvement within a classroom. In addition, several state deaf-blind projects have shared the instrument with programs serving students with other complex impairments, and feedback has supported the use of the instrument for populations beyond deaf-blindness.

One limitation of the *Classroom Observation Instrument* is that it has only been validated in educational settings at the primary, intermediate, and early-middle-school levels. It has not been used in early childhood education settings or in late-middle-school and high-school settings. Modifications should be made for these environments.

Conclusion

Technical assistance providers, teacher education faculty, and school district personnel can use the *Classroom Observation Instrument for Educational Environments Serving Students with Deaf-Blindness* to assist in the identification of model classrooms, classroom-based technical assistance, practicum placements, and as a vehicle for guided classroom observations for both pre-service and in-service teachers. The instrument will be available on the NTAC Web site in February 2006.

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Achieved	Nearly Achieved	Making Progress	Non-Existent
All receptive communication cues are based upon the expectation of student response (e.g., type, wait time, expectations).	Some receptive communication cues are based upon the expectation of student response.	Few receptive communication cues are based upon the expectation of student response.	No receptive communication cues are based upon the expectation of student response.

Figure 1. Classroom observations of receptive communication.

Project SPARKLE

Linda Alsop
SKI-HI Institute, Utah State University

Project SPARKLE (Supporting Access to Resources, Knowledge, Linkages, and Education) was developed by the SKI-HI Institute at Utah State University with funding from the U.S. Department of Education's Office of Special Education Programs (OSEP). It is a unique model of individualized learning for parents of children and youth who are deafblind, that was developed in response to their requests for information and training that would be accessible in their homes anytime, day or night, that would be directly applicable to their children, and that they could share with educators, service providers, and extended family members. Project SPARKLE combines DVD technology and the Internet to make deafblind-specific information, training, materials, and resources available to parents in their homes to be used at their convenience. It also gives them the opportunity to network with other families all over the country.

The SPARKLE model has five components:

- ◆ **Training Program.** The SPARKLE training program is provided to parents by means of DVD technology and is supported by a parent guidebook and the SPARKLE Web site at <http://www.sparkle.usu.edu>.
- ◆ **Child Profile.** The child profile is a database program that supports the family in collecting data and information specific to their child. They can then share this profile with educational teams, service providers, medical personnel, and others.
- ◆ **Family Support and Networking.** The SPARKLE Web site has a Family Room component where parents can access an evolving collection of family stories for inspiration and support. Also, the SPARKLE Listserv helps parents interact with each other to share ideas, information, and encouragement.
- ◆ **Ongoing Support.** Each participating state has a facilitator who is affiliated with the state deafblind project and who can provide appropriate guidance, support, and resources to families.
- ◆ **Resources and Materials.** The SPARKLE Web site has a glossary of terms and a re-

source section with links to related Web sites. It also has a unique video library where parents can watch presentations by professionals about deafblindness.

Parents from the states of Utah, Minnesota, Texas, and Georgia participated in the training program as the SPARKLE model was being developed. The evaluation data collected from those parents indicated the following:

- ◆ Parents increased their knowledge of the training topics from an average pre-training score of 68% to a post-training score of 93%. This indicated an overall knowledge gain of 25%. (More recent data collected from families shows an overall knowledge gain of 31%.)
- ◆ When asked about training content, 95% of the parents thought the information was relevant, met their needs, reinforced their present skills, and taught them new skills that would benefit their child.
- ◆ 97% of parents thought the DVD training programs were easy to use, understandable, and enjoyable.
- ◆ Parents found the program to be convenient for their scheduling needs, and 48% viewed the training between 6:00 p.m. and 2:00 a.m.

Since the SPARKLE model was developed, it has been extended to other states through state deafblind projects. Currently, there are over 200 families in 18 states (Arizona, Connecticut, Florida, Georgia, Kansas, Maine, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nebraska, New Hampshire, Ohio, Pennsylvania, Texas, Utah, and Virginia) participating in Project SPARKLE. In addition, there is now a network of 35 specialists in deafblindness from across the country involved with Project SPARKLE.

Overall, Project SPARKLE has been shown to be an effective, accessible, and enjoyable model of parent training and networking. Ongoing efforts will include the addition of training topics and resource materials and expansion of the training program to new families of deafblind children around the country. Any parents who are interested in participating may contact their state deafblind projects or the SPARKLE Project directly. For additional information, contact Linda Alsop, SKI-HI Institute, Utah State University, 435-797-5598, lalsop@cc.usu.edu.



Coming of Age: 2005 International CHARGE Syndrome Conference

Betsy McGinnity
DB-LINK, Perkins School for the Blind

More than 500 people gathered in Miami last summer for the 7th International CHARGE Syndrome Conference. Since the first one in St. Louis, Missouri, in 1993, each CHARGE Syndrome conference has grown in participation and in the scope of information offered. It is both an extraordinary professional conference and an old-fashioned family reunion. This year was no exception.

The majority of conference participants have traditionally been family members and the conference organizers always make a special effort to offer overview information for new families. This year, Meg Hefner, Sandra Davenport, Kim Blake, and Rob Last—professionals well known in the CHARGE community—teamed up to offer “CHARGE 101: The Basics for New Families.” This year’s program also included presentations about emotional health for parents and children with CHARGE and special sessions for grandparents and siblings. With the support of the Lee E. Norbury Scholarship, twenty families received financial support to attend their first CHARGE Syndrome conference.

Conference presentations covered a wide range of medical and educational issues. Several sessions explored the impact of the recent discovery of a gene (CHD7) for CHARGE Syndrome, including a presentation by Conny van Ravenswaaij, who represented the group from The Netherlands that first identified the CHD7 gene. She talked about the discovery and the function of the gene. Other medical topics also emphasized recent research. Jeremy Kirk spoke about the rate of growth in those with CHARGE Syndrome and the response to growth hormone. Kim Blake shared information about her research into adolescent and adult issues. Other presentations covered osteoporosis, balance problems, puberty, and vision problems, including cortical visual impairment.

Several sessions dealt with behavioral issues, including behavior as communication, repetitive behavior, and the impact of sensory and neurological impairments on behavior. Educational topics addressed were communication, literacy, orientation and mobility, gross motor development, physical activity, and feeding and speech problems.

At each conference the CHARGE Syndrome Foundation presents the “Star in CHARGE” award. Recipients this year were David Brown and Tim Hartshorne. Each was acknowledged for his contributions to the literature and knowledge base about the impact of CHARGE on children and their development.

The conference spanned two-and-a-half days and included a meeting of the CHARGE Syndrome Foundation. In addition to keynote speakers and breakout sessions, Camp Fiesta, an activity-packed camp experience, was offered for younger attendees. Plenty of time was provided for participants to gather and meet informally. People whose only previous connection had been via the CHARGE Syndrome Listserv finally had a chance to meet face-to-face, families with younger children met families of older children, and young people with CHARGE shared their experiences with one another.

For many in attendance the most noticeable change in the program was the significant presence of young adults with CHARGE Syndrome. These young adult participants attended presentations, asked questions, and learned about the latest research. Belinda Arnell gave an inspiring keynote address that was both informative and humorous, and during a panel presentation, several young adults offered insight into their experiences growing up with CHARGE. While the majority of people who have CHARGE syndrome are still young enough to prefer the activities offered at Camp Fiesta, the presence of teenagers and young adults was a significant change.

With the discovery of the CHD7 gene and thus the establishment of CHARGE as a “syndrome” and the impact of the presence of young adults, the 2005 International CHARGE Syndrome Conference was a “coming of age” event. The Miami gathering sets the bar very high for the next conference in 2007, which is planned for a location in the western region of the U.S.

Further information about the presenters, program, and handouts is available from DB-LINK (800-438-9376, 800-854-7013 TTY, or dblink@tr.wou.edu).



