

## A Personal View of Changes in Deaf-Blind Population, Philosophy, and Needs

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During the past quarter century there have been significant changes in the population of children who are deaf-blind. At the same time there has been a steady increase in understanding and knowledge of effective educational strategies to help this group of children. As deaf-blind education specialists, we have experienced firsthand the influence of these changes on our work with children and their parents, teachers, and other service providers. In this article we relay some of our own experiences and offer our personal perspective on changes that have occurred in the field.

### Changes in Population

In 1983, a national survey of the population of children with deaf-blindness in the UK suggested that Congenital Rubella Syndrome was declining as a leading cause of deaf-blindness, while the number of other identified etiologies was steadily increasing, as was the proportion of children with additional severe disabilities. The author of the survey made the point that, "If this apparent change in population is a long-term one then it has implications for the provision of placements, staffing and the development of appropriate teaching techniques and appropriate measures for assessment" (Best, 1983, p. 11).

Subsequent writers (Collins, Majors, & Riggio, 1991; Riggio, 1992; Brown, 1997; Chen, 1998; McInnes, 1999; Miles & Riggio, 1999) have confirmed that the change in population has, indeed, been long-term, and has gone further than could have been imagined 20 years ago. This is also supported by data from the 2003 National Deaf-Blind Child Count, which lists more than 70 possible causes of deaf-blindness and identifies characteristics that underscore the complexity of these children. Of the approximately 10,000 children on the census, 60% also have physical impairments, 68% have cognitive impairments, and 40% have complex health care needs (National Deaf-Blind Child Count Summary, 2004).

Explanation of these changes is complex, and there are many contributing factors (Brown, 1997). The availability of a rubella vaccine and associated public health campaigns drastically decreased the incidence of Congenital Rubella Syndrome. Advances in medicine have increased survival rates for infants with severe disabilities and for premature infants (approximately 10% of children on the national child count are deaf-blind as a result of complications of prematurity). There has also been a growing awareness of the prevalence of sensory impairments and sensory processing difficulties in the population of children with multiple and profound disabilities. Two decades ago, many of these children would probably have been perceived simply as having "severe brain damage" or "mental retardation" without any consideration of their sensory status.

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As the needs of deaf-blind children have become more complex, educators, especially those working in an advisory capacity with young children, have had to familiarize themselves with an increasingly complex array of medical and therapeutic procedures and equipment. Of course, significant levels of complexity and learning difficulty, as well as a very wide range of ability, have been a feature of the population since the early days of deaf-blind education. Then and now, educators have been introducing teachers and parents to long-standing educational methods and techniques in the specialty of deaf-blindness, supporting children who are following academic curricula in regular classes, training staff and family members in techniques like tactile signing and adapted orientation and mobility, and helping vision specialists to adapt Braille instruction. They have also supported children who are functioning at the earliest stages of awareness and communicative ability. But now, these same educators are increasingly likely to be involved in cases where it may seem that their primary role is to help a family to implement an early educational program entirely within the confines of overwhelming medical, nursing, and therapy routines that fill up most of the child's day. These include the use of ventilators, suctioning, gastrostomy tube feedings, techniques for monitoring oxygen saturation, hormone treatments, a growing range of drug therapies, sensory integration therapy, physical therapy, and technological innovations like cochlear implants.

Many of the questions put to educators by parents as primary concerns these days are related to medical and therapy issues that are not (and have not traditionally been) within the area of competence and responsibility of teachers. Medical issues influence not only how we teach children but sometimes even what we teach. In order to help a child gain an understanding of his own environment and activities, early vocabulary that is part of a communication and language program might include ways to represent such things as "oxygen mask," "suction tube," and "G-tube button cleaning." In a small number of cases, a child's "natural environment" might be a special room built on to the family home, complete with everything to be found in a hospital room including round-the-clock nursing, with peers, and even siblings, excluded because of the risk of infection.

Accurate predictions of developmental progress are increasingly confounded by episodes of regression that result from recurrent illnesses and hospitalizations. It is often difficult to ascertain the exact cause of significant distress, loss of function, or behavioral problems in children with this level of complexity.

