Deafblind International World Conference on Deafblindness

Peggy Malloy
Managing Editor

This issue of *Deaf-Blind Perspectives* is devoted to a report on the 13th Deafblind International (DbI) World Conference on Deafblindness held last August in Mississauga, Ontario. Deaf-blind people, family members, and professionals came together from all over the world to share their knowledge, experiences, and philosophies and to celebrate the theme of the conference, *Communication is the Key to Opening Doors Worldwide for Persons Who Are Deafblind*. The more than 500 participants from 48 countries had an opportunity to exchange information about research, educational methods and programs, ongoing advocacy efforts at the international level, and the unique experiences of many children and adults who are deaf-blind.

Deafblind International (DbI) began in the 1960s as a small group of parents and teachers interested in information about the education of deaf-blind children. Over the years it has expanded into a much broader organization encompassing the interests and needs of all people with deaf-blindness at every stage of life. As part of its many activities, DbI holds a world conference every four years.

This conference demonstrated the range and depth of experience that exists worldwide in the field of deaf-blindness and it emphasized the value of sharing information. Although the presenters and participants, including 70 people from developing regions of the world, came from many different cultures, used a variety of communication methods, and spoke many different languages, it was clear that everyone had much in common.

The conference provided a phenomenal range of opportunities to learn about all aspects of deaf-blindness. There were four plenary presentations, more than 100 workshop sessions, meetings of Deafblind International’s topic-specific networks and focus groups, poster sessions, exhibits, and numerous social and art events. The host organization, the Canadian Deafblind and Rubella Association (CDBRA), put all of this together in a very efficient way while at the same time providing an environment that was relaxed and friendly.

Thanks to our wonderful volunteer reporters, we are able to report on a sample of these events. The complete conference program is available on the conference web site, http://www.dbiconferencecanada.com. The site also contains ordering information for audio- and videotapes that were recorded at the conference. Conference proceedings will be available soon. For more information about DbI visit http://www.deafblindinternational.org.

We hope that you enjoy this issue. Sharing information is essential in order to develop and communicate knowledge about deaf-blindness, and *Deaf-Blind Perspectives* is committed to being part of this. If you have questions about anything you read in this issue or want more information about specific topics, contact DB-LINK (800-438-9376, 800-854-7013 TTY, or dblink@tr.wou.edu).

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Workshop Presentations

Maintaining Independence: A Lifestyle Survey of People With Usher Syndrome Living in Six Different European Countries
Presented by Liz Cook and Marylin Kilsby (United Kingdom)
Reported by Katrina Arndt

Liz Cook and Marylin Kilsby authored *A Report on the CAUSE Usher Lifestyle Survey*, undertaken as part of CAUSE (CHARGE and Usher Syndrome in Europe), an 18-month project that was funded by the European Union Rare Diseases Programme to promote awareness of Usher Syndrome and CHARGE Syndrome through the exchange of information, experience, and best practice. The idea that a group of people who have Usher Syndrome had been systematically surveyed was exciting to me. I looked forward to hearing what these researchers had found, and I was not disappointed. Sixty-seven people with Usher Syndrome from six countries—Italy, Germany, Spain, the United Kingdom, Ireland, and France—responded to the survey.

I found two points especially interesting. First, people with Usher Syndrome experience “almost constant change” resulting in continual uncertainty about the future. Second, people surveyed were asked about the subjects that were important to them. Research about Usher Syndrome was ranked most important, followed closely by communication support. Retinitis pigmentosa and access to work were ranked third and fourth.

The report is well organized and presented and is an exceptional resource about individuals who have Usher Syndrome. The full report as well as additional information about the CAUSE project is available on the web: http://www.deafblindinternational.org/cause/. Print copies of the report are also available for a minimal cost. Contact Marylin Kilsby at MKilsby@sense.org.uk.

Touch: A Magical Means of Communication
Presented by Sheela Sinha (India)
Reported by Marianne Riggio

Sheela Sinha, coordinator of the Helen Keller Institute for the Deaf and Deafblind in India, gave a very insightful presentation on the importance of touch as the primary means of creating a link between a deafblind person and everyone and everything in his or her environment. She emphasized the importance of using strategies to promote joint exploration through mutual touch by offering our hands as co-explorers to children who are deafblind. This is a way to stimulate children’s interest in the
world around them. Through jointly exploring the world, natural conversations occur, trust is built, and a desire to communicate blossoms.

She presented a case study of a 16-year-old woman who is totally deafblind and attends the vocational program at the Helen Keller Institute. Yogita has excellent orientation and mobility skills and is very independent in many daily living and vocational tasks. Staff members at the school, however, were very concerned that she had no interest in people and in building relationships. Whenever someone approached her, even gently, she would pull away and cry and bite herself. The staff tried various strategies that were considered educationally sound, such as:

- creating activities with objects that Yogita liked;
- removing her from group activities and limiting the number of people who interacted with her to those whom she found most tolerable;
- teaching in a quiet, low stimulation environment;
- beginning each day with activities that she expressed some interest in.

There was some limited success with these strategies, but Yogita remained quite withdrawn.

After the educational team from the Helen Keller Institute met with staff at the school and the hostel where Yogita lives, a new strategy was devised. A schedule was developed that included many interactive and group sessions. A major difference between this strategy and previous strategies, however, was that this time no one initiated interactions with her. Instead, staff members sat close to her, making their hands available whenever she chose to participate. The outcome for Yogita is that she is now much happier. She initiates interactions and indicates when she would like hand games or other interactions to continue. She has also become a more willing participant in her vocational program.

Sheela stressed that the following points should be considered when using this type of strategy:

- The hands that are jointly exploring the world should be those of someone familiar and trusted.
- Topics of natural discussion must come from the child’s own environment.
- The pace of co-exploration must be comfortable for the child.

Sheela also talked about the use of massage at the Helen Keller Institute, where it has become an integral part of their program. She reported that through gentle massage, restless children become calm and asocial children become more interested in building relationships with others. She presented several case studies of how massage helped make dramatic changes in several children at the school. She also highlighted the importance of infant massage in the bonding process and in helping families tune into the body language of their child.

Sheela concluded her presentation by saying that touch becomes the eyes and ears of a deafblind person and, more than that, the seat of all their perceptions, emotions, and feelings. She emphasized that sighted hearing people should be mindful of their use of touch. They should not poke or prod or constantly, tap, pat, pull, hold, or guide in a constraining manner. We should be gentle and respectful of how we use touch. We should show personal regard for the type and frequency of touch preferred by the person who is deafblind. She ended with a poem:

**Touch**

There is no need to speak: I understand  
Each quick impulsive movement of your hand,  
By some strange magic of the heart I guess  
The meaning of each gesture, each caress.

Your fingers can be gentle, firm, or kind;  
Or fierce when anger surges through your mind  
Or they can trace, with such exquisite grace,  
The tenderness love mirrors in your face.

Oh, when I reach to take you by the hand,  
It is because I need to understand  
That I am not alone in this broad land.  

*Robert Smithdas*

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**Strategies for the Fitting of Hearing Aids for Communication and Travel Purposes**

Presented by Julie Dufour and Agathe Ratelle (Canada)  
Reported by Ed Gervasoni

Julie Dufour, an audiologist at Institut Raymond-Dewer in Montreal, and Agathe Ratelle, an orientation and mobility specialist at Montreal’s Institut Nazareth et Louis-Braille, shared the results of a research program that evaluated the use of programmable hearing aids to enhance a person’s abil-
As many of us in the field know, audiologists are more concerned with hearing frequencies that are important for speech and communication than with the lower frequencies needed for safe travel purposes. It was great to learn about a research study designed to consider the use of hearing aids for travel purposes. Case studies of individuals who had hearing aids equipped with three programs were presented. One program was used primarily for speech in normal environments. The second program was also used for speech but included a directional microphone to use when communicating in noisy environments such as on a bus or in a store. The third program, set to a low frequency range, was used for determining traffic distance and patterns. The hearing aid could be switched from one program to another using a remote control device easily carried in a pocket.

For these hearing aids to work for sound localization, it is necessary to have an equal amount of hearing in both ears. It appears from the case presentations that this system increased the ability of deaf-blind individuals to manage safe and efficient street crossings. The presenters are currently conducting a structured research project to validate the observed results of the case studies.

**Project Arteiros**

Presented by Daniella Forchetti and Laura L.M. Ancilotto (Brazil)

“Beyond Words:” A Musical Project Exploring the Various Ways People with Complex Support Needs and Dual Sensory Impairment May Interact with and Affect the Environment

Presented by David McCluskey and Jay Townsend (United Kingdom)

Reported by Lauren Lieberman

I attended two wonderful presentations about the use of music and dance for self-expression and communication. The first, about Project Arteiros, was presented by Daniella Forchetti and Laura Ancilotto, who work at AHIMSA, a school for children with multiple disabilities in São Paulo, Brazil and are part of Grupo Brasil de Apoio ao Surdocego e ao Múltiplo Deficiente Sensorial. Daniella is a dance teacher and Laura is the official translator of the group. Project Arteiros is a dance program that uses methods of communication through movement developed by Jan van Dijk along with alternative communication methods such as pictures, symbols, communication boards and books, and the manual alphabet. The goals of the program are “cooperation, respect, and quality of life,” and it emphasizes increasing self-esteem for the participants. The types of dances include circle dances and folk dances, and they use a variety of sounds, rhythms, and position changes. Modifications and props used to enhance the experience include extensive use of touch, a long and wide transparent tarp, ribbons to wave, formation of the dancers into parallel lines with dancers moving through the lines, and dancing in pairs.

Several dances were demonstrated. First, Claudia Sofia I. Pereira, a woman who is deafblind, demonstrated a solo dance. In a beautiful way, she incorporated the use of a string held by two people to help her keep her place on the dance floor. In another dance, Claudia and Daniella danced together using coactive movement and a string held between their hands to help coordinate their movements. It was a truly spectacular performance. I was amazed at the way they were able to stay in touch with one another.

The workshop participants also had an opportunity to take part in a dance that began as a moving circle with everyone’s hands touching, wound around in a spiral as a line, and then became a circle again moving in and out. It was a great experience.

In the second session, David McCluskey, a music tutor at Sense Scotland shared his wonderful music curriculum for individuals who have sensory loss in combination with other disabilities. In this presentation he showed a video of his students and then let the workshop participants try out some of the instruments that he uses. His approach to music is individualized. He focuses on each participant’s strengths and interests and uses a variety of instruments including a spring drum, a vibrato, rain sticks, African nuts, an ocean drum (a drum with ball bearings inside), an African seed pod, plastic eggs with BBs inside, a fan with a ribbon attached, chimes, a drum with a handheld fan, and a bowl with a wooden stick. He begins teaching the use of instruments using hand-over-hand instruc-
tion until students can perform on their own. He is able to get children to do things independently that they wouldn’t have done without the involvement of music. The variety of instruments coupled with the individual approach would make any child want to be part of the music!