Research Update

Persons Aging with Hearing and Vision Loss

**B. J. LeJeune, Project Director
Rehabilitation Research and Training Center
on Blindness and Low Vision
Mississippi State University**

The goals of the Persons Aging with Hearing and Vision Loss Project are to identify the number of people over age 55 with both hearing and vision loss, investigate issues that affect their independence and quality of life, identify and evaluate assistive technology and service delivery programs for these individuals, and explore psycho-social issues related to their adjustment to hearing and vision loss. The project is focusing on the needs of those who had one sensory loss prior to age 55 and then acquired the additional loss after age 55. This five-year research and training project is a collaborative effort by Mississippi State University, the Helen Keller National Center (HKNC), and San Diego State University and is funded by the National Institute of Disability Rehabilitation Research (Project Number H133A20701).

The project is currently in its fourth year. During the first three years, a nationally representative study sample of 410 people over age 55 with both hearing and vision loss was developed. The major data collection activities to date include analysis of national databases, such as the 2000 U. S. Census and the National Health Interview Survey (a research effort by the Centers for Disease Control and Prevention), informal interviews, focus groups, and surveys of individuals in the study sample. Additional surveys will be sent to service providers and assistive technology vendors.

Data analysis is in the preliminary stage since surveys and interviews are still in progress, but a wealth of information has been gathered. A few initial findings indicate:

- ◆ Affected individuals need much more information. As was expected, individuals who were deaf first have very little information about low vision, blindness, and assistive technology for persons who are blind. Those who were blind first have limited information about and access to hearing aids and cochlear implants.
- ◆ Service providers also need more information. One surprising finding was that blindness staff in independent living programs are often aware of hearing loss in program participants but do very little to accommodate for it in group settings.

- ◆ There are too few trained professionals providing services and guidance to seniors losing vision and hearing. Some participants felt that since they were not eligible for vocational rehabilitation services, they had no other options. Others felt that there are unique issues related to aging and sensory loss that professionals are not equipped to address.
- ◆ Use of telecommunications, especially cell phones and email, is difficult for many people with dual sensory loss, no matter when the onset.
- ◆ Transportation is a critical issue for many people.
- ◆ Generally people interviewed felt that they had neither the financial resources nor training that would allow them to access available technology.
- ◆ There is a lack of resources to assist individuals with their psychological and social adjustment to combined sensory loss.
- ◆ There is a related concern about limited housing options and loss of independence. For some persons, moving in with working adult children is their only option, and as a result, they feel very isolated and dependent.

Based on the project's research findings, a number of training opportunities for professionals and consumers will be offered. The project will host a national conference, *Creating Roads to Independence for Persons Aging with Hearing and Vision Loss* in Atlanta, Georgia, February 8–10, 2006. For additional information about the conference, check the Web link <http://www.blind.msstate.edu/drrpconference2006.html>, contact Stacy Butler at sbutler@colled.msstate.edu or 800-675-7782, or Roy Freeman at 662-325-8693 (videophone or TTY).

In April, May, July, and September, HKNC will offer week-long training seminars on communication options, community integration, psychosocial issues, and the enhancement of services. For more information, see page 15 of this issue of *Deaf-Blind Perspectives*.

B. J. LeJeune may be contacted at RRTC on Blindness and Low Vision, P. O. Box 6189, Mississippi State, MS 39762; or at 662-325-2001 (Voice), 662-325-8693 (TTY/video phone), bjlejeune@colled.msstate.edu, or <http://www.blind.msstate.edu/PAHVL>.

New Deaf-Blind Research Listserv

NTAC and DB-LINK are sponsoring a new Listserv that is open to persons interested in learning about or sharing information on all aspects of research in deaf-blindness. To subscribe send a blank e-mail message to db-research-subscribe-request@tr.wou.edu or contact Randy Klumph at klumphr@wou.edu.

New Research Articles

Dobbelsteyn, C., Marche, D. M., Blake, K., & Rashid, M. (2005). Early oral sensory experiences and feeding development in children with CHARGE: A Report of Five Cases. *Dysphagia*, 20, 89-100.

Horvath, L. S., Kampfer-Bohach, S., & Kearns, J. F. (2005). The use of accommodations among students with deafblindness in large-scale assessment systems. *Journal of Disability Policy Studies*, 16(3), 177-187.

Lim, M. et al. (2005). Development of visual acuity in children with cerebral visual impairment. *Archives of Ophthalmology*, 123(9), 1215-20.

Kono, E., & Oda, K. (2005). Favorite activities for deaf-blind children. *International Congress Series*, 1282, 873-876.

If you have information that you would like to include in "Research Update," contact:

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National Task Force on Deaf-Blind Interpreting

Susanne Morgan, MA, CI, CT
Registry of Interpreters for the Deaf,
Deaf-Blind Special Interest Group

Jamie Pope, Executive Director
American Association of the Deaf-Blind

At the Registry of Interpreters for the Deaf (RID) National Conference in San Antonio, Texas, we submitted a motion for the creation of a national task force to increase awareness of and improve training in deaf-blind interpreting. The motion was passed unanimously. The rationale for the creation of a task force is that RID, the leading organization in the field of interpreting services, has

yet to address the urgent communication access needs for the countless number of individuals who are deaf and have a vision loss. This lack of attention is in direct conflict with RID's philosophy "to strive for no less than excellence in the provision of interpreting/transliterating services." As a national body, RID must address the lack of understanding, training, skills, and quality of services currently provided that directly affect the constituents for whom this organization was founded. The mission of the task force will be to raise the standard of services to a level equivalent to that currently offered to the deaf community. The Deaf-Blind SIG/Member Section and the American Association of the Deaf-Blind Board are in support of this collaborative effort.

The task force's first step will be to compile a comprehensive list of the issues that consumers, interpreters, and interpreter-trainers face regarding deaf-blind interpreting. Then, a plan of action will be developed that addresses these issues. If you would like to be involved in this initiative or want further information, contact Susie Morgan at morgansusie@att.net.



For Your Library

Bruce, Susan, & Conlon, Kim. (2005). Colby's Daily Journal: A School-Home Effort to Promote Communication Development. *TEACHING Exceptional Children Plus*, 2(1).

<http://escholarship.bc.edu/education/tecplus/vol2/iss1/art3>

Daily communication journals are a powerful tool to promote communication development in children with severe disabilities. This online article describes the components of a communication journal created for Colby, a 4-year-old boy with deaf-blindness, and includes a videotape of him using the journal. Each page of the daily journal features three parts: a print or braille label, a recording device, and a tangible symbol. The review of the daily journal in the home creates opportunities for children to recall school events and to share those events with family members. Includes a list of tips for developing communication books.

Reaching Out: A Toolkit for Deafblind Children's Services

London: Sense, 30 pages

In the United Kingdom, local authorities have legal responsibilities to provide services for deaf-blind children. They are required to provide specialist assessments, appropriate information, and services designed to meet the needs of deafblind people. This guide was developed to help agencies meet those requirements. Topics covered include identifying and assessing deafblind children, services (e.g., one-to-one support, intervenors, family support), service coordination, and resources. Available on the web: <http://www.sense.org.uk/publications/professionals>

Quality Standards in Education and Support Services for Children and Young People who are Deafblind/Multi-Sensory-Impaired

Boothroyd, Eileen, et al. London: Sense, 22 pages.

These are educational standards for children who are deaf-blind in the United Kingdom. They are arranged by the following categories: assessment, early years, school years, transition to adulthood, beyond school, and management (practice, professional skills, monitoring, and evaluation). Each section sets out a series of recommended standards. Available on the web: <http://www.sense.org.uk/publications/professionals>

reSources (newsletter)

California Deaf-Blind Services

This newsletter, published by California Deaf-Blind Services, includes articles that are informative to everyone in the field of deaf-blindness as well as news specific to California. The theme of the most recent issue was the brain, the senses, and cognition. The current and back issues are available on the Web: <http://www.sfsu.edu/~cadbs>.

CVI Perspectives (Video or DVD)

American Printing House for the Blind (APH), 2005

Explores cortical visual impairment (CVI) from three perspectives: medical, educational, and personal. Neonatologist Dr. Alan Lantzzy presents a medical perspective on the causes of CVI, APH CVI Project Leader Dr. Christine Roman presents an educational perspective focusing on characteristics and recommended approaches, and in the final segment, seven families talk about their personal experiences from the difficulty of the diagnosis to finding help and hope. Cost: \$25.00. Available from APH, P.O. Box 6085, Louisville, KY 40206-0085. Phone: 800-223-1839. E-mail: info@aph.org. Web: <http://www.aph.org>.

Adapt My World: Homemade Adaptations for People with Disabilities

J. Rose Plaxen. Santa Ana, CA: Seven Locks Press, 2005

This book features simple homemade adaptations for children with disabilities at home, school, and play. The home chapter includes adaptations for mealtime, bath time, bedtime, and dressing to make children feel more independent at home. The school chapter has accommodations to help children study and socialize. The play chapter includes adaptations for all types of play, including sports and fitness. Cost: \$14.95. Available from Seven Locks Press. Phone: 800-354-5348. E-mail: sevenlocks@aol.com. Web: <http://www.sevenlockspublishing.com>.



Conferences and Events

Jan van Dijk Conference
July 22–24, 2006
Greensboro, North Carolina

Dr. Jan van Dijk is a world renowned educator from the Netherlands who has pioneered teaching approaches for individuals who are deaf-blind. This national conference, sponsored by the North Carolina Deaf-Blind Project, North Carolina Department of Public Instruction, and Western Carolina University, will also include a panel of experts presenting information on innovative educational practices from around the world.

For more information contact Chris Jones, Coordinator, North Carolina State Deaf-Blind Project. Phone: 919-807-3991. E-mail: cjones@dpi.state.nc.us.

American Association of the Deaf-Blind 2006 National Conference
Call for Papers


The AADB conference will be held June 17–23, 2006 in Baltimore. The theme is "AADB on the Move: No Deaf-Blind Left Behind." AADB is currently requesting submissions for presentations. Possible topic areas include emergency preparedness; SSP Issues; employment; self-determination; politics and advocacy; updates in laws, federal government services, and medical research; technology advances; community resources; interpreting; and aging issues. The deadline for submissions is February, 15, 2006. For more information go to <http://www.aadb.org> or contact Elizabeth Spiers at AADB. Phone: 301-495-4403. TTY: 301-495-4402. E-mail: espiers@aadbb.org.

Deafblind International 14th World Conference
 September 25–30, 2007
 Perth, Western Australia

The conference will be hosted by Senses Foundation. The theme is “Worldwide Connections: Breaking the Isolation” and its goal is to make progress toward breaking the isolation that people with deafblindness experience by breaking down barriers and building worldwide connections and networks amongst countries and organizations. For information see <http://www.senses.asn.au>.

You are welcome to copy articles from *Deaf-Blind Perspectives*. Please provide the appropriate citations.

Helen Keller National Center National Training Team Seminars 2006 Sands Point, NY	
April 3–7	Communication Options for Persons Aging with Hearing & Vision Loss
April 24–28	Expanding the Arena: The Magic of Technology
May 1–5	Community Integration for Persons Aging with Hearing & Vision Loss
May 21–26	Orientation & Mobility Techniques for Deaf-Blind Travelers: Same but Different
July 24–28	Addressing Psychosocial Issues Faced by Persons Aging with Hearing & Vision Loss
August 7–11	Interpreting Techniques for the Deaf-Blind Population: Touching Lives
September 11–15	Enhancing Services for Older Adults with Vision & Hearing Loss: The Best is Yet to Come
September 25–29	Disability Rehabilitation/Research Project Persons Aging with Hearing & Vision Loss (On-line Seminar)
October 23–27	Person-Centered Approach to Habilitation: Transformation
November 13-17	Technology Seminar: The Magic of Technology
Contact HKNC: Phone: 516-944-8900, Ext. 233. TTY: 516-944-8637. E-mail: ntthknc@aol.com . Web: http://hknc.org/FieldServicesNTTSchedule.htm	




DB-LINK Selected Topics

Find information about...

Orientation and Mobility

One of the easiest ways to locate current, well-organized information on a variety of subjects is to hitch a ride from the Selected Topics section of the DB-LINK Web site: <http://www.dblink.org>. This month we invite you to look at what is currently organized under the topic of Orientation and Mobility. Here you will find links to full text publications and other resources.



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