The increasing importance of medical issues has also been noted in older children and adults. As the population identified as having deaf-blindness back in the 1960s and 1970s has matured, a further change and challenge has been the discovery of late-onset health problems, fluctuations in sensory status, and resulting behavioral changes.

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Many of these developments appear to be neurologically determined, though there is still insufficient understanding of precise causes and appropriate remediation techniques. As a consequence of this ongoing process, our field has evolved very different, more complex, and comprehensive pictures of syndromes such as Congenital Rubella Syndrome and CHARGE Syndrome.

## Changes in Educational Philosophy

During the past quarter century there have also been significant changes in educational philosophy, sometimes imposed by changes outside our narrow specialty and sometimes originating from our own experiences and research. Rodbroe and Souriau (1999) chronicle a major change in the emphasis of deaf-blind education, from the tight “behavioristic approach” of the 1960s, when children were taught primarily by having things done to them, to a strong focus beginning in the late 1980s on “reciprocal social togetherness,” which encouraged following a child’s lead and building positive relationships in order to foster the development of communication and other skills. Increasing awareness of the importance, for all children, of developing attachments and forming positive relationships has been accompanied by growing evidence of the negative impact of stress on early brain development. Jan van Dijk has been an outstanding advocate for the consideration of stress as an inherent feature in deaf-blindness (Nelson & van Dijk, 2001) and its extremely deleterious impact on the development of children who are deaf-blind. He has also advocated for the need to consider these children at a biobehavioral level if assessment and teaching is to be successful, a view shared by other recent writers (Blaha, 1996; Brown, 2001). As a result, we now place a much greater emphasis upon meticulous observation and upon individualization of assessment and teaching approaches than we did 25 years ago.

At the 13<sup>th</sup> Deafblind International World Conference on Deafblindness in 2003, Tony Best presented a view of this history from a different perspective. He described how ways of defining or thinking about deaf-blindness as a medical condition have changed over the years. According to Best (2003), in the early days of deaf-blind education, collaboration between educators and medical experts was based on a narrow medical model that focused primarily upon the combination of vision and hearing loss. In this context, educators often worked with pediatricians; ear, nose, and throat specialists; audiologists; and ophthalmologists. Later, there was a move away from this view of

deaf-blindness as primarily a medical condition and toward a more social model—evident also within the broader field of disability—which was concerned with environmental adaptations and staff training needs. The emphasis shifted from the degree of vision and hearing loss of the children to their academic ability levels.

Because of changes in the population of deaf-blind children, and advances in the field of genetics and neurology, Best proposed that it was time, once again, to consider the influence of the medical aspects of conditions causing deaf-blindness on children’s educational needs. He stated that, “the neurological involvement of the vast majority of deafblind people under the age of 10 makes it a medical condition as much as a sensory disability,” and he proposed a “new medical model,” that emphasizes collaboration between educators and specialists in genetics and neurology (Best, 2003, p. 1).

It would be fascinating to study to what extent the evolution of the various educational models described by Rodbroe and Souriau and by Best, occurred as a result of changes in the identified population, and to what extent the advent of the new models themselves have altered our perception of who exactly constitutes the population of “children with deaf-blindness.” Since deaf-blindness is a spectrum disability, it seems inevitable that the field will continue to experience these periodic significant changes of emphasis and focus, manifested most clearly in the persistent search for a satisfactory and comprehensive definition of deaf-blindness.

## What Have These Changes in Population Meant for the Field?

Although the impact of these population changes has been immense it is important to remember that we never worked with a homogeneous and noncomplex group of children, even though some of us might have viewed our caseloads in precisely that way a long time ago. It is true that the vastly expanded range of etiologies has removed the old certainties derived from teaching a class or supporting a caseload predominantly of children with Congenital Rubella Syndrome (to know a lot about Congenital Rubella Syndrome used to be synonymous with knowing a lot about deaf-blindness, and vice versa). How many of us can claim similar facility and familiarity in working with children with Cockayne Syndrome, Cogan Syndrome, Turner Syndrome, Klippel-Fell Sequence, Trisomy 18, or even a quar-

ter of the other 70 or so etiologies included in the national census? It is also now unusual to find teachers with the high level of facility in adapted sign language and finger-spelling found among longer-standing, "pioneer," teachers in this field, since an increasing proportion of the younger (but surviving and growing) children in the current population are at a pre-language or very early level of language development. Even with appropriate teaching, this group's subsequent progress is often extremely slow. One need not travel far to hear complaints that these more complex and medically involved children are excessively challenging, develop slowly and inconsistently, and are using up an unfair proportion of the scarce resources that our services have available.

Less frequently discussed is the abundance of evidence that working with the more complex and profoundly disabled children has helped educators to develop skills and insights that also improve the quality of their work with the whole population of students with deaf-blindness and children with other disabilities. These benefits include increased creativity and flexibility, improved observation skills, greater empathy, more genuinely holistic and multisensory approaches to assessment and teaching, a stronger emphasis on individualized programs, and a more urgent awareness of the need for collaborative approaches. Above all, working with these most challenging children has helped to expand the parameters of what we previously thought possible for people with deaf-blindness in all areas of development, including adaptive skills, compensatory abilities, short- and long-term memory, social awareness, and differentiated behaviors. And just think, for example, how much even the most academically gifted child with deaf-blindness benefits from being considered from a biobehavioral perspective and how much more effectively we could have supported every child on our caseloads had we enjoyed these many invaluable insights decades ago.

### Where Next?

What are the implications of all of these changes? What should specialists in deaf-blindness, parents, and others involved in the education of deaf-blind children do in the light of this knowledge? Along with our colleagues in California, we have had many discussions on this topic. Although we would not wish to return to a time when deaf-blindness was considered primarily a medical condition, increased collaboration with neurologists and geneticists, as Tony Best sug-

gests, is essential. There are already exciting examples of this process at work. For example, within the CHARGE Syndrome Foundation there is a long-standing collaboration among medical specialists (with a significant representation of geneticists), families, psychologists, and teachers that has led to a rapid increase in knowledge about this condition. Except where they step forward though, it is probably unrealistic to expect much from most medical specialists in terms of engaging with developmental or educational issues, which are, after all, our prime focus and concern. An exception to this, however, may be the physicians and researchers involved in developmental and behavioral pediatrics, pediatric neurology, and neuropsychology, or rehabilitative medicine. For example, at the 2003 Deafblind International World Conference, Jude Nicholas, a neuropsychologist in Norway, spoke about cognitive neuroscience and how it "helps us to understand the communication in the nervous system and is the scientific key in understanding how the brain processes information" (Nicholas, 2003, p. 4). His comments on neuroplasticity (how the brain modifies itself in response to sensory deprivation), on the possible role of emotion in cognition, and on the emotional aspects of the communication process suggest a tantalizing new perspective that reinforces some of the more recent changes in our educational philosophy mentioned above.

It is also apparent that we need to read, research, document, and discuss far more about recent discoveries and developments in the fields of neurology and genetics and make our own inferences and decisions, while also becoming better able to formulate more appropriate questions to pose to the relevant medical specialists. Experts within the field of deaf-blindness are beginning to become more involved with these issues. At the 2004 NTAC Topical Workshop on Early Intervention, the presentations on early brain development and on the impact of the neonatal intensive care unit (NICU) on the early sensory development of premature babies were well attended and of great relevance for anyone working with the current population of children with deaf-blindness aged birth to ten. And increasingly, newer literature intended for teachers in our own and in closely associated fields has included a focus on neurological development, multisensory perspectives, health issues, and sensory integration difficulties that would have been very unusual 15 years ago (Liefert, 2003; Alsop, 2002; Orelove, Sobsey, & Silberman, 2004). Research into the patterns of change in the annual national deaf-blind census

and a planned forum for discussion of the findings seems an urgent necessity, particularly since our perception is that the changes in the nature of the population described in this paper are most marked among infants and young children. Issues about the changing population of deaf-blind children are often raised and debated, but in casual ways resulting from specific local events such as a new referral, the death of a child, or an inquiry about a rare syndrome. The time and opportunity to examine these issues in any kind of depth rarely presents itself.

As a field, it is important to regroup and reexamine what we are doing and with whom. As deaf-blind specialists, we are uniquely placed to take a holistic view of children. Creating opportunities to explore and discuss the nature of the changing population, the history of deaf-blind education, and the implications of these on our current work should now be a priority for the field.

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## Getting In Touch The Perkins Museum

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A new museum at the Perkins School for the Blind tells the history of the remarkable institution, now celebrating its 175th anniversary. Located in the main hall of the Howe Building on the school's Watertown, Massachusetts, campus, the museum illustrates the pioneering role of the school in blind and deafblind education. All the display cases have multiple modes of information, including printed text, Braille, individual audio guides, and at least one tactile component. There are also computers available for additional information and a thoughtful and well-written gallery guide by Curator Betsy McGinnity, Research Librarian Jan Seymour-Ford, and Volunteer Kathleen Andries.

The role of the Perkins School in developing writing and reading systems for blind and deafblind students is illustrated through an extraordinary collection of machines for producing raised type. These document a number of systems going back to the "Boston Line Type" that was developed by the school's first director, Samuel Gridley Howe. As Braille became the accepted standard, Perkins's own Howe Press published many books and other publications and developed the "Boston Braille Writer" and "Perkins Braille" for personal use. One of the great treasures on exhibit is an 1868 edition of *The Old Curiosity Shop* in Boston Line Type. The author, Charles Dickens, who visited the Perkins School on his American tour, paid for the publication of the three-volume book.

Tactile methods for teaching music, science, mathematics, and geography are all explored in the museum's displays. Hands-on maps, carved from wood or stitched onto fabric, have been part of the school's curriculum from its earliest days. A new map of the campus, made specifically for the museum, vies for favorite status among students and alumni with a giant wooden globe, made in 1837 and recently restored to go on exhibit.

Among the Perkins students who rose to national prominence were Laura Bridgman, Anne Sullivan, and Helen Keller (whose parents were referred to the school by Alexander Graham Bell in 1886). The exhibition includes a number of objects related to these three women, including ex-

amples of letters written by Bridgman and Keller using the "square-hand writing" taught at the Perkins School, lace made by Laura Bridgman, and a lovely photographic record of the relationship between Sullivan and Keller.

The prominent role of the Perkins School in Boston philanthropic circles is made clear in several sections of the museum. Named for the China Trade merchant Thomas Handasyd Perkins, who donated his house to the school in 1833, the institution drew the attention of some of the most prominent writers and social activists of the area. Julia Ward Howe, the wife of the first director, was one of the most influential women in America in the nineteenth century. A major figure in the abolitionist movement and in the struggle for women's rights, she was a dynamic lecturer and a poet, best remembered today for having written the "Battle Hymn of the Republic." Louisa May Alcott donated the profits from her story "Blind Lark" to the school's building fund, and Henry David Thoreau applied to teach at the Perkins School in 1841. His application letter is reproduced in the museum, along with the astonishing report that he wasn't hired, despite the fact that Ralph Waldo Emerson was one of his references!

This is not the first museum to be created at the Perkins School. In the late nineteenth century, when natural history museums were opening in cities all over America and Europe, Perkins Director Michael Anagnos established his own version. As the label text explains, "Students who are blind do not have the benefit of incidentally learning about the natural world as sighted children do. To give students direct experience of the world, Director Anagnos in 1880 established a tactile museum featuring objects related to natural history and science."

Photographs of the early displays, examples of animal skulls, and an extraordinary model of a complex plant, which comes apart to reveal all of its component parts to the touch, give the visitor a hint of that earlier museum. Most of the surviving collection, including a large number of wonderful bird and animal mounts, are still part of the active teaching collection of the school.

The contrast between the early museum and the new museum illustrates important changes at the Perkins School in the last century. While Anagnos conceived his museum for the students in the school, McGinnity and the Museum Committee have clearly approached their task with a much wider audience in mind. The new museum teaches alumni, outside school groups, and the general public about the Perkins School itself. The

two important functions of the school are made very clear: educating people who are vision impaired, blind, and deafblind, locally and globally; and providing library services to the larger community by distributing Braille and audio books.

Despite its central place in the field, the general public in Boston today knows less about the Perkins School than the population did 175 years ago, when there were many fewer schools and nonprofit organizations competing for attention, charitable contributions, and government funds. The museum is a positive way of bringing greater attention to the school and its important role in the local, regional, and national community.

The museum is currently visited by two or more school groups per month and a number of local Brownie troops. The new Massachusetts state elementary school curriculum has a unit on Helen Keller, which will almost certainly ensure a growing number of school visits in the future.

The museum is fully accessible and is open to the public on Tuesdays and Thursdays from 2:00 p.m. to 4:00 p.m. More information is available on the Perkins Web site at <http://www.perkins.org>.



## Research Update

“Research Update” is a regularly recurring feature consisting of announcements related to research in deaf-blindness. Researchers and other interested individuals or agencies may use this column to share information about new, ongoing, or recently completed research projects and new publications. If you have information about a research topic that you would like to include, contact:

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## Research Project Update

### Functional Hearing Inventory: Project to Identify Criterion-Related Validity and Interrater Reliability

Submitted by Pamela Broadston  
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*Background.* Deafblindness is a multifaceted disability that impacts an individual in compound and complex ways. Children who are deafblind require instruction in the use of residual hearing and vision and appropriate access to the environments in which they live and learn. The development of goals and objectives for educational intervention should be based on the needs of each individual child as revealed through appropriate assessment. Information about a child’s access to the environment is an important part of the assessment process (Olson, Miles, & Riggio, 1999).

*Purpose.* The Functional Hearing Inventory (FHI) was developed to obtain information about how deafblind children use residual hearing within their natural environments. It was designed to be both diagnostic and prescriptive by providing a process to record a child’s present level of functional hearing as well as a way to focus intervention strategies. The information obtained from the inventory can be used to plan educational programs that optimize the use of hearing to develop language and communication skills, document a child’s progress in the development and use of residual hearing, and guide environmental adaptations. Access to the environment is crucial for the development of communication and language. The information gleaned from the FHI can be used to help parents and educators manipulate environmental background noise levels in the classroom or at home, maximize students’ use of residual hearing, and provide a better listening environment for learning.

*Goal.* The goal of this five-year project is to establish the validity and reliability of the FHI as a tool to provide accurate information about the use of hearing by students with deafblindness. Approximately 180 students will be assessed, rigorous field testing of the *FHI Instruction Manual* will be conducted to assure clarity of its instructions and procedures, and a training CD-ROM will be developed. Training activities on the use of the FHI will be held and the completed FHI materials will be disseminated.

*Current Status.* Members of observational teams from the three participating universities have been trained, and interrater reliability has

been established among team members. Approval from the Institutional Review Board for the Protection of Human Subjects at all three universities was obtained. So far, the FHI has been administered to students in six states. Additional students are being recruited.

*Project Coinvestigators.* Roseanna Davidson, Ed.D, Texas Tech University; Pamela Broadston, Ed.D, University of Arkansas at Little Rock; and B. J. LeJeune, M.Ed., Mississippi State University-RRTC.

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Olson, K., Miles, B., & Riggio, M. (1999). Environments that encourage communication. In B. Miles & M. Riggio (Eds.), *Remarkable conversations: A guide to developing meaningful communication with children and young adults who are deafblind* (pp. 76–93). Watertown, MA: Perkins School for the Blind.

## New Research Articles about CHARGE Syndrome

The March issue of the *American Journal of Medical Genetics Part A* (Vol. 133A, Issue 3) is devoted to articles about the behavioral aspects of CHARGE Syndrome. A few additional articles about other aspects of CHARGE Syndrome are also included.

## Web Site on Research in Young Children with Developmental Disabilities

The Research and Training Center on Early Childhood Development Web site (<http://www.researchtopractice.info>) includes information about research-based practices for infants, toddlers, and preschoolers with or at risk for developmental disabilities. There are a number of products available including *Centerscope* articles that provide detailed information about the history and nature of evidence-based practice; *Bridges*, practice-based research syntheses of topics related to early childhood development; *Bottomlines*, one- to two-page summaries of the practice-based research syntheses; and *Solutions Tool Kits*, user-friendly brochures, newsletters, video tapes, and PowerPoint presentations that describe methods and strategies that can be implemented to achieve an effect similar to that reported in a particular research synthesis.



## Letter to the Editor

To the editor,

We are writing to *Deaf-Blind Perspectives* to comment on the recently published article “Collaboration Achieves Travel Success (Project CATS)” by Houghton, et al. (Winter 2005), explaining a program that is illustrated with an example attributed to Kansas. We applaud the transdisciplinary approach to children’s travel safety, and agree with the need for collaboration when educating deafblind travelers. However, we have serious concerns about the pedagogical approach and the orientation and mobility techniques incorporated in the program.

We are troubled that people will assume that articles prominently placed in a professional newsletter such as *Deaf-Blind Perspectives* have been peer-reviewed by qualified professionals and will therefore believe that the information presented represents “best practices.” Our main concern is the need for a Certified Orientation and Mobility Specialist (COMS). In the model presented in the article, a COMS is an optional component to the team, to be consulted only for such things as checking traffic-related or other safety concerns. A COMS should be involved in the development of deafblind children’s educational programs from the onset of planning and continuing throughout. The development of safe and efficient travel skills for most deafblind children is something that should be part of their entire educational process.

Further, the only professional with sufficient knowledge of these skills and concepts is an orientation and mobility specialist. We feel that the inclusion of a COMS on the team should be a requirement; without a COMS on the team, this situation is rife with the potential for danger for deafblind travelers.

Our second concern relates to the actual orientation and mobility practices used as examples in the article. Although we realize the writers did not

intend the piece to teach specific mobility methodology, the inclusion of several irregular practices causes apprehension. Perhaps the most obvious example involved the text and picture relating to the youngster crossing the street. Flagging moving vehicles and assuming they will all stop is not a safe practice (Sauerburger, 1998, 2003). Children are especially vulnerable to the dangers of using such strategies, as they are not usually capable of processing the very complex rules and risks associated with such tasks.

We agree that there is a severe shortage of COMS, especially COMS who are experienced with and prepared to serve deafblind children, but we advocate for more personnel preparation programs, appropriately designed educational programs and IEPs, and a greater involvement of COMS in working with deafblind youth and adults rather than the establishment of programs that provide O&M services with teams that don't include COMS. It is a time for innovation, creative thinking, and maintaining best practices in our programs, research, and authorship.

Thank you for your attention to our concerns.

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## For Your Library

Integrated Functional Behavior Assessment Protocol (IF-BAP): Holistic Behavioral Assessment of Students with Deafblindness and Severe Disabilities

Kevin D. Arnold & Thomas M. Stephens, *Universal Publishing, 2004, 80 pages*

The IF-BAP assessment strategy is intended to create a comprehensive view of a student who is deaf-blind or has severe disabilities in order to increase a teacher's understanding of the interaction among various behavioral and sensory systems. Once teachers understand those interactions, they can design a program that not only addresses each of those systems, but also the combined effects of each system's unique contribution to the whole student. IF-BAP relies on a transdisciplinary approach, in which a variety of specialists conduct assessments, which are then integrated by one individual into an overall picture of the student. The material is presented as an instructional manual to be used by qualified professionals who are competent in psychological assessment, applied behavioral analysis, and instructional interventions. Cost: \$15.95. Available from Universal Publishing. Phone: 800-940-2270. Web: <http://www.upub.net>.

Words in My Hands: A Teacher, a Deaf-Blind Man, an Unforgettable Journey

Diane Chambers. *Ellexa Press, 2005, 263 pages*

After his wife died when he was 86, Bert Reidel, a man with Usher Syndrome, moved to Colorado to live with his son and daughter-in-law. Although Bert was an expert Braille reader, he had never learned sign language and his wife had been his "eyes and ears" to the world. This book tells the story Bert's life and how he learned sign language beginning at age 86. It illustrates that it is never too late to learn as it describes how sign language transformed not only Bert's life, but the lives of his family, friends, and the interpreter who was his sign language teacher. Cost \$15.95. Available from Ellexa Press LLC, 32262 Steven Way, Conifer, CO 80433. Fax: 303-838-7010. E-mail: [dlc@ellexapress.citymax.com](mailto:dlc@ellexapress.citymax.com). Web: <http://www.ellexapress.citymax.com>.

HomeTalk: A Family Assessment of Children who are Deafblind (Spanish Version)

*Bringing It All Back Home Project, 2003*

A Spanish translation of this assessment tool (*HomeTalk: Una evaluación familiar para niños sordos y ciegos*) is now available on the Web. *HomeTalk* is designed to help parents and care providers of children who are deaf-blind and have other disabilities participate in their children's education by giving them a way to provide a broad picture of a child's skills, special interests, and personality. Available on the DB-LINK Web site (<http://www.dblink.org>) in the Selected Topics section and on the Design to Learn Web site (<http://www.designtolearn.com>) in the Products section. If you don't have access to the Web, call DB-LINK at 800-438-9376 or 800-854-7013 (TTY).

Child-Guided Strategies for Assessing Children Who Are Deafblind or Have Multiple Disabilities [CD-ROM] (Spanish Version)

*Aapnootmuis Educaïment*

A Spanish translation (Windows version only) of this resource has been recently released. This interactive CD-ROM addresses approaches of assessment and teaching for children with multiple disabilities. Strategies are demonstrated through the use of over 40 video clips. Cost: \$40.00. To order, send a check or money order payable to Mr. Joe Franken, 4619 Spyglass Drive, Dallas, TX 75287. For more information contact Aapnootmuis Educaïment. E-mail: [info@aapnootmuis.com](mailto:info@aapnootmuis.com). Web: <http://www.aapnootmuis.com>.

Strategies for Teaching Children with CHARGE Syndrome and other Multiple Disabilities [DVD]

*Aapnootmuis Educaïment*

In this 30 minute DVD recording of a presentation given at a recent Australian CHARGE Syndrome conference, Dr. Jan van Dijk demonstrates and explains 5 important teaching principles based upon his 40 years of work with children with multiple disabilities and derived from theories on attachment, contingent learning, and neuro-biology. The new Dutch findings related to the genetics of CHARGE Syndrome are also explained. Cost: \$15.00. To order, send a check or money order payable to Mr. Joe Franken, 4619 Spyglass Drive, Dallas, TX 75287. For more information contact Aapnootmuis Educaïment. E-mail: [info@aapnootmuis.com](mailto:info@aapnootmuis.com). Web: <http://www.aapnootmuis.com>.

AccessWorld (online magazine)

*American Foundation for the Blind*

This online magazine about technology for people with visual impairments is available for free on the Web. It is published 6 times per year and includes feature articles, news, and product reviews of computer and other technologies for people who are blind. The specific needs of deaf-blind people are often addressed. Published 6 times per year. Web: <http://www.afb.org/accessworld>.

Cortical Visual Impairment (CVI) Web Site

*American Printing House (APH) for the Blind*

A Web site devoted to the topic of CVI. It includes lists of articles and videos, stories of children with CVI, educational information such as environmental supports and intervention strategies, and information about products and resources. Web: <http://www.aph.org/cvi>.

National Early Childhood Transition Center (NECTC) Web site

NECTC's mission is to examine factors that promote successful transitions between infant/toddler programs, preschool programs, and public school programs for young children with disabilities and their families. Its primary objective is to investigate and validate practices and strategies that enhance the early childhood transition process and support positive school outcomes for children with disabilities. The Web site includes a searchable database of transition research, policy, and practice. Web: <http://www.ihdi.uky.edu/nectc>.



## Conferences and Events

Enchanted Hills Deaf-Blind Conference and Camp  
*June 11-15, 2005*  
*Napa, California*

A conference and camp for Deaf-Blind adults 18 years of age and older. Registration priority will be given to those who apply from California, Nevada, Arizona, and Hawaii. People applying from other areas will be placed on a waiting list and admitted based on availability. For more information contact Frank Lester, Conference/Camp Coordinator ([frester@comcast.net](mailto:frester@comcast.net)) or call Sook Hee Choi, Deaf-Blind Employment Access Specialist, Rose Resnick Lighthouse (415-431-4572 TTY). Web: <http://www.lighthouse-sf.org>.

Colorado Summer Institute on Deafblindness  
June 27-29, 2005

The topic this year is "Active Learning: Movement, Exploration, and Early Literacy for Children with Deafblindness." The guest speaker is Kathee Scoggin, Co-Director, Deaf-Blind Services, Washington Sensory Disabilities Services. For more information contact: Tanni Anthony, Colorado Services for Children with Combined Vision and Hearing Loss. Phone: 303-866-6681. E-mail: anthony\_t@cde.state.co.us.

Nebraska Deaf-Blind Summer Institute  
July 18-22, 2005  
University of Nebraska - Lincoln

The following sessions will be held: "What Constitutes a Successful Psychological Evaluation," presented by Pam Ryan, School Psychologist, Deafblind Program, Perkins School for the Blind; "Challenges and Possibilities: Curriculum for Deafblind Learners," presented by Martha Majors, Assistant Supervisor, Deafblind Program, Perkins School for the Blind; "Get Ready, Get Set . . . LET'S Move!: Learning About the World Through Movement," presented by Carolina Martinez, Certified Orientation and Mobility Specialist, Texas School for the Blind and Visually Impaired. For more information contact Teresa Coonts, Coordinator, Nebraska Deaf-Blind Project. Phone: 402-595-1810. E-mail: tcoonts@esu3.org.

Nebraska Family Workshop: Get Ready, Get Set  
. . . LET'S Move!"  
July 23, 2005  
University of Nebraska - Lincoln

This half-day training event will be for parents and family members of children who have combined hearing and vision loss. It is designed to introduce parents to strategies to help their children develop movement skills through effective orientation and mobility techniques. For more information contact Teresa Coonts, Coordinator, Nebraska Deaf-Blind Project. Phone: 402-595-1810. E-mail: tcoonts@esu3.org.

7th International CHARGE Syndrome  
Conference  
July 22-24, 2005  
Miami, Florida

Speakers will be from medical, educational, and other related professions and a wide range of topics will be offered. There will also be time to visit with other families and share experiences. Childcare is provided for the meetings. For more information contact the CHARGE Syndrome

Foundation. Phone: 800-442-7604.  
E-mail: marion@chargesyndrome.org.  
Web: <http://www.chargesyndrome.org>.

NTAC/NFADB Annual National Parent  
Conference  
August 25-27, 2005  
Salt Lake City, Utah

This conference co-sponsored by NTAC and the National Family Association for Deaf-Blind provides an opportunity for family members of children who are deaf-blind to get together to network and learn about a specific topic. The topic this year will focus on psychosocial issues related to family life when there is a child who is deaf-blind in the family. For more information contact Tracy Jess. Phone: 425-576-5527. E-mail: jesstracy@yahoo.com.

## Announcements

### *Deaf-Blind Perspectives* Readers Forum

A new listserv has been established for readers of *Deaf-Blind Perspectives*. The purpose is to share opinions, ideas, and resources related to articles and information in *Deaf-Blind Perspectives*, following the publication of each issue. To subscribe, send a blank email message to: [dbp-forum-subscribe-request@tr.wou.edu](mailto:dbp-forum-subscribe-request@tr.wou.edu) or contact Randy Klumph for assistance.

### Want a LISTSERV® of Your Own?

Would you or your organization like to have your own LISTSERV? The Teaching Research Institute can help you set it up and will host it for you, free of charge. The only requirements are that it must be non-commercial and be related to Deaf-Blindness. For examples of current lists hosted at TRI, see <http://www.tri.wou.edu/archives>.

Contact:  
Randy Klumph  
LISTSERV Administrator  
[klumphr@wou.edu](mailto:klumphr@wou.edu)

## *Deaf-Blind Perspectives*

Paper copies of *Deaf-Blind Perspectives* are available free of charge to subscribers within the United States. E-mail subscriptions (provide notification that a new issue has been placed online) are available for International subscribers and others who prefer the online format.

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

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