**CHARGE into the Adolescent and Adult Decades**

Presented by Dr. Kim Blake (Canada)
Reported by Michelle Clyne

This session focused on information gathered by Kim Blake and her colleagues at the Department of Pediatrics, Dalhousie University and at IWK Health Centre in Halifax, Nova Scotia, about individuals between the ages of 13 and 30 who have CHARGE Syndrome. Because of the physical changes that take place during the teen years, this is a time when medical monitoring of growth and puberty may be crucial. Dr. Blake covered a number of issues in her talk, but the part with the most medical implications was that related to maturation among youth with CHARGE. She explained that young people with CHARGE often have growth deficiencies. In addition, eating difficulties sometimes lead to inadequate nutrition and add another challenge to growth. Youth with CHARGE also often experience a lack of pubertal development. Both of these maturational delays can lead to problems with health and self-concept.

Dr. Blake recommended that general growth be measured with several assessments, including growth charts, multiple tests for growth hormone, and a test of bone age. The bone age test is critical because one of the lesser known concerns associated with CHARGE is osteoporosis. When a youth’s chronological age is greater than their bone age they are at greater risk for developing osteoporosis. This can lead to scoliosis and bone fractures.

Dr. Blake cited a case study of a young lady given growth hormone. In addition to height and weight increases, improved self-image, as evidenced by the larger and more detailed self-portraits she drew, was an unexpected benefit. She also had a better appetite, improved sleep, better hair, and improvement in her signing skills, and she reported that she generally “felt better.” Similarly, delays in the onset or completeness of puberty can be treated with hormone replacement therapy. Like growth issues, delayed puberty can lead to problems with self-esteem and other health concerns.

Timing is critical in order to properly coordinate treatment for growth and puberty. Growth treatment should be completed prior to treatment for puberty.

Dr. Blake recommended that youth with CHARGE be followed by an endocrinologist from infancy on. Given the medical and psychosocial implications of the maturational issues associated with CHARGE, this seems like great advice.

**Nalaga’at (Do-touch): A Theatrical Group in Israel**

Presented by Adina Tal and Earan Gur (Israel)
Reported by Ed Gervasoni

This presentation told the story of Nalaga’at, a theatrical group comprised of twelve deaf-blind individuals. Four years ago, Adina Tal, an actor, writer, and director in Israel, was asked to do a workshop with some individuals who are deaf-blind. Initially, she only planned on making a temporary commitment, but she was so taken by their plight as deaf-blind individuals living in Israel that she could not walk away. In time she was able to get the deaf-blind individuals to open up and express their dreams, challenges, and hopes.

Through the course of this process, a theater production, “Light is Heard in Zig-Zag,” was developed that conveyed the experience of living with deaf-blindness. When performed for the public, the show exceeded all expectations of success and is now considered one of the greatest plays in Israel this year. It is receiving critical acclaim and high-profile media attention and continues to play before sold-out audiences.

More importantly, the actors have come to realize that they have something to contribute to society and to feel more attached to real life than ever before. One goal of the group is to create awareness and establish independent living services for all deaf-blind people in Israel. At the writing of this article, there are plans in the works for the group to travel to Montreal, Toronto, and Boston sometime in the summer of 2004 in order to perform their show before North American audiences. For more information visit the Nalaga’at web site at http://www.nalagaat.org.il. DB-LINK has a videotape and CD-ROM about Nalaga’at that can be borrowed. Contact DB-LINK at 800-438-9376, 800-854-7013 (TTY), or dblink@tr.wou.edu.
Signed Conversations of Deafblind People

Presented by Dr. Johanna Mesch (Sweden)

Reported by Katrina Arndt

Dr. Mesch is a linguist and a senior lecturer at Örebro University, works part-time for the Swedish National Association for the Deaf, and teaches sign language. She presented detailed information about specific strategies that people who are deafblind use when they converse. Her report focused primarily on turn-taking strategies but also included information about differences between signers who are sighted and signers who are deafblind.

**Turn-taking.** Communication partners signal a change in turn via hand movement changes in vertical and horizontal planes. Positions in the vertical plane indicate when a signer is at rest. Sighted signers typically position their hands at their waist when at rest, while deafblind people typically hold their hands midline at chest height. Horizontal space is also used in an interesting way. Dr. Mesch has noticed that there are three horizontal signing zones: a zone close to the person—they own signing zone; a middle zone signifying that the person is listening; and a movement zone, from the signer toward the middle zone, indicating that the person signing is ready for the listening person to change roles and begin signing.

**Differences between Sighted and Deafblind Signing Pairs.** Dr. Mesch’s observations include:

- Sighted signing pairs often use pointing to indicate perspective shifts. This is rare when both communication partners are deafblind.
- Deafblind signing pairs are more likely than their sighted peers to use fingerspelling to clarify.
- Question formation in Swedish Sign Language (SSL) does not include facial grammar when the communication partners are deafblind, while sighted signers do use facial grammar for questions.

The most interesting part of this presentation was the idea that tactile sign is significantly different from standard sign language. Close examination uncovers strategies for smooth and efficient communication between two people who are deafblind. I was fascinated by Dr. Mesch’s examination of this topic and am pleased to report that she has authored several publications:


**Balance and CHARGE Syndrome**

George Williams, The Children’s Hospital, Westmead NSW (Australia) and Tim Hartshorne, Central Michigan University (United States)

Reported by Lauren Lieberman

This was a wonderful overview of the variables of the body that contribute to balance. When these variables are understood, the cause of balance problems in a child who has CHARGE Syndrome may be appropriately addressed. In particular, the presentation focused on the impact of abnormal vestibular function.

In order to maintain equilibrium, a child must have input from the eyes, cerebral cortex, muscles and joints, hearing, touch, and vestibule. The vestibule is in the inner ear and is responsible for balance or equilibrium. In one study, 85 percent of children with CHARGE had abnormal vestibular function. Some are overly sensitive to vestibular stimulation and are afraid of ordinary movements associated with such activities as swinging, sliding, and climbing. Others have an undersensitive vestibular mechanism and pursue intense experiences involving whirling, jumping, or spinning. Many children seem to change from one extreme to the other at different times.

It is important to include interventions for vestibular dysfunction in the developmental and educational programs of children with CHARGE. The presenters recommend consultation with occupational specialists or sensory integration specialists early in the child’s life. Suggestions for improving vestibular function include moving slowly, stabilizing the child’s torso when seated in a chair, actively involving the child when pushing on equipment like a stroller or scooter, improving ocular input, weighting objects for better muscle and joint awareness, offering a variety of different movement activities, and having the child walk and crawl on a variety of surfaces (making sure this is explained to the child before beginning).
Lessons from the Study of the Post-School Lives of Youth with Deafblindness
Presented by Dr. Jerry Petroff, The College of New Jersey (United States)
Reported by Kat Stremel

Dr. Petroff, presented the findings of three studies conducted during the past five years that surveyed parents of youth who are deafblind about their children’s current adult life outcomes. Parents completed paper surveys for the first two studies. Ninety-seven responded to the first and 57 to the second. State deafblind projects assisted with data collection for the third study using either phone or online surveys. So far there have been 47 respondents. Hopefully, more data will be collected before more thorough analysis.

Data from the first two studies showed that approximately 50 percent of the youth did not use a symbolic or linguistic system of communication. Additionally, a large percentage was nonambulatory.

Although the employment outcomes for the groups evaluated in all three studies were not good (the second study found that only about 19 percent were employed), they were better than those for youth with severe disabilities reported in the National Longitudinal Transition Study. Collectively, the three studies show positive trends toward earlier and improved planning for transition services. However, there was still a lack of community involvement and limited social networks.

Interestingly, many of the parents did not think that their children were able to work. The majority, however, reported that they were pleased with their children’s educational outcomes even in the first study, which showed a lack of positive post-school outcomes.

A report of the first study, Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives is available on the Web: http://www.tr.wou.edu/ntac/publications.htm.

How to Teach Tactile Sign Language
Presented by Marjan Jonk and Sanny van der Schoot (the Netherlands)
Reported by Katrina Arndt

Marjan Jonk and Sanny van der Schoot from Viataal (formerly the Instituut voor Doven) in the Netherlands teach Dutch Sign Language and tactile sign language. They have an eight-year history of working together with people who are deafblind and teach tactile sign to both deafblind people and to their friends, family members, colleagues, and service providers. They have adapted their teaching strategies to meet the needs of people who are deafblind and those who are not deafblind because each group learns in different ways and has different motivations for learning tactile sign.

In the first group are people who are vested in learning tactile sign because they are deafblind or are becoming deafblind. Their reason for taking a class is based more on need rather than a sense of obligation. The participants decide which sign vocabulary to use (Dutch Sign Language or their own lexicon), the number of signs they learn is arbitrary, and the use of sign includes short sentences adapted to communication.

In contrast, the second group is composed of hearing-sighted people who are associated with a person who is deafblind or who provide assistance in some capacity. They may have an obligation to take the class. In these cases the instructors decide which vocabulary is taught. The number of signs learned is fixed, exercises include long sentences, and discussion takes place as part of the lesson.

I was interested in the idea of considering the underlying motivation for learning tactile sign and using that information to shape instruction. The presenters can be contacted by e-mail at m.jonk@viataal.nl and s.vdschoot@viataal.nl.

Never Say Die: The Story of Irene McMinn
Written by Irene McMinn (Australia)
Presented by Sharon Barrey Grassick (Australia)
Reported by Lauren Lieberman

Irene McMinn is deafblind and has cerebral palsy. She uses a wheelchair for her mobility. She has been the president of the Australian Deafblind Council for the last seven years, president of the Deafblind Association New South Wales for the last four years,
and she was the representative for the South Pacific on the Steering Committee of the World Federation of the Deafblind. She also carried the Olympic Torch in the torch relay in Sydney in 2000. She lives her life with the belief that her quality of life is up to her. She truly makes her life worth living.

In this presentation Irene described her own life and also shared her experience of teaching a congenitally deafblind woman named Cathy to develop her ability to communicate. Cathy lived in a group home, and the staff there believed that she was unable to learn. But Irene taught Cathy some tactile signs, and eventually Cathy was able to communicate her needs and desires. Irene said that Cathy’s face would just light up when she was able to do something like ask for a drink and someone would get it for her.

In addition to teaching others, Irene has made the most of modern day technology to promote her own independence. She uses a Tact-Aid and a Mini-Guide to enhance her mobility. These are devices that help a person with a vision loss to know if there is anything in his or her way. Irene uses them on her body or on the front of her wheelchair to alert her to objects or people in her way. She even places one at her computer so she knows when someone is approaching.

Irene is a person with determination, perseverance, and drive. Her motto, “Never say die,” rings true.

Elizabeth Camacho from Costa Rico stated that communication is the highest priority for educators who work with deaf-blind children in her country. Communication interactions that occur during all activities in the context of daily life are carried out in ways that are most accessible to each child in order to ensure that all children develop and reach their goals.

Eunice Aoko Akumu told the audience that in her country, Kenya, communication is a celebration. Teachers use gestures, pointing, tactile experiences, and hand support to build communication strategies around real activities occurring within a community.

Janka Sarisska from Slovakia used a video to demonstrate communication activities at a residential school in her country. In the video, a young student is shown using a combination of signs and an events calendar to participate in daily school activities and to take part in a play.

Linda Mamer described Canada’s commitment to the philosophy of intervention. Formed by a core belief that all persons must have access to communication, intervention services create access for the deaf-blind person to his or her environment using communication strategies particular to each individual. She stressed that it is never too late to learn to communicate.

Sheela Sinha told the audience that in India teachers share a common will to give each child the right to communicate, and they believe that nothing should prevent a child from developing communication abilities. She said, “Joyful communication is the lifeblood of human interaction and the joy of communication is magic from the heart.”

Relationships Are the Key to Communication

The theme of communication continued with a plenary session held the fourth day of the conference. Three panelists—Cherry Bulmer, a parent from Canada, Dimitar Parapanov, a deaf-blind man from Bulgaria, and Joe McNulty, director of the Helen Keller National Center in the United States —spoke about the importance of relationships for communication.

Cherry described the importance of family relationships in facilitating communication for her daughter Kara. She spoke about the right of deaf-blind persons to have the opportunity to develop relationships with their family and to develop self-identity in the context of family and community. She also stressed the importance of preserving local cultural values about family membership and using those to
support a young deaf-blind person’s movement into adulthood.

Dimitar stressed the need for deaf-blind people to have relationships with other deaf-blind people. “Deaf-blind persons share the same destiny,” he said. He explained that the most ideal situation is one where each deaf-blind person has an opportunity to develop friendships independently. In Bulgaria there are groups of deaf-blind persons who get together on a regular basis to participate in activities in which they share interests, such as music, chess, painting, or poetry. These groups deepen the relationships between deaf-blind people.

Joe shared his observations from 25 years of working in the field about social relationships between professionals and deaf-blind people. He described his early days at HKNC, when the saying “always friendly, never friends” was used to emphasize the importance of preserving a professional relationship because it was thought that friendship would impair objectivity. But Joe came to believe that friendship was an important factor in helping deaf-blind clients to open up. He said that communication is at the heart of any relationship, and the better the relationship, especially one based on integrity, respect, and trust, the better the communication between professionals and deaf-blind people that they work with.

Pre-Conference Intervenor Training Course
Betty Hane

I attended Communication and Intervention for Those Who Are Congenitally Deafblind, an intervenor training course held prior to the main conference. The course was excellent, and the instructor, Joyce Olson, was a fantastic teacher. I came away with a new understanding of deafblindness and learned a better way to work with my child and other children who are deafblind.

The most important thing I learned is that all children with or without disabilities do communicate. We just need to watch and listen and give children who are deafblind time. Often, as parents and educators we do not give children sufficient time to respond. In children who have combined vision and hearing loss, it takes longer for the brain to react, understand, and then return a signal. Each child learns at a different pace and reacts differently to any situation.

I also learned about the importance of building a trusting relationship with a child. It may take at least six months for a child to come to know and recognize an educator or intervenor. It is not in the best interest of the child to keep switching aides or teachers. In order to succeed, children need to build trust and bond with the people who work closely with them. Establishment of this bond promotes growth in the areas of education and communication. Being an intervenor means doing with a child not for a child, and trust is essential.

During the course, we participated in a simulation of deafblindness. Being sighted and then being deaf and blind even for a short period of time is an eye opener. Time is never ending. Touch can be very intrusive and frightening. You do not realize where you are, where you are going, and who is in the area with you. This activity helped us to learn the proper way in which to approach an individual who is deafblind and to always acknowledge his or her presence.

There are two resources that I would recommend for parents, educators, and intervenors. Intervention: A Guide to Getting Started ($15.00) is a manual that gives practical suggestions from experienced intervenors. The Heart of Intervention with Children Who Are Deafblind ($40.00) is a video that gives insight and meaning into the world of deafblindness. These are available from:

Provincial Outreach Program for Students with Deafblindness
10300 Seacote Road
Richmond, BC V7A 4B2 Canada
604-668-7810 or 877-294-2934

This was a forty-hour course with testing every day and a final exam at the end. There was so much presented that I cannot describe it all. I want to thank my fellow students and the instructor, Joyce Olson, for giving me the tools with which to enrich the lives of people who are deafblind and for teaching me to always feel with my heart so that I can be the type of intervenor whom deafblind individuals need.

Rubella Focus Group Report
Nancy O’Donnell

Approximately 25 people, all interested in Congenital Rubella Syndrome (CRS), met for two-and-a-half hours during the DbI conference. Participants were from Canada, Africa, Denmark, England, Scotland, Ireland, and the United States and included individuals with CRS, several family members, and many professionals in the field. As we sat in an informal circle, everyone had an oppor-
tunity to talk about their concerns. Here is a summary of the topics we discussed:

**Immunization.** Many countries still do not have immunization policies for rubella. Ninety percent of school-age children in one program in Kenya are deaf-blind from rubella! South America also has many school-age children with CRS. Because of the continuing presence of CRS, what we learned through the focus group’s efforts to gather information about adults with the condition will benefit children and families around the world for years to come.

It was interesting to learn that some people who receive the vaccine do not maintain their immunity. One mother reported that she had been vaccinated for rubella five times, another one four times, and their blood tests still did not show adequate immunity. This information is also reported in the research. A recommendation was made for all women to have their rubella titer level checked to make sure that they do have immunity, especially if they are in childbearing years.

**Late Onset Medical Concerns.** We all agreed that there is insufficient formal research about the relationship between CRS and various medical and mental health issues that occur in adulthood. We are hoping to rally support for research in this area.

**Life Expectancy.** The question was raised about whether people with CRS have a shorter life expectancy than average because of the late onset medical problems. I would like to emphasize two important points. First, the majority of people with CRS do not report late-onset medical problems. In fact, many are very healthy as they enter their forties. Second, in previous rubella epidemics, individuals with the most serious medical problems often did not survive childhood or were institutionalized. By the 1960s and 1970s, medical care had improved to the point where heart problems, diabetes, and other illnesses could be controlled with medication. As this group ages, we are trying to collect as much information as possible. The Helen Keller National Center maintains a national registry of individuals who are deaf-blind. If you know of someone with CRS who should be on the registry, please contact me at HKNCNOD@aol.com or at 516-944-8900, extension 326, or fill out a registry form online at http://www.hknc.org.

**LISTSERV®.** The group was informed of a LISTSERV dedicated to discussions about CRS that can be accessed via the Internet. It is a free service, and all correspondence is carried on via e-mail. To sign up for this service or for more information, send an e-mail to me at HKNCNOD@aol.com.

**A Bit of History.** In the 1950s, there were no services in England for children who were deaf-blind. Peggy Freeman, a woman from England who has a daughter who was born with CRS, started the first parent group there with three other families. This parent group went on to become SENSE, England’s national organization for deaf-blindness. While her child was young, Peggy wrote one of the first books about rubella children. She recently updated it. Her web site for the book is www.geocities.com/trombology. At the conference, Peggy received the first-ever lifetime achievement award from DbI. It was a great moment!

And, last but not least, the group agreed that we wanted to formalize and become part of the official network of Deafblind International. I will keep you posted as this develops.

**A Wonderful Opportunity**

Sumitra Mishra

This was my first experience attending a world conference on deafblindness, and all things around me looked bright and friendly. To have a chance to attend a conference of this nature and magnitude was encouraging but also set in motion many responsibilities. At the conference learning was a high priority.

The first plenary session on celebrating communication was a good beginning. It reinforced the fact that communication knows no boundaries and knows no financial or resource crunch. The presentation by Janka Sarisska of Slovakia will stay in my mind, particularly for the smart use of crafts and music in developing communication, which leads in turn to overall healthy personality development. The presentation by Eunice Aoko Akumu about her program in Kenya impressed me with its similarities to the beginning of programs in India and the limitless possibilities for developing indigenous cost-effective deafblind programs in rural India. Sheela Sinha’s presentation was a true celebration. She gave a “different” kind of presentation in the sense that she didn’t just talk about tools, techniques, and strategies. She spoke about the essence and the joy of communication and how all of the tools, strategies, and techniques that we use ultimately may lead to blissful joy in the life of deafblind children at a time when they do not even recognize their own mothers!

I tried very hard to understand what Jude Nicholas was saying about deafblindness and the brain (to put his presentation very simplistically!) during his plenary session *Communicating Research to Practice and Practise to Research*, but after some time I
Deaf-Blind Perspectives
gave up. The usual “rehabilitation” role in me took over and I thought of leaving his research results to the doctors and researchers. It seemed they were not meant for teachers like me, but they started to make sense to me later when I attended the workshop *New Concepts in Deafblindness*, presented by Tony Best. He spoke about the need for teachers and practitioners to bridge the gap between the rehabilitation and medical worlds. He gave lively examples demonstrating where we miss opportunities to provide the right intervention for a deafblind child just because we believe that the doctor has done his job already and it is up to us to “teach” the child now. The thoughts that have come to my mind since then will stay with me for a long time.

The final plenary session, *The Global Fight against Disease: The Impact of Quality Services*, presented by Stephen Lewis, was about advocacy and the rights of deafblind persons. This is another area that practitioners may tend to leave for people who do the “talking,” but in the current context of my work, what I learned will have a direct bearing on my responsibilities. It will prompt me to make the best use of every opportunity to highlight the needs of deafblind persons and their family members and the work that Sense International (India) has been doing to promote the cause in India.

Attending the world conference was an excellent opportunity for some of us from India to spend time together and share our experiences. It was a time to reflect on our own work and on the capacity of our organizations to lead the work of the deafblind field within our regions and to integrate our efforts to create an enviable national deafblind infrastructure. And certainly the India team left a worldwide mark at the conference.

The overall opportunities provided by this one trip to the world conference widened my horizon on the deafblind field in that I

- met and networked with world-class professionals;
- gained knowledge about developments around the world;
- met up with old friends and contacts and learned more about the pace of development and individual challenges in different countries;
- learned about new resources;
- saw examples of brilliant presentation skills;
- represented India’s place in the deafblind field;
- viewed very closely the role of Deafblind International and its impact worldwide.

I will take advantage of these experiences to expand my own role as the Programmes Manager of Sense International (India). And I shall particularly cherish the opportunity that I had to represent India and Sense International (India) in the concluding session of the world conference, *Opening Doors to the Future*.

**An Awesome Experience**

Debbie Ethridge

Attending the conference was a once-in-a-lifetime experience for me. I met people who are deaf-blind, parents of children who are deaf-blind, and leaders in deaf-blind education, training, and service provision. Meeting Peggy Freeman, the parent who started the first groups for parents of children with deaf-blindness caused by rubella, was thrilling. She has been an inspiration to so many people and has had a positive impact on the lives of many people who are deaf-blind. As a parent and as an officer in the National Family Association for Deaf-Blind (NFADB), a parent organization, I draw courage and strength from her example. She, and others like her, paved the way for parents of this generation. It seems that many programs and services were started by parents around the world who wanted a better life for their children. This shows that parents can be a driving force in the lives of their children as well as in the lives of many other families of individuals who are deaf-blind.

Most of the workshops that I attended were on the topic of communication. Communication is the main issue for individuals who are deaf-blind. Everything else revolves around it. I got some great ideas about communication books, and I learned how to create a personal book for my son, who is nonverbal and vi-

Peggy Freeman
sually impaired, to use to communicate his experiences to others. Using pictures and written descriptions, we can share his experiences with teachers, extended family members, and his peers.

Another thing that I found interesting about the conference was that I learned that many people involved in deaf-blind education in their own countries arrived at some of the same conclusions about educational best practices as educators in other countries without knowing what was going on in other parts of the world. This illustrates that people who work with individuals who are deaf-blind are very creative and innovative and will try anything and do whatever works and is best for the individual.

Watching Joe McNulty and others who have made great contributions in the area of deaf-blindness receive awards and be honored for their service was wonderful. Joe has done so much to help NFADB over the last several years and has contributed so much to the field of deaf-blindness through his leadership at the Helen Keller National Center. He is always upbeat and provides great words of wisdom and guidance for our group.

I hope that at some point in the future I am able to attend another DbI conference. I found this to be one of the best conferences that I have ever attended. The presentations were great because they were given by the best people the world has to offer! The networking opportunities were fantastic, especially the parent social. Our Canadian hosts outdid themselves with their hospitality. In fact, I think you could sum up the entire conference with one word, awesome!

**Conference Impressions**

Betty Hane

The conference was a fascinating and educating experience. There was an air of friendliness and openness to different people from different cultures and from different backgrounds. The atmosphere was conducive to learning and to sharing experiences with individuals from around the world.

As a parent I felt a common bond with everyone else. We all wanted to gain knowledge and information to help children and adults who are deaf-blind feel more comfortable in their surroundings and to help them receive the education, services, and training they need to succeed in our ever-changing world. In addition to the many workshops and plenary sessions, there were networks and socials set up for parents to meet each other and to talk about our children and our hopes and dreams for their futures.

I cannot express in words the feelings, both emotional and physical, that I had during all the sessions and the speeches. I am proud to be a member of this organization and extremely blessed to have a child with deaf-blindness. I learned much about what has been accomplished so far and what still needs to be done in order to ensure a future for all people with deaf-blindness. We still have a long way to go, but with parents, advocates, and educators fighting to get necessary funding and training, we have a chance to change the future of all people who are deaf-blind and to promote acceptance and tolerance in the everyday world.

**Reporters for This Issue**

Katrina Arndt
Doctoral Student in Special Education
Syracuse University

Michelle Clyne
Deaf-blind Specialist
Project Reach: Illinois Deaf-Blind Services
Debbie Ethridge
Secretary, NFADB
(also took photographs for this issue)

Ed Gervasoni, Ed.S.
Certified Orientation & Mobility Specialist
Arizona State Schools for the Deaf and the Blind and
Arizona Association for the Deaf-Blind, Tucson Chapter

Betty Hane
Parent

Gail Leslie
Project Coordinator
DB-LINK

Lauren Lieberman, Ph.D.
Associate Professor
Physical Education and Sport Department
State University of NY at Brockport

Sumitra Mishra
Programmes Manager
Sense International (India)

Nancy O’Donnell
Coordinator of Special Projects
Helen Keller National Center

Marianne Riggio
National Educational Consultant
Hilton/Perkins Program

Kat Stremel
Director
NTAC
The importance of sharing research information was a hot topic at the DBI conference. Many presentations were about ongoing or completed research studies, and there was a focus group meeting to discuss issues related to research in the field, which a large number of people attended. This underscores the interest in using research results to guide educational and rehabilitation strategies for people who are deaf-blind and the importance of widely distributing this information. If you have information about ongoing or completed research, we encourage you to send it for inclusion in this column in Deaf-Blind Perspectives. Contact:

Peggy Malloy
malloyp@wou.edu
503-838-8598 (V/TTY)
Teaching Research
Deaf-Blind Perspectives
345 N. Monmouth Ave.
Monmouth, OR 97361

The following are announcements of some current research projects.

**U.S. Department of Education**

**Research Projects in Deaf-Blindness**

Three new research grants were awarded by the Department of Education this past autumn.

**Functional Hearing Inventory Project to Identify Criterion-related Validity and Inter-related Reliability.** This project was designed to establish the validity and reliability of the Functional Hearing Inventory (FHI), a tool to help parents and teachers assess how children and youth with deaf-blindness use their residual hearing within their natural environments.

Contact:
Dr. Roseanna Davidson, Project Director
Texas Tech University
Virginia Murray Sowell Center
P.O. Box 41071
Lubbock, TX 79409-1071
806-742-2345, ext. 246
tdavi@ttacs.ttu.edu

**Validation of Evidence-based Assessment Strategies to Promote Achievement in Children Who Are Deafblind.** The goals of this project are to identify the instruments used to assess children ages 2–8 who are deaf-blind, to conduct validation studies on instruments used to generate instructional goals and monitor student progress, to replicate the validation studies in multiple sites, and to produce final products that summarize the findings of these studies and translate the data into recommendations for the use of specific assessment instruments.

Contact:
Dr. Charity Rowland
OHSU Design to Learn Projects
1600 SE Ankeny St.
Portland, OR 97214
503-238-4030, ext. 115
rowlandc@ohsu.edu

**Research Programs at the Netherlands Knowledge Center for Deaf-Blindness**

The following research projects are being conducted by the Netherlands Institute for Care and Welfare (NIZW) under the direction of the Netherlands Knowledge Center for Deaf-Blindness (LED) to study:

- The prevalence of deaf-blindness in the Netherlands.

- How to increase the knowledge of professionals who work with deaf-blind persons. This involves evaluating the type of information about deaf-blindness that is currently available in institutions that work with deaf-blind clients, identifying the information needs at these institutions, and determining how information can be made...
available to professionals who work with deaf-blind people.

- The state of the art in tactile sign language. Who is using tactile sign language in the Netherlands and how many people use it? What are the international developments related to tactile sign language?

For more information contact the Netherlands Knowledge Center for Deaf-Blindness (LED) at info@doofblind.nl. You can visit the center’s website at: http://www.doofblind.nl.

For Your Library


These DVDs provide information and instruction to help families, teachers, service providers, and medical personnel gain a better understanding of what it means to be deaf, blind, or deafblind. The program includes information on sensory losses with simulations of different types of vision loss, hearing loss, and combined vision and hearing loss. These illustrate for the viewer the impact of sensory losses on an individual’s learning and interactions with the world. Cost: $65.00. Available from HOPE Publishing, Inc. Phone/Fax: 435-245-2888. E-mail: hope@hopepubl.com. Web: http://www.hopepubl.com.


Written to assist teachers and other professionals who support children with visual impairment and additional disabilities, this book examines the role of touch in teaching and learning. It includes background information about the anatomy, physiology, and functions of touch and considers how to identify and reduce barriers to independent learning through touch.


This small book of reflections on what it means to be deaf-blind was written in Montreal by clients and employees of the Institut Raymond-Dewar as a result of a workshop. From the prologue: “This tiny book’s desire is to be the starting point in a reflection on the human condition in a world where image is more important and often precedes the profound essence of life itself.” The book was presented during a workshop at the DbI Conference. It is written in both French and English and is available from Institut Raymond-Dewar, 3600 Berri, Montreal, Québec H2L 4G9. Phone: 514-284-2214, Ext. 3600. E-mail: sgrignon@raymond-dewar.gouv.qc.ca. Cost: $10.00 plus postage.

### Conferences and Events

**Workshops on Communication Strategies for Children with Severe and Multiple Disabilities**

- **2-Day Workshop: June 2–3, 2004**
  - Parent Workshop: June 4, 2004
  - Baton Rouge, LA

Learn how to help nonverbal children with severe disabilities communicate their needs to caregivers and teachers in these workshops presented by Philip Schweigert, M.Ed. The two-day workshop, designed for professionals and parents, addresses pre-symbolic communication, Tangible Symbol Systems, and cognitive skill development. A special half-day seminar for parents is also offered, free of charge. Academic, continuing education credit, and ASHA credit will be available for the 2-day workshop. For more information contact Shawn Fleming at 877-453-2721 or 225-342-3640. Online registration is available: http://www.doe.state.la.us/DOE/specialpop/registration2.asp?E=comcog.

**Low Vision and Blindness in Infants and Children with Special Emphasis on Cortical Visual Impairment**

- **June 3–5, 2004**
  - Pittsburgh, Pennsylvania

This conference is for physicians, teachers, and parents of children with cortical visual impairments. Speakers include Christine Roman. For more information contact the Western Pennsylvania Hospital, Department of Continuing Medical Education at 412-578-6927 or wphcme@wpahs.org.

**7th Australian National Deafblind Conference**

- **July 2–5, 2004**
  - Richmond, Australia

The theme of this conference, hosted by the Australian Deafblind Council and the Deafblind Association (Victoria), is “Deafblind and Moving On.” The keynote speaker is Mark Landreneau from the Seattle Lighthouse for the Blind. For more information con-
Deafblindness and Multiple Disabilities Division Day
Association for the Education and Rehabilitation of the Blind and Visually Impaired (AER) Conference
July 13–19, 2004
Orlando Florida

The AER Conference in Orlando next summer will include strands throughout the conference that address topics relevant to deafblindness and multiple disabilities such as early intervention, education, personnel preparation, support services, and rehabilitation. In addition, there will be a designated division day. The tentative theme of the Deafblindness and Multiple Disabilities Division day is “Implications of Education Reform for Learners who are Deafblind and Multiply Disabled.” It will focus on practical information for teachers, family members, and program administrators. For information about the conference or to join AER visit the AER Web site: http://www.aerbvi.org or call 877-492-2708. For more information about the Deafblindness and Multiple Disabilities Division (Division 3), contact Marianne Riggio, Chair, Division 3. E-mail: Marianne.Riggio@perkins.org.

Pennsylvania Events
August 2004

The following are upcoming activities of Hand in Hand in Hand (the Pennsylvania Deafblind Project).

Deafblind Summer Institute: Tactile Learning Strategies, August 2–3, 2004. The key presenter, Dr. Deborah Chen, will discuss strategies to identify and implement tactile learning strategies to optimize instruction for children and youth who are deafblind. Audience: Team members of children and youth (early intervention, preschool, school-age) who are deafblind. Location: Pennsylvania State University, State College, PA.


For more information contact Juli Baumgarner. Phone: 800-446-5607, ext. 6845 (PA only) or 412-826-2336. TTY: 412-826-2338. E-mail: jbaumgarner@pattan.k12.pa.us.

Announcements

Anne Sullivan Medal Awards

Front: Michael Collins, Director, Hilton/Perkins Program; Yolanda Ramos. Back: Galina Konstantinova Epifanova; Sam Boshielo; Joseph McNulty; Cherry Bulmer; Steven Rothstein, President, Perkins School for the Blind.

The Anne Sullivan Medal, established in 1966 by Perkins School for the blind recognizes “exemplary contribution, efforts, and achievement on behalf of individuals who are deafblind.” The most recent awards were made at the DbI Conference to:

- Sam Boshielo, South Africa
- Cherry Bulmer, Canada
- Galina Konstantinova Epifanova, Russia
- Joseph McNulty, United States
- Yoanda Ramos, Argentina

HSBC Indo-British Award

On October 8, 2003, Akhil Paul, Director of Sense International (India) received the award in the Community Category for his exemplary contribution to the field of deaf-blindness. The 4th HSBC (Hongkong and Shanghai Banking Corporation) Indo-British Award was instituted in 1997, to commemorate India’s 50 years of Independence. Initially, the award was given to an individual, company, or organization that had played a key role in promoting trade and business relations between India and the United Kingdom. This year the scope was broadened to recognize outstanding contributions in the community. It is estimated that there are more than 450,000 deafblind people in India.
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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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