

DbI
R

THE MAGAZINE
OF DEAFBLIND
INTERNATIONAL

Number 32 • July-December 2003

Review



Social relationships

Deafblind International was formerly known as the International Association for the Education of Deafblind People.

Dbl Review appears twice yearly, the two editions are dated January-June and July-December.

The editor will be pleased to receive articles, news items, letters, notices of books and information on forthcoming events, such as conferences and courses, concerning deafblind children, young adults and older people. Photographs and drawings are welcome; they will be copied and returned.

All written material should be in the English language and may be edited before publication. It should be sent for publication to arrive by the date below.

Opinions expressed in articles are those of the author and should not be understood as representing the view of Dbl.

Dbl Review is also available in Spanish or on disk. If you are interested in receiving your copy in either of these formats please contact:

Dbl Secretariat
11-13 Clifton Terrace
London N4 3SR
dbi@senseinternational.org.uk

Editors

Eileen Boothroyd
Frances Hampton

Spanish Edition

Judith Varsavsky

Design & Print

Intertype

Distribution and Dbl Membership

Dbl Secretariat

Dbl Website

Malcolm Matthews

Editorial Office

Sense
11-13 Clifton Terrace
London N4 3SR
United Kingdom

Tel: +44 (0)20 7272 7774
Fax: +44 (0)20 7272 6012
Email: eboothroyd@sense.org.uk
<http://www.deafblindinternational.org>

Cover: Eminescu School, Bucharest, Romania

A message from the president

After working in the deafblind field for 30 years the role of Dbl President is an honour that I truly cherish. Throughout my life I have been involved in international activities – co-ordinating World and European Conferences, organising international seminars and networking events and securing funds for transnational activities. Bringing people together from different countries has been my constant theme as I believe that, in doing this, opportunities can be created for people to meet, talk and share ideas. This, I believe, is essential if our field is to grow and flourish.

Over the next four years Dbl will continue to build on sound foundations with plans to develop and maintain its identity as a significant international organisation. This will mean breaking down the barriers to involvement; including younger people in leadership roles and involving our natural partners – especially deafblind people and members of their families. We will need to become even more accessible and offer support to enable people to participate more fully. I was honoured to join friends and colleagues at the launch of the European Deafblind Union in Denmark in November. You can read more about this wonderful occasion in the magazine.

The recognition of deafblind people as equal partners is at the heart of Dbl's work and I believe that it is vital that our organisation



works closely with others to secure the rights and recognition for deafblind people wherever they live. My wish would be that everyone – whether they are new to our field or old friends – feels at home in our organisation. To make this possible our activities, newsletters and papers must encompass what our members want, so they value their membership and feel they want to contribute. Our Networks are developing. They are thematic or geographical and they will play a key role in achieving our aims. I have recently been fortunate enough to visit the Ukraine, with the team from Slovakia, to make new contacts there!

As we continue to empower deafblind people, the roles for professionals are changing and Dbl will need to address itself to new ways of working. Lobbying for change on the main stages of the world, including the United Nations, in partnership with other organisations and individuals from across the world, is high on the agenda. Already planned and

underway is the campaign in Europe, starting in January, at the European Parliament in Brussels. I urge you all to get involved as it unfolds.

As Dbl continues to develop and grow we will need to monitor our constitution and practices to ensure that they remain appropriate and effective. We must also invest time in our strategic planning in order to fulfil our wishes for the future.

On a personal level, and on behalf of you all, I would like to extend our deepest sympathy to the family and colleagues of Dietrich Bunck, whose untimely death is reported in these pages. He

was a good friend whose tremendous contribution will not be forgotten. And to Sam Boshelio and his family, our love and thoughts are with you.

I look forward to working with you all – whether you are a professional, a deafblind person or a family member. Over the next four crucial years our important work will continue to meet our goal of ensuring that quality services are available for both deafblind children and adults and, as a result, their full participation in all aspects of life comes closer to being achieved.

William Green

EDITORIAL

Life has been very busy here and we have been scrambling to get the magazine out to you all in time for the New Year! We hope you like the new look!

The contributions are wide ranging, with articles about the work we do, the countries we work in, the organisations we work for and the people we are! Tim Hartshorne highlights the importance of social competence, explores it as a concept in very clear terms, and relates these ideas to deafblind children. Connie Miles, who is consultant at the Center for Study and Treatment of Usher syndrome, describes her work with families, focussing on informed choice and consent and what it means for genetic research. We also have the first of two articles from Isabel Amaral related to recent work on communication – which provide a detailed analysis of her study in this edition and some guidelines for practitioners in the next.

The news we have from all over the world continues to show that more of you are getting in touch to tell us about your projects and to share your thoughts. Its easy to get the "full flavour" from the things you write and photos we receive! The holiday in Poland was clearly a fantastic experience – and it shows in the report we have here. Work in the Eastern European countries, including the former USSR is really developing, as are a huge number of very successful long term projects in Latin America. And, last, but not least, the Canadians deserve our heartfelt thanks for a wonderful conference.

So please think of us. We would love to hear about your programme, or your passion and, if you feel shy because of having to write in a foreign language, we can help with that too!

Good wishes

Eileen and Frances

eileen.boothroyd@sense.org.uk

CONTENTS

| | |
|--|--------------------|
| Positive Behavioural Supports and Social Relationships <i>Tim Hartshorne</i> | pages 4–6 |
| Informed Choice and Informed Consent in Usher Syndrome <i>Constance Miles</i> | pages 7–11 |
| Analyzing teacher/child interactions: What makes communications successful? <i>Isabel Amaral</i> | pages 12–18 |
| The Peer Mentor Programme <i>Chris Sherlock</i> | pages 19–20 |
| Through creative activities ... to communication and integration <i>Mária Podhájecká & Janka Sarišská</i> | pages 21–23 |
| Working Together: A Deaf Association and Deafblind People <i>Nataly Kremneva</i> | pages 24–25 |
| Natural moral law and the right of deafblind people to the service of guide-interpreters <i>Jan Jakeš</i> | pages 26–27 |

NETWORK NEWS **pages 28–34**

REGIONAL NEWS

| | |
|----------------------|--------------------|
| Slovakia and Ukraine | page 35 |
| Poland | pages 36–37 |
| Kazakhstan | page 38 |
| Russia | page 38 |
| The Philippines | page 38 |
| Spain | page 39 |
| Latin America | page 40 |
| India | page 41 |
| Venezuela | page 41 |
| Canada | page 41 |
| Colombia | pages 42–43 |
| Slovakia | page 44 |
| New Zealand | page 44 |

CONFERENCES

| | |
|---------------------------------------|--------------------|
| Helen Keller International Award 2004 | page 46 |
| London | page 47 |
| NUD | page 48 |
| Denmark | page 49 |
| Canada | pages 50–51 |

MANAGEMENT NEWS **pages 53–54**

| | |
|---------------------|----------------|
| Dbl Membership Form | page 55 |
|---------------------|----------------|

Positive Behavioral Supports and Social Relationships

Tim Hartshorne, Central Michigan University,
tim.hartshorne@cmich.edu



Tim Hartshorne

All people should live in an environment where they can succeed and where they can feel good about themselves. In some environments, having a disability can get in the way of success and feeling good. With some disabilities, children may have difficulty learning the social skills they need to interact well with others, and may also develop some behaviors that are actually counter productive to positive social relationships. In this article I use Positive Behavioral Supports as an umbrella concept for examining the behavioral and social competence of children, followed by a closer examination of the concept of social competence. Finally, I examine a method for supporting children who are deafblind in their development of behavioral and social competence.

To illustrate the concepts, I will use a specific (fictitious) example. Justin is a 9-year-old boy with multi-sensory impairments. Often, when he is touched, either purposefully or accidentally, by students and teachers, he will strike out at them.

Positive Behavioral Supports

In the past, we have focused our energies on trying to change the child. Justin would have been subject to various punishments in order to teach him that striking out is inappropriate. The Positive Behavioral Supports movement has changed this focus. PBS "looks at the system, setting, or skill deficiency rather than the individual. Behavior management attempts to 'fix' the person, while PBS adjusts the systems and settings, focusing on improving skills" (Travnikar, 2001). Behavior always occurs in a context. PBS looks for deficiencies in that context, either in the environmental conditions, or in the behavioral skills of the individual (Carr, Horner, Turnbull, Marquis, Magito McLaughlin, McAttee, et. al., 1999). The goal of PBS is not just the reduction or elimination of challenging behavior, "but rather improving people's lives" (Carr, et. al., 1999, p. 5).

PBS has two primary steps. First, a Functional Assessment of Behavior is conducted to understand the purpose of the behavior. Second, a Behavior Intervention Plan is developed to address the supports needed to improve skills.

Functional Assessment of Behavior (FAB) is a process for gathering information about the "why's" of particular behavior (Carr, Levin, McConnachie, Carlson, Kemp, & Smith, 1997). In other words, functional assessment is used to identify the purpose of problem behavior. If you know the purpose, the behavior is understandable.

Why does Justin strike out at those who touch him? What does his behavior communicate to us about Justin and his experience in his environment? We might be tempted to label Justin "aggressive". But instead, we could consider what Justin might be saying or communicating by striking out. What might be its purpose or function? Douglass (1995) suggests the following possibilities:

- I hate surprises;
- I don't like being touched;
- I wanted to acknowledge your presence;
- I like you very much;
- I need more warning before you approach me;
- I have been touched too much and I cannot tolerate it any more;
- I was telling you that I'm ready for work;
- I was asking you to come back later.

In other words, there are many possible purposes for this behavior, some of which may not be obvious.

The four main goals of a FAB are to (1) describe the behavior; (2) predict the times and situations when the behavior will occur; (3) identify the purpose or goal of the behavior; and (4) propose interventions linked to the context and purpose of the behavior (Travnikar, 2001). A comprehensive FAB will consider the contexts in which the behavior occurs, and the consequences to those behaviors, in order to identify the purpose. Hypotheses are developed based on the assessment, and interventions are selected based on the hypotheses. The success of the interventions provides support for the hypotheses, or, if unsuccessful, suggests the need for additional assessment.

A Behavior Intervention Plan (BIP) is a written, individualized behavior support plan that addresses both the deficient environmental conditions that may be present and the deficient skills that a person may

POSITIVE BEHAVIORAL SUPPORTS

possess. Examples of deficient environmental conditions include the physical setting, social setting, activities and instruction, scheduling and predictability, and choice-making opportunities. Deficient skills may include communication, social skills, self-management, and adaptive behaviors. Multiple intervention components are employed to change the environment and build skills, with a goal of not just changing the targeted behavior, but rather of considering the broader quality-of-life issues for the person (Travnikar, 2001).

If, for example, Justin is communicating that he needs more warning when people approach him, and that the purpose of the behavior is to avoid such contacts and to protect himself, then what skill building or environmental changes might be warranted? Can he be taught alternative methods for expressing his desire to avoid sudden contact with others? Can the environment be modified to reduce the likelihood of such contact? Can students and teachers be taught alternative ways to approach Justin? What part of a quality life is touch, and how can that be incorporated into Justin's experience in a way that he enjoys?

Social Competence

"The degree to which students are able to establish and maintain satisfactory interpersonal relationships, gain peer acceptance, establish and maintain friendships, and terminate negative or pernicious interpersonal relationships defines social competence and predicts adequate long-term psychological and social adjustment" (Gresham, Sugai, & Horner, 2001). Social competence is the ability to perform competently on social tasks. Social skills are the specific behaviors a person uses to perform competently. Clearly, Justin's behavior of striking out when touched is not a good social skill and might suggest some problems with social competence. PBS considers social competence in terms of contexts, both the social skills the person has developed, and the environment in which social action occurs.

Social Skills

Social skills can be placed into several categories (Caldarella & Merrell, 1997):

- Peer relations skills (complimenting others, offering help, inviting peers to play)
- Self-management skills (controlling temper, following rules, compromising)
- Academic skills (completing work independently, listening to the teacher, not distracting)
- Compliance skills (following directions, following rules, using free time appropriately)
- Assertion skills (initiating conversations, acknowledging complements, making requests)

Deficits in social skills can also be classified (Gresham, Sugai, & Horner, 2001):

- Acquisition deficit – never learned it
- Performance deficit – learned it but can't or won't do it

- Fluency deficit – does not do it very well or in all contexts

Justin may have a deficit in assertion skills, or the socially appropriate way to let other people know what he likes and does not like. He may have never acquired this skill, he may lack practice, or he may not wish to use the skill. His striking out may be just his preferred behavior, or it may be because he does not know any other. Social skills can be taught; generally in a group setting using guided rehearsal, feedback, reinforcement, and practice (Waas & Graczyk, 1998). But PBS requires that we address both skills deficits and environmental deficits.

Environmental Conditions

A consequence of the lack of social skills can be peer rejection. But peer rejection is not just due to the lack of social skills; it is also a result of negative relational schemas (Waas & Graczyk, 1998). Relational schemas are the scripts and rules you have about your relationships with others. For example, other students may have relational schemas about Justin that "he is aggressive," "he is unpleasant to be near," "he should be avoided." Many children with disabilities likely suffer from both a lack of social skills and negative relational schemas about them. They may themselves have negative relational schemas about other people. These negative relational schemas are a part of the environmental context that exists when negative behavior is expressed.

The consequence of negative relational schemas can be an environment that is not conducive to the learning and displaying of social skills. If Justin strikes out to warn others that he needs more time for them to approach him, his behavior is probably successful in keeping others away from him. He effectively creates a context of avoidance, which is supported by negative relational schemas that others have of him. He pushes away, and others stay away. Teaching Justin alternative behavior is a start, but unless the environment changes, he will have no reason to use the new behavior.

Person-Centered Planning and Circle of Friends

Person-Centered Planning (PCP) is a process that facilitates the inclusion of persons with disabilities into their natural communities, including neighborhood, school, and work. The general goals of PCP for the individual include:

- being present and participating in community life
- gaining and maintaining satisfying relationships
- expressing preferences and making choices in everyday life
- having opportunities to fulfill respected roles and to live with dignity
- continuing to develop personal competencies (Kincaid, 1996, pp. 440–441).

All PCP approaches begin with a focus on the wants and needs of an individual and recognize the importance of both formal and informal supports in assisting the person to achieve his or her dreams. PCP represents a

POSITIVE BEHAVIORAL SUPPORTS

shift in focus from finding out what is wrong with a person and how to fix it, to identifying capacities, and how to enhance them so that a person can live the life they or we envision (O'Brien, O'Brien, & Mount, 1997).

One form of person-centered planning used for people with disabilities of all ages is MAPS: Making Action Plans (Pearpoint, Forest, & O'Brien, 1996). It is frequently carried out by the person and their Circle of Friends. The group considers several questions such as: Who is this person? What are this person's dreams? What are your nightmares for this person? What strengths does the person have? What would a perfect day look like for this person?

PCP helps to define the desirable environmental conditions for the person. From this, action plans may be developed to implement the perfect social encounters in the person's day, at school or at work, which take into account the person's strengths and needs, and help them move toward their dreams. We might envision Justin's perfect day at school as teachers and peers approaching him carefully but positively in a way that he can accept and enjoy.

A Circle of Friends is a circle of support, which forms around a person with a disability (Pearpoint, Forest, & O'Brien, 1996). It is meant to be a support to the person's inclusion into the school, community, and workplace. The person (or when communication skills are limited, someone who is close to the person) invites those he or she wishes to be involved in the circle, based upon who they feel supports them in their lives. Circles of Friends may or may not involve professionals. Ideally the members stay with the Circle over time, providing a natural social support network for the individual.

Circles of Friends provide one avenue for avoiding or dissipating negative relational schemas. Frederickson and Turner (2003) found that while a Circle had little impact on the child's self-perception, or on the teacher's perception of the child's behavior, it did have a positive impact on the child's social acceptance. Justin's Circle of Friends can support his development of social competence by (1) learning how to interact with him in a manner that he can accept and respond to positively, (2) helping to teach him social skills, and (3) letting other people know that they are Justin's friends and that Justin has many positive qualities. Nobody develops social competence or learns social skills in isolation. And nothing overcomes negative relational schemas better than positive peer interaction.

Summary

The fact that a particular child lacks behavioral and social competence is of concern. But the Positive Behavioral Supports approach makes this a shared concern, a shared problem, and a shared solution. Blame is not assessed. Instead the environmental sources for the problems are sought out, the purposes that the negative behavior serves for the child are identified, and alternative ways for the child to meet

their goals are developed. A Behavioral Intervention Plan is developed in the context of Person-Centered Planning, and a Circle of Friends ensures that the child is supported through the process.

References

- Caldarella, P., & Merrell, K. (1997). Common dimensions of social skills of children and adolescents: A taxonomy of positive behaviors. *School Psychology Review, 26*, 264-278.
- Carr, E. G., Horner, R. H., Turnbull, A. P., Marquis, J. G., Magito McLaughlin, D., McAtee, et. al. (1999). *Positive behavior support for people with developmental disabilities: A research synthesis*. Washington, DC: American Association on Mental Retardation.
- Carr, E. G., Levin, L., McConnachie, G., Carlson, J. I., Kemp, D. C., & Smith, C. E. (1997). *Communication-based intervention for problem behavior*. Baltimore: Paul H. Brookes.
- Douglass, L. W. (1995, Summer). The role of positive behavior in the education of students with sensory impairments. *California Deaf-Blind Services, RESOURCES, 7*(3), p. 4.
- Frederickson, N., & Turner, J. (2003). Utilizing the classroom peer group to address children's social needs: An evaluation of the Circle of Friends intervention approach. *Journal of Special Education, 36*, 234-245.
- Gresham, F. M., Sugai, G., & Horner, R. H. (2001). Interpreting outcomes of social skills training for students with high-incidence disabilities. *Exceptional Children, 67*, 331-344.
- Kincaid, D. (1996). Person-centered planning. In L. K. Koegel, R. L. Koegel, & G. Dunlap (Eds.), *Positive behavioral support: Including people with difficult behavior in the community* (pp. 439-465). Baltimore: Paul H. Brookes.
- Pearpoint, J., Forest, M., & O'Brien, J. (1996). MAPs, Circles of Friends, and PATH: Powerful tools to help build caring communities. In S. Stainback and W. Stainback (Eds.), *Inclusion: A guide for educators* (pp. 67-86). Baltimore: Paul H. Brookes.
- O'Brien, C. L., O'Brien, J., & Mount, B. (1997). Person-centered planning has arrived ... or has it? *Mental Retardation, 35*, 480-484.
- Travnikar, B. (Ed.) (2001). Positive behavior support: Raising awareness about how positive behavior support contributes to environments that assure learning for all. *Newsline, 9*(1). Michigan Department of Education.
- Waas, G. A., & Graczyk, P. A. (1998). Group Interventions for the Peer-Rejected Child. In K. A. Stoiber & T. R. Kratochwill (Eds.), *Handbook of group intervention for children and families* (pp. 141-158). Boston: Allyn & Bacon.

Informed Choice and Informed Consent in Usher Syndrome Genetic Research – An update

Constance Miles, Consultant, Center for the Study and Treatment of Usher Syndrome at Boys Town National Research Hospital

The diagnosis of Usher syndrome is now being made at increasingly earlier ages due to scientific advances made by a variety of investigators worldwide. Dr. Claes Möller observed that a child who walks after the age of 18 months most likely would have Usher syndrome type I (Möller et. al. 1989). Today, in many cases, a molecular diagnosis is possible and may be made at birth (Kimberling et. al. 1999, 2003). Now babies with Usher syndrome can be identified following newborn hearing screenings while still in the hospital. Early diagnosis of Usher syndrome allows families to consider the benefits of interventions including cochlear implants and participation in upcoming clinical trials.

Today many children are entering school with a diagnosis of Usher syndrome while others learn of the diagnosis during their teenage years. While actual educational adaptations may be minimal during elementary school, parents will begin seeking the advice of educators earlier as scientific research continues to learn more about the three different

types of Usher syndrome. Educators and other professionals will need to keep informed of medical advances to appropriately plan individualized programs and support services for children with various types of Usher syndrome.

The late eminent child psychologist, Fred Rogers, offered these thoughts to ophthalmologists when working with children:

You were a child once, too. That may be obvious, but knowing that and remembering what it was like being a child can make a significant difference in the relationship between you and your child patient ... Children sense very quickly what their parents are feeling, and they are especially attuned to their parents' anxieties. Whatever you can do to help parents feel confident and calm will go a long way toward calming their children ... Most anxieties grow out of fear of the unknown or lack of information or understanding.

Parents in our outreach meetings often talk about the initial diagnosis and have offered advice to professionals who enter their child's life. Do not, they

Constance Miles



request, tell my child or me that she failed a hearing test, failed an eye exam or other procedure. The parents advise professionals to say that a hearing loss was identified or that a hearing loss was detected. Fail is a powerful word that takes away hope. Remember to smile and speak directly to our children. Do not tell us to

have our child learn Braille. Remember they are people first and research subjects second. Remember that they are children.

Teenage years

Many adults identified with Usher syndrome during their teenage years have shared with us their belief that the diagnosis was, in many ways, more difficult for their parents than it was for them. The teens often knew that something was different about their vision, especially at night. Many had noticed situations in which they could not see sign language conversations that their friends could read, could not navigate as easily as their friends in a movie theater after the lights were turned back on, or could not see well during a sudden storm that darkened the skies. In her interviews with 40 individuals, all said that they knew there was something wrong with their eyes by age 12 even though they had not yet been diagnosed or told. (Miner, 1995).

I conducted a series of personal interviews and surveys with 125 families whose children were diagnosed with Usher syndrome in their teens. The survey was done in 1986 while working for the Helen Keller National Center to determine unmet needs of families and teenagers diagnosed with Usher syndrome. The responses are per family.

When asked, "What do you remember about first being told that your child has Usher syndrome?"

- ◆ 125 of the families indicated that receiving the diagnosis was stressful.
- ◆ 119 said they remembered little that the medical

professional said after the disclosure of diagnosis.

- ◆ 119 had never heard of Usher syndrome before the diagnosis and had never met anyone with Usher syndrome.
- ◆ 32 of the mothers attributed the visual loss to something they had done before or during pregnancy – even after hearing that Usher syndrome is genetic.
- ◆ 97 parents wanted to keep the diagnosis from their children for as long as possible.
- ◆ 67 parents wanted to keep the news from family members.
- ◆ 78 families wanted to keep the diagnosis from school officials.
- ◆ 1 mother had placed one of her two diagnosed children up for adoption.

Following this survey we arranged a study group for psychologists and psychiatrists responsible for working with children who are deafblind or who have Usher syndrome. Speakers included Dr. McCay Vernon, Dr. Paul Wheatley, Art Roehrig, deaf psychologist Dr. Larry Stewart, psychologists from the University of California at San Francisco, and others. Dr. Joann Boughman discussed the genetics of Usher syndrome. All of the participants recognized the importance of genetic research information and updates in supporting individuals with Usher syndrome and their families.

Research updates

In an effort to keep families informed of research updates and answer questions about the types of Usher syndrome, outreach meetings are held by the Center for the Study and Treatment of Usher

syndrome at Boys Town National Research Hospital. Dr. William Kimberling provides research updates and answers questions from the audience. The meetings are always individually arranged to correspond to the information needs and requests of the audience. Some meetings are just focused on Usher syndrome type II perhaps followed by one to discuss Usher syndrome type I. Anyone with any type of Usher syndrome may attend all meetings to learn and ask questions. Parents and family members are always welcome. The meetings are free of charge. The outreach sessions often permit families to talk to other families or individuals with Usher syndrome for the first time. People do not need to identify themselves to the group or give any information about why they are attending the meeting.

Some have told us that the diagnosis of Usher syndrome was almost a relief because they now had a name for what was happening to them and knew that there were others in the world with the same experience. But, of course, the diagnosis is usually difficult and haunting for the parents and for the child. And each parent and child reacts differently to the diagnosis of Usher syndrome. One mother, an artist, began painting with her child knowing that although her child might not see the paintings one day, he might still remember them because they entered his soul through his hands.

And after the diagnosis there is life. There are choices to be made, one can move forward, recognize and accept the change within their lives and embrace the future or one can choose to

There are choices to be made, one can move forward, recognize and accept the change within their lives and embrace the future ...



Connie, Bill and Claes with a participating family

withdraw from life. There is moving forward or staying still. There are decisions to be made and chances to be taken. There are new skills to be learned requiring much energy, tenacity, and spirit. Skills required for the ongoing ability to travel independently in the evening or on stormy days. Skills to supplement the ability to sign and read sign language, to lip-read, or to use cochlear implants out in the world. There are decisions to be made about further education, working, socializing with friends, and even attending family celebrations and traditional life styles in the community. There are also decisions to be made about opportunities to participate in the scientific research at centers focusing on treating and ultimately arresting, reversing and curing Usher syndrome. All of

Informed choice is more than signing a form to agree to participate in research and for people with Usher syndrome it can be much more complicated.

these decisions are interrelated in life.

The diagnosis of Usher syndrome impacts the entire family and all that share the genes. All have emotions and opinions about scientific research. Although each adult with Usher syndrome decides independently whether or not to participate in the research, he may be the conduit of information to his extended family. In the majority of families the medical advances are of great interest and are seen as beneficial. If additional blood samples or other information are needed from family members, each adult is given an opportunity to make his or her own decision based on their informed choice and informed consent. It is important to know that medical information about one family member will not be shared with another family

member by the researchers or their hospitals. This is an ethical agreement in informed consent.

Informed choice

Informed choice is the process of being given and obtaining information, asking questions, understanding, and independently deciding whether or not to participate in Usher syndrome genetic research. It is the process of learning the possible risks and benefits of participating in the research. A blood test may hurt or the research results may take longer for one person than another. Participation may lead to the identification of the type of Usher syndrome. Informed choice is more than signing a form to agree to participate in research and for people with Usher syndrome it can be much more complicated.

Opportunities to learn about Usher syndrome research programs are limited due in part to limited funding available for medical centers to conduct Usher syndrome research. Not many research centers are funded to conduct Usher syndrome research.

In cases of a progressive visual loss concomitant with deafness or hearing loss, person-to-person conversations are often compromised without the bridge of an interpreter familiar with special accommodations for people with Retinitis Pigmentosa (RP). There are sometimes transitional periods of adjustment when a person who signed fluently must now stand a certain distance from another person using sign language. The lighting must be correct and the room cannot be too bright or too dark. The person signing must be wearing an appropriate color with sufficient contrast to their skin but not too contrasting. For example, black may be too severe a contrast to white skin tones. Tan might blend in with a skin color so that the signs are not discernible. Wearing dots or a print could make someone watching the sign language dizzy. The retinitis pigmentosa may cause islands of visual loss within the restricted visual fields. Peripheral vision loss may necessitate the use of more concise or more compact sign language closer to the interpreter's face. All of these seemingly small details can prevent eloquent signed communication from being understood. All of these details are magnified when an individual has RP combined with deafness or hearing loss.

There can also be transitional periods of adjustment if an individual with RP experiences a field loss or change in central vision requiring them to physically track sign language. This is the process of placing their hand on the signer's arm to more easily follow the hand movements. It requires a time of transition to accommodate the new form of receiving information. Communication may go a little more slowly in the interim. Occasionally an individual with Usher syndrome will become a tactile signer and read signs with their hands placed over the interpreter's hands. There is, once again, a learning period during which time communication may be slower for a while. A loss of vision can change a person's ability to lip-read, see signs, or just read print. A change in the retina may require new ways of processing information. It can take longer to understand the same information that could easily be understood a year ago in the same office meeting with the same doctor. Communication must be understood or informed choice cannot occur.

Informed choice means meeting the current communication needs of an individual with Usher syndrome. It is an evolution. As more information is acquired, more time may be required to process it. Changes in the communication bridge may be necessary.

Informed choice allows adults to independently decide whether or not to become part of scientific research including Usher syndrome research. Informed choice allows self-

determination in Usher syndrome genetic research. If adults choose to participate, then they give their informed consent to become involved in the research. Parents make those decisions for, and usually with, their children with Usher syndrome. Children can give their assent.

Parents attending outreach meetings of BTNRH Center for the Study and Treatment of Usher Syndrome have reported feeling optimistic just by meeting a researcher who is working to cure Usher syndrome. When the researcher is available to answer their questions they feel connections to others with Usher syndrome. They also feel hope.

Global research

As Usher syndrome research and collaboration becomes more global new challenges in communication are present. Not only are the researchers and professionals traveling around the world, but also the world is coming to us all through ongoing migrations of people to new places in the world. Sometimes a person with Usher syndrome is fluent in the local sign language, but may not be literate in the written language of the country where they live. Some cultures are oral and do not have a traditionally written language. Sometimes older family members speak one language while the younger ones, including people with Usher syndrome, know more than one language. This introduces other links in the communication bridge to informed choice and informed consent, especially if more than one family member

With increased understanding, individuals with Usher syndrome are independently deciding whether or not they want to participate in genetic research programs around the world.

wants to enroll in the research. Some cultures have beliefs about the onset of Usher syndrome. Sometimes these beliefs enter into the decision process. Scientific research has disproved some locally held beliefs about Usher syndrome. For example, Usher syndrome occurs around the world not just in one community or ethnicity. More than one person in a family may have Usher syndrome but it is not contagious-it is genetic. In one community this information encouraged members of a Deaf community to visit with four siblings with Usher syndrome after twenty years of misunderstanding the etiology.

Individuals with Usher syndrome and parents of young children with Usher syndrome need to have

ongoing opportunities to learn about research updates, advances, and opportunities for participation in research and clinical trials. Educators and other professionals will need to keep informed of medical advances to appropriately plan individualized programs and support services for children with different types of Usher syndrome. With increased understanding, individuals with Usher syndrome are independently deciding whether or not they want to participate in genetic research programs around the world. Self-determination in Usher syndrome genetic research is opening the doors of increased understanding for individuals with Usher syndrome and their families.

Email:
cmilesusa@houston.rr.com
kimber@boystown.org

References

- Jones, B. (1991) Proceedings 6th European Usher Syndrome Study Group. Orebro Sweden
- Kimberling, W. J., Weston, M. D., Pike-Dahl, S., Usher Syndrome Type I, (USH1. Includes: USH1A, USH1B, USH1C, USH1D, USH1E, USH1F) Initial posting 10 December 1999. Update 20 November 2003 GeneReviews. www.genetests.org
- Kimberling, W. J., Weston, M. D., Orten, D. J., Usher Syndrome Type II (USH2. Includes: USH2A, USH2B, USH2C, USH2D) Initial posting 10 December 1999. Update 20 November 2003 GeneReviews. www.genetests.org
- Moller C. G., Kimberling W. J., Davenport S. L., Prilluck I., White V., Biscone-Halterman K., Odqvist L. M., Brookhouser P. E., Lund G., & Grissom T. J. (1989) Usher syndrome: an otoneurologic study. *Laryngoscope* 99:73-9 (Medline)
- Miner, I. (1995). Proceedings from the Eighth European Usher Syndrome Study Group. Sense, London.
- Rogers, F., Sharapan, H., Biglan, A. (1993). *Duane's Clinical Ophthalmology* Vol. 6 Chapter 80, p. 12. Philadelphia: J.B.Lippincott Company.
- Vernon, M., Boughman, J. and Annala, L. (1982) Considerations in Diagnosing Usher syndrome: Retinitis Pigmentosa and Hearing Loss. *Journal of Visual Impairment and Blindness*.

EdbN European Campaign – NOW

Lucy Drescher writes:

EdbN (European Deafblind Network) is working with Richard Howitt MEP, Chair of the Disability Intergroup in the European Parliament, on a campaign to get deafblindness recognised as a separate disability at the European level.

In 2002 Richard Howitt MEP spoke at the Social Inclusion seminar organised by Sense International, Lega del Filo D'Oro and Casa Pia de Lisboa, promising to support the Charter for deafblind citizens of Europe. When EdbN met in London in March 2003 Sense UK agreed to take the lead on campaigning work and so I have taken on the responsibility for this. Following up on Richard Howitt's promise I went to Brussels in July this year to meet Richard and Sophie Beaumont from EDF (European Disability Forum).

Richard and Sophie are both

very keen to work with deafblind people, to get deafblindness recognised at the European level. This recognition of deafblindness could be used by people in the various member states, to persuade their government to give deafblind people the rights they need to play a full part in society.

Following these discussions we have agreed to hold a reception for MEPs and other interested people in the European Parliament at the beginning of January, to launch a Written Declaration on the needs of deafblind people. In the same week



we will be holding an exhibition in the parliament to highlight the needs of deafblind people.

How can you help!

A Written Declaration is 200 words long and it is a statement of what we believe should happen within the European Union. If we can persuade more than half of all the MEPs to sign up to the declaration then it will be adopted by the European Parliament. For this to happen it is going to be vital for deafblind people, their families and professionals working in this field to lobby the MEPs in their country to sign up. Please do contact me if you would like to be involved in this campaign.

My email address is
ldresch@sense.org.uk

Analyzing teacher/child interactions: What makes communication successful?

This article is the first of two articles by Isabel Amaral from Escola Superior de Educação de Lisboa, Portugal. The first, published here, relates specifically to a piece of research carried out by the author with the help of teachers and pupils. The second part, which has emerged from the findings of this research study, offers guidelines for communication intervention, and is designed to support specialist staff. This will appear in the next edition of DbI review



Introduction

Communication with children with multiple disabilities requires the use of non-linguistic modes of communication that are not always mastered by teachers and other adults in school.

This study intended to describe the communicative characteristics of interactions between two multiply disabled children and their teachers, as well as to present the results of an intervention process designed to reduce the number of children's behaviors that are not responded to by teachers.

Results indicate that teachers miss opportunities for communication, and that an intervention procedure that decreases the number of behaviors that are not responded to by teachers does not substantially change interactions. Issues emerged from data analyses that need to be attended to when interacting with learners who do not use speech to communicate. A discussion of such issues is included in the discussion of results.

Results of data analysis support the development of suggestions for practice aimed at helping teachers, with no training in special education, plan their communication intervention.

Children with multiple disabilities¹ often do not use speech or any other language form to communicate. Nonetheless, when immersed in a context or routine with which they are familiar, they do communicate through the use of forms such as movement, smiles, and manipulation of objects (Siegel-Causey & Guess, 1989). Partners in learners' environments are therefore challenged to discover how the alternate modes these individuals use to communicate can be transformed into

communicative interactions that will allow people with multiple disabilities to discover and enjoy life to their full potential.

Research has not yet provided sufficient information on how these children learn, and how schools and services can better meet their unique needs. But there is little question that unless children are able to interact with environments, and *communicate with people* in those environments, their developmental process will be seriously affected and their access to school opportunities will decrease.

More than just a skill, the ability to communicate effectively is an art. This "art" becomes a real challenge when partners in communication cannot use speech as their usual form of communication. The absence of standard forms of communication interferes with the communication process and creates additional difficulties in the establishment of meaningful interactions and learning.

Some of the questions we need to ask are: How do children with multiple disabilities gain access to meaningful information from the world around them? What do these children learn, in the absence of effective means of communication, what lays the foundations for successful human interactions?

Developing Interactions

The success of interactions between caregivers and learners with multiple disabilities depends largely on the ability of the caregiver to interpret and respond to the learner's nonsymbolic forms of communication. Although parents of normal developing children respond to children spontaneously, research has shown that signals sent by infants with developmental delays are more difficult to read and to be responded to by

¹ Combination of severe to profound mental retardation with sensory, motor and/or health disabilities (Orelave and Sobsey, 1991)

SUCCESSFUL COMMUNICATION

parents (Walden and Knieps, 1996, Clark and Seifer, 1983). Also, children with disabilities may have problems with reading parents' signals (Walden and Knieps, 1996). These difficulties may have important consequences in a child's development, as parental responsivity to children's signals is related to later social and emotional development and to children's communication abilities.

Some authors suggest that learners with multiple disabilities are not as predictable as nonsymbolic normal developing children (Siegel-Causey et al, 1988). This might lead to a decrease in the quantity and quality of the caregiver's responses, as well as a possibility for asynchronous interchanges. Caregivers often do not perceive learners with multiple disabilities as their partners in social interactions, which might in turn create less opportunity for the child to receive contingent responses. In such situations, caregivers tend to assume responsibility for initiating and controlling interchanges (Hanzlik & Stevenson, 1986; Mahoney & Robenalt, 1986) without the guidance of the children's signals and cues.

Siegel Causey et. al. (1988), looking at characteristics of interactions between mothers and their deafblind babies, point out three aspects: sensitivity, timing and contingency and predictability.

Sensitivity refers to the caregiver's ability to read and respond to children's unique behaviors. Children with multiple disabilities often do not vocalize, which is the behavior more often responded to by caregivers of normally developing babies, therefore requiring caregivers to learn to respond to other behaviors such as movement.

Timing of responses is difficult to keep when children's signals are not understood by caregivers as communicative. Deafblind children often show less responsiveness and less interactive rhythmical skills, leading caregivers to respond at the wrong time, either by responding too quickly or by leaving some behaviors un-responded to. In some cases caregivers over-stimulate by continuously vocalizing and therefore creating fewer pauses, which decreases the opportunities for the child to respond to, or to initiate, communication.

Contingency and predictability of caregivers' responses develop a sense of success of children's communicative attempts. Children learn that their behaviors are acknowledged by others. Still, contingency of caregivers' behaviors is often decreased as a result of the unique characteristics of deafblind babies, such as non-responsiveness, limited response repertoire, reduced opportunities for social interaction or caregivers' feelings related to the disabilities.

The attachment process described by Bowlby (1969), through which the child develops a secure bonding with his primary caregiver, allowing him/her to explore and access new opportunities for experience and learning, is endangered in children with multiple disabilities due to the described difficulties in establishing readable signaling systems. Visual impairments have an

important role in the attachment process and can cause additional difficulties for a child with multiple disabilities as it impacts on the development of eye contact between the child and his mother (van Dijk, 1986, Fraiberg, 1975). Children with a vision loss are therefore at risk in the development of secure relationships with their caregivers.

Communication Goals

Success in the development of communication skills for learners with multiple disabilities depends on various communication characteristics essentially related to the role of teachers in their interactions with learners. These characteristics are: a) the ability to consider learners with multiple disabilities as equal partners in interactions, (Miles and Riggio, 1999), b) the ability to read and interpret potential communicative signals (Sigafoos et. al., 2000), c) the ability to respond contingently to learners behaviors (Siegel-Causey et. al., 1988) and, d) the ability to provide access to meaningful experiences that will support communication development and learning (Miles and Riggio, 1999, McLetchie and Riggio, 2002, Cripe and Venn, 1997).

Little research has been done that deals with the communication needs of learners with multiple disabilities. This is partly due to the heterogeneity of the population, but also to the lack of belief that individuals with multiple disabilities can be taught and can develop. For such individuals the reduced number of environments they visit and the reduced number of communicative partners in each environment represent an additional problem to the development of functional communication. The teachers' ability to maximize opportunities for communication will then depend on the ability to seize and select meaningful opportunities, including identifying particular partners, as well as the capacity to detect the best forms of communication for an individual in a given environment.

The Research Project – Methods and Procedures

This study is part of a larger study intended to describe and analyse interactions between children with multiple disabilities and their teachers. The purpose of this study is to analyse missed opportunities for communication between children with multiple disabilities and their teachers during school activities, and to describe the results of an intervention process designed to reduce the number of missed opportunities.

The study uses a case study design (Yin, 1994; Stake, 1995) of two children with multiple disabilities and their teachers. Four activities were videotaped for each case. An intervention procedure was carried out between the third and fourth videotaped activity.

Videotapes were analyzed and missed opportunities for communication were counted. Using a nine item five point scale a group of judges observed the videotapes and expressed their opinion on the quality of interactions.

SUCCESSFUL COMMUNICATION

Participants

Participants in this research are two non-speaking learners with multiple disabilities and their teachers. Anna is a small ten-year old girl, who likes to sit quietly and enjoys playing with play dough. Her medical profile indicates that she has a chromosomal disease related to chromosome X. Anna shows good tactile skills that contrast positively with her hearing and vision abilities. Maria is a ten-year-old girl who spends most of her time in a wheelchair. She likes the sound of loud music and people being sociable with her. She has spastic quadriplegia and retinopathy related to prematurity. She responds to sounds but does not understand speech.

Both teachers are preschool teachers with more than 15 years of experience and no training in special education. It is their first year working with learners with multiple disabilities.

Data collection

Use of video recording

Systematic observations of teacher/child interactions were carried out through the use of videotapes. Four activities were videotaped for each child. In each case a videotape was made after the intervention process as a way of gathering data for assessment of the intervention procedure. Activities were selected randomly from the daily calendar.

The video system used was a portable non-professional VHS compact camera. The camera was focused on the child or on the teacher/child dyadic interaction. As displacements were very occasional, a fixed camera was used to make videotaping as invisible as possible. Videos were transcribed and time coded.

Videotape analysis covered;

- the child's behaviors that were responded to by the teacher and,
- missed opportunities for communication.

Counting of missed opportunities for communication was used to assess pre and post intervention sessions.

Criteria for "communicative behavior"

Before starting video analysis, criteria were set up to define what is a communicative behavior. It was considered that any behavior exhibited by the child could be considered as potentially communicative and therefore responded to by teachers.

To obtain additional information on the pre- and post-intervention differences observed in systematic observations, videos were shown to a group of judges, who were asked to express their opinions on a five point scale that included nine items. The judges, 26 in total, were made up of speech and language pathologists and psychologists all with appropriate advanced training.

The scale was made up of nine statements (Table 1) aimed at informing about:

- the potential for communication in the activities,
- the children's communicative initiations,
- the teacher's responses to the child's initiations and,
- the teacher's ability to include communicative and learning opportunities in the activity.

The Intervention Process

Communication was a problem for both teachers and they both expressed their desire to know more about ways to communicate with children with multiple disabilities.

The intervention procedure carried out was conducted after three of the four systematic observations. Methodologies for intervention included: 1) discussions with teachers watching their communication behaviors on videotape and, 2) development of a communication intervention plan aimed at increasing communicative interaction between teachers and children. In both cases strategies for answering potentially communicative behaviors were included. The teacher/child interactions were re-observed a month after the intervention procedure.

Table 1: Opinion Scale – Assessment of Teacher/Child Interactions

| | Strongly disagree | Disagree | Somewhat agree | Agree | Strongly agree |
|-----|---|----------|----------------|-------|----------------|
| FDI | The activity helps facilitate interactions | | | | |
| IAT | The teacher incorporates turn taking into the activity | | | | |
| CIC | The child initiates communication | | | | |
| RIC | The teacher responds to child's initiations | | | | |
| AAM | Enjoyable and motivating activity | | | | |
| ICC | The child interprets child's behavior as communicative | | | | |
| RRF | The teacher paces interaction according to the child's needs | | | | |
| POI | The teacher misses opportunities for communication | | | | |
| IPA | The teacher develops interactions that provide opportunities for learning | | | | |

SUCCESSFUL COMMUNICATION

Data Analysis

Content analysis and basic counting of behaviors were used as methodologies to analyze systematic observations. The average number of missed opportunities for communication per minute in the three pre intervention sessions was calculated. The obtained number was used to calculate expected missed opportunities for communication in the post intervention session. Expected and obtained results were compared and described.

Data resulting from the opinion scale were analyzed through descriptive statistics. Modal values of each pre-intervention session were compared with values of the post-intervention session to assess the intervention procedure. The Kolmogorov-Smirnov "goodness of fit" test was used to determine agreement among judges.

Results

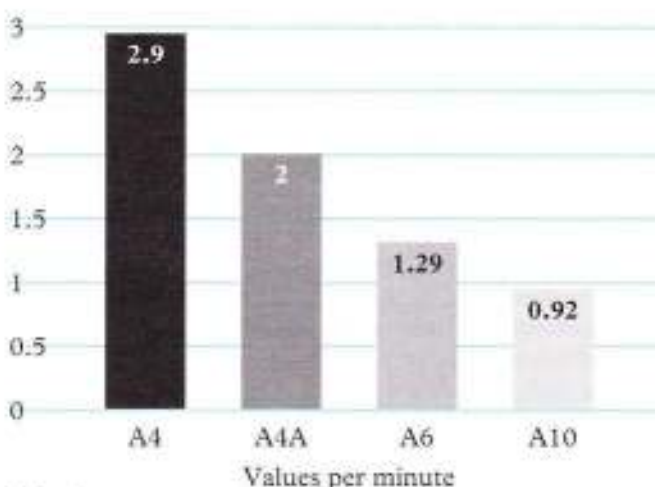
Systematic Observations

In Anna's case, 67 potentially communicative acts were missed during the 35 minutes that represent the total time of the three pre-intervention sessions. Based on these figures an amount of 1.91 missed opportunities per minute was calculated. Considering the duration of the post intervention activity (13'), an amount of 24.8 non-responded behaviors in session A10 (music) was anticipated. The results of the post intervention session, for non-responded behaviors, indicate a number of 12 non-responded behaviors.

In Maria's case, from a total of 32 non responded behaviors across the 56 minutes that represent the total time of the pre intervention sessions, an amount of 0.57 missed opportunities per minute was calculated. Using this figure, an expected number of 9.77 missed opportunities for the post intervention session was

Table 2: Missed opportunities for communication

Anna



Maria

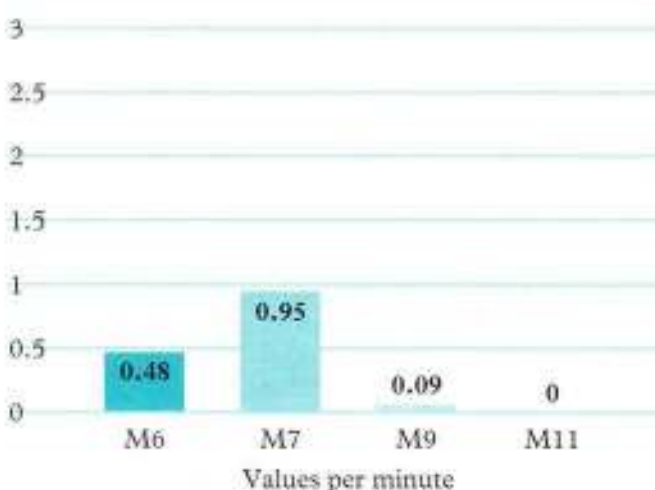


Table 3: Modal Values for Both Cases

Anna

| | Pre-intervention | | | Post-intervention |
|-----|------------------|-----|----|-------------------|
| | A4 | A4A | A6 | A10 |
| FDI | 4 | 4 | 4 | 4 |
| IAT | 1 | 2 | 2 | 3 |
| CIC | 2 | 4 | 2 | 4 |
| RIC | 2 | 3 | 2 | 2 |
| AAM | 4 | 4 | 2 | 2 |
| ICC | 2 | 4 | 2 | 3 |
| RRF | 2 | 2 | 2 | 1 |
| POI | 1 | 2 | 1 | 2 |
| IPA | 1 | 2 | 2 | 2 |

Maria

| | Pre-intervention | | | Post-intervention |
|-----|------------------|----|----|-------------------|
| | M6 | M7 | M9 | M11 |
| FDI | 4 | 4 | 2 | 4 |
| IAT | 2 | 3 | 2 | 3 |
| CIC | 4 | 4 | 3 | 4 |
| RIC | 2 | 4 | 2 | 3 |
| AAM | 3 | 4 | 3 | 3 |
| ICC | 2 | 4 | 2 | 2 |
| RRF | 2 | 3 | 2 | 2 |
| POI | 2 | 2 | 2 | 2 |
| IPA | 2 | 3 | 2 | 3 |

FDI-Activity facilitates interactions; IAT-Teacher includes turn-taking; CIC-Child initiates communication; RIC-Teacher responds to child initiation; AAM-Enjoyable and motivating activity; ICC-Teacher interprets child's behavior as communicative; RRF-Teacher paces interaction; POI-Teacher misses opportunities for interaction; IPA-Interaction provides opportunity for learning

SUCCESSFUL COMMUNICATION

obtained. The observed number of missed opportunities in the post intervention sessions is zero (Table 2). This leads to the conclusion that there are differences between pre and post intervention sessions in the teacher's responding to child's potentially communicative acts. Still, it should be noted that the nature of the activity (with a strong rhythmical component) and the way it was developed by the teacher (actively searching for Maria's responses) somehow created natural opportunities for Maria's responses to be picked up by the teacher.

As the intervention procedure included information on ways to respond to the child's potentially communicative behaviors, a conclusion can be made that there was a change in the way the teachers responded to potentially communicative behaviors that points out to possible positive results of intervention.

Opinion Scale

Results of the opinion scale were described through the use of modal values for each item and session. Table 3 shows modal values for each session and item.

The distribution of responses was tested through the use of the Kolmogorov-Smirnov "goodness of fit" test in order to determine agreement among judges. D values

(a statistical value resulting from the KS test) and significance levels for item and session are shown in Tables 4 and 5.

Results of the opinion scale used to assess interactions between Anna and her teacher reveal that the teacher misses opportunities for communication, does not provide for learning opportunities and does not pace interaction according to Anna's needs. Although agreement was found on responses related to the teacher not responding to Anna's initiations, judges' responses related to Anna initiating communication were not significant in any session, therefore leading to the conclusion, much as in participant and systematic observations.

Pre and post intervention mode differences analyzed in conjunction with significance levels, revealed that differences found are based on results that do not always show significant levels of agreement and therefore, we must conclude that intervention did not impact on interactions between teacher and Anna.

In Maria's case judges' responses on items RRF (*teacher paces interaction according to child's needs*), POI (*the teacher misses opportunities for communication*) and IPA (*interactions provide an opportunity for learning*)

Table 4: Anna – D-Values Per Session and Item and Significance Levels

| | A4 | sig. | A4A | sig. | A6 | sig. | A10 | sig. |
|--|-------|------|-------|------|-------|------|-------|------|
| Activity facilitates interactions (FDA) | 0,2 | | 0,37 | .01 | 0,122 | | 0,331 | .01 |
| Teacher includes turn-taking (IAT) | 0,408 | .01 | 0,292 | .05 | 0,446 | .01 | 0,119 | |
| Child initiates communication (CIC) | 0,161 | | 0,246 | | 0,162 | | 0,208 | |
| Teacher responds to child initiation (RIC) | 0,331 | .01 | 0,285 | .05 | 0,408 | .01 | 0,361 | .01 |
| Enjoyable and motivating activity (AAM) | 0,162 | | 0,285 | .05 | 0,446 | .01 | 0,246 | |
| Teacher interprets child's behavior as communicative (ICC) | 0,446 | .01 | 0,2 | | 0,331 | .01 | 0,324 | .01 |
| Teacher paces interaction (RRF) | 0,485 | .01 | 0,4 | .01 | 0,524 | .01 | 0,408 | .01 |
| Teacher misses opportunities for communication (POI) | 0,485 | .01 | 0,446 | .01 | 0,485 | .01 | 0,523 | .01 |
| Interaction provides opportunity for learning (IPA) | 0,485 | .01 | 0,285 | .05 | 0,331 | .01 | 0,284 | .05 |

Table 5: Maria – D-Values Per Session and Item and Significance Levels

| | M6 | sig. | M7 | sig. | M9 | sig. | M11 | sig. |
|--|-------|------|-------|------|-------|------|-------|------|
| Activity facilitates interactions (FDI) | 0,2 | | 0,418 | .01 | 0,173 | | 0,155 | |
| Teacher includes turn-taking (IAT) | 0,4 | .01 | 0,2 | | 0,31 | .05 | 0,309 | .05 |
| Child initiates communication (CIC) | 0,15 | | 0,464 | .01 | 0,264 | | 0,2 | |
| Teacher responds to child initiation (RIC) | 0,263 | | 0,2 | | 0,355 | .05 | 0,309 | .05 |
| Enjoyable and motivating activity (AAM) | 0,309 | .05 | 0,464 | .01 | 0,127 | | 0,264 | |
| Teacher interprets child's behavior as communicative (ICC) | 0,309 | .05 | 0,199 | | 0,201 | | 0,309 | .05 |
| Teacher paces interaction (RRF) | 0,327 | .05 | 0,264 | | 0,372 | .01 | 0,418 | .01 |
| Teacher misses opportunities for communication (POI) | 0,509 | .01 | 0,263 | | 0,509 | .01 | 0,418 | .01 |
| Interaction provides opportunity for learning (IPA) | 0,418 | .01 | 0,264 | | 0,327 | .01 | 0,401 | .01 |

SUCCESSFUL COMMUNICATION

indicate that interactions between Maria and her teacher have significant problems related to pacing the interaction according to Maria's needs, seizing opportunities for communication and including learning opportunities in the interactions.

Analysis of differences between each pre-intervention session's results and post intervention results show that intervention did not impact on the quality of interactions between Maria and her teacher.

Results of both Anna and Maria's cases show:

- missed opportunities for communication,
- problems with pacing interactions according to the child's needs and,
- developing interactions that do not provide for learning are the most salient characteristics of teacher/child interactions across sessions.

Discussion

The analysis of missed opportunities for communication during systematic observations, which took into consideration children's behaviors that teachers did not respond to, showed that teachers do leave many children's behaviors un-responded to, and also that this number can be decreased through intervention.

An analysis of responses on the opinion scale pertaining to the post intervention session indicates no significant differences in teacher/child interactions. Items that more closely relate to interaction, (RIC, POI, and IPA) are rated low and do not indicate difference from the pre- intervention session.

In both cases the teachers had mentioned the need to increase interactions as an important concern for them. Both the programs were designed to include strategies for increasing interaction through reducing the number of non-responded behaviors, as well as alternative modes of communication (such as tactile and object cues in Maria's case) or strategies to increase the child's initiation (such as increasing participation in setting up activities in Anna's case).

A major question remains that relates to the time teachers had available to experiment with the program (one month), which seems to be too short a period of time to produce significant effects in teacher/child interactions. It was only the fact that the school year was about to finish and both teachers were moving out of school that dictated the time of implementation. A second question relates to the absence of support from the researcher during the implementation period, which might have helped teachers to become more comfortable with using the program. Recent research on teacher preparation (Janssen, 2001) related to communication with deafblind children points out the need for ongoing support in order for teachers to be able to improve their communicative interactions.

Implications for Practice

As a result of this study, two implications for practice emerge. The first one concerns the need to develop communication centered programs that prepare teachers to

work with learners with multiple disabilities; the second one relates to the need to set up *intervention guidelines* for communication intervention with learners with multiple disabilities who do not speak.

Teacher Training and Preparation

Training in the area of communication with learners with multiple disabilities should prepare teachers to assess learners' communication needs and to design intervention plans that meet those needs. Best practices in teacher training should therefore include opportunities for teachers to develop:

- positive expectations (awareness of learners as communicative partners and of positive attitudes about learners' ability to participate in the learning process),
- theoretical knowledge (providing teachers with in-depth information related to communication with an emphasis on pre-linguistic communication, communication characteristics of interactions with learners with multiple disabilities and the need for communication intervention to be based in meaningful contexts that set the basis for access and development of content) and,
- practical skills about prelinguistic communication (the way communication should be used to support teaching and learning and also strategies, such as supervision of practice, that help teachers reflect and discuss the results of their work).

Changing communication behaviors is not always easy for teachers who are used to speech as their main form of communication. Training and experience may be needed for an adult to become fluent in the use of less used communication modes such as signs or objects (Kaizer and Goetz, 1993). It requires time and supervision to learn to respond to the communicative needs of the learner (Janssen, 2001). Teachers should leave preparation programs with skills, both in the use of techniques to apply, including the ability to use alternative means of communication, and in reflective habits that lead them to question their practice as a basis for assessment and intervention change whenever necessary.

References

- Adamson, L. B., Chance, S. E. (1998). Coordinating attention to people, objects and language. In A. Wetherby, S. Warren, J. Riechle (Eds.), *Transitions in prelinguistic communication*. Baltimore: Paul Brookes.
- Bates, E., Camaioni, L., Volterra, V. (1975). The acquisition of performatives prior to speech. *Merrill-Palmer Quarterly*, 21, 205-224.
- Bowlby, J. (1969). *Attachment and loss*. Vol. 1 Attachment. New York: Basic Books.

SUCCESSFUL COMMUNICATION

- Brazelton, T. B., Koslovski, B., Main, M. (1974). The origins of reciprocity: The early mother-infant interaction. In M. Lewis and L. A. Rosenblum (Eds.), *The effect of the infant on its caregiver*. New York: John Wiley & Sons.
- Bruner, J. S. (1975). From communication to language: A psychological perspective. *Cognition*, 3, 225-287.
- Bruner, J. (1983). *Child's talk*. New York: Norton.
- Bruner, J., Sherwood, V. (1983). Thought, language and interaction in infancy. In J. Call, E. Galenson, R. Tyson (Eds.), *Frontiers to infant psychiatry*. New York: Basic Books.
- Clark, G. N., Seifer, R. (1983). Facilitating mother-child communication: A treatment model for high-risk and developmentally delayed infants. *Infant Mental Health Journal*, 4, (2), 67-81.
- Cripe, J., Venn, M. (1997). Family guided routines for early intervention services. *Young Exceptional Children*, 1-1, pp. 18-26.
- Cronkhite, G. (1976). *Communication and awareness*. Menlo Park: Cummings.
- Fraiberg, S. (1975). The development of human attachments in infants blind from birth. *Merrill-Palmer Quarterly*, 21 (4), 315-34.
- Goldbart, J., O'Kane, J. (2000). *Communication before speech: Development and assessment* (2nd ed.). London: David Fulton.
- Hanzlik, J. R., Stevenson, M. B. (1986). Interactions of mothers with their infants who are mentally retarded, retarded with cerebral palsy or non-retarded. *American Journal of Mental Deficiency*, 90, 513-520.
- Janssen, M. (2001). Enhancing quality of interaction with deafblind children. 5th DBI European Conference on Deafblindness. Holland, Noordwijkerhout. 25-29 July.
- Kaiser, A., Goetz, L. (1993). Enhancing communication with persons labeled severely disabled. *The Journal of the Association of Persons with Severe Handicaps*, 18, 137-142.
- Mahoney, G., Robenalt, K. (1986). A comparison of conversational patterns between mothers and their Down Syndrome and normal infants. *Journal of the Division of Early Childhood*, 10(2), 172-180.
- Mc Letchie, B., Riggio, M. (2002). Trusting relationships. In *Understanding Deafblindness*. SKI:HI Institute.
- Miles, B., Riggio, M. (1999). *Remarkable conversations. A guide to developing meaningful communication with children and young adults who are deafblind*. Boston: Perkins School for the Blind.
- Mundy, P., Willoughby, J. (1998). Nonverbal communication, affect and socio-emotional development. In A. Wetherby, S. Warren, J. Reichle (Eds.), *Transitions in prelinguistic communication*. Baltimore: Paul Brookes.
- Reddy, V. (2000). Prelinguistic communication. In M. Barrett (Ed.), *The development of language*. Hove: Psychology Press Ltd.
- Searle, J. (1984). *Minds, brains and science*. Cambridge, MA: Harvard University Press.
- Shatz, M. (1983) Communication. In P. Mussen (Ed.), *Handbook of Child Psychology*. J. Flavell, E. Markam, (Eds) Vol 3. New York: John Wiley & Sons.
- Siegel-Causey, E., Downing, J. (1987). Non-symbolic communication development: Theoretical concepts and educational strategies. In L. Goetz, D. Guess and K. Stremel-Campbell (Eds.), *Innovative program design for individuals with dual sensory impairments*. Baltimore: Paul Brookes.
- Siegel-Causey, E., Guess, D. (1989). *Enhancing nonsymbolic communication among learners with severe disabilities*. Baltimore: Paul Brookes.
- Sigafoos, J., Woodyatt, G., Keen, D., Tait, K., Tucker, M., Roberts-Pernell, D., Pittendreighn. (2000). Identifying potentially communicative acts in children with developmental and physical disabilities. *Communication Disorders Quarterly*, 21, 77-88.
- Stake, R. (1995). *The art of case study research*. Newbury Park, CA: Sage Publications.
- Stern, D. (1985). *The interpersonal world of the infant*. New York: Basic Books.
- Trevarthen, C. (1977). Descriptive analysis of infant communicative behavior. In H. R. Shaffer (Ed.), *Studies in mother-child interaction*. London: Academic Press.
- van Dijk, J. (1986). Educational curriculum for deaf-blind multi-disabled persons. In D. Ellis (Ed.) *Sensory impairments in mentally disabled people*. London, Sydney: Croom Helm Publishers.
- Vygotsky, L. (1993). The fundamentals of defectology. In R. W. Rieber, A. S. Cartoon (Eds.), *The collected works of L. S. Vygotsky*. Vol 2. New York: Plenum.
- Walden, T., Knieps, L. (1996). Reading and responding to social signals. In M. Lewis, M. Sullivan (Eds.), *Emotional development in atypical children*. New Jersey: Laurence Earlbaum Associates, Publishers.
- Westling, D. Fox, L. (1995). *Teaching learners with severe disabilities*. Englewood Cliffs: Prentice Hall, Inc.
- Yin, R. (1994). *Case study research: Design and methods* (2nd ed.). Beverly Hills, CA: Sage Publishing.

The Peer Mentor Programme, UK

Mary Guest introduces this programme describing the motivation behind it and Chris Sherlock discusses the training and supervision aspects, which are crucial to its success. This work was presented at the Usher Study Group at the Dbl conference in Canada.

One of the consequences of becoming deafblind may be isolation from family, work place and society. Isolation and loss of skills, such as communication, in turn may cause periods of extreme mental anguish for people who are losing, or have lost, sight and hearing. Deafblindness in the general population is rare. It is not easy to meet others similarly affected or professionals trained and experienced in this area.

The main thrust of the Peer Mentor Project which started in 2000 was to fill this gap by training deafblind people so that they could be equipped to act as mentors to others and help to reduce some of the isolation and depression which often comes with encroaching deafblindness.

As we embarked on the Project our aim was to provide, through the specialist training programme, a person able to listen empathetically, who knows from inside about the Usher experience. This person would be aware of, and knowledgeable about, different forms of Usher, able to answer general questions as well as provide information. Mentors are able to affirm or clarify understanding and, most importantly, connect the mentee to others who might provide ongoing support.

The training programme devised by Chris Sherlock and Gloria Ward, who is the project co-ordinator, aims to equip mentors who are living productively with Usher, and who are able to give support, to help restore a future to others who may have lost it, albeit temporarily.

The Training and Supervision of Peer Mentors

Training takes place in two stages. The first stage begins with residential training over two days. Orientation of new surroundings presents the mentors with their first challenge – needing to

familiarise and orientate themselves to the new venue suggests how prospective mentors would cope in travelling to meet a mentee out of their familiar environment.

someone to turn to
sense

become much more since talking with who also has Usher

deafblindness and associated difficulties

Sue's new start

"After my sight got worse, I lost my job and, after several years of being a housewife, I needed to find a new challenge and purpose in my life."

"I met my mentor, who has Usher, and she helped me to find a job and to get my sight and hearing checked. She helped me to find a job and to get my sight and hearing checked. She helped me to find a job and to get my sight and hearing checked."

"My mentor also has Usher and since I met her a year ago she has given me so much support."

An initial presentation of the **history of the project** helps mentors place themselves within the development of the whole Peer Mentor Programme.

Time is spent on a brainstorming activity that explores mentors' perceptions of **'what is mentoring'** compared to **'what is counselling'**. A framework is drawn up of the many facets of the mentor relationship where a balance is needed between 'I do it for you' and 'you do it for you'. The mentor is on a journey with their mentee, guiding them through their own particular process of need at that time. The need may be practical and/or emotional and flexibility is an essential skill for mentors to develop in their work.

Mentors are given an opportunity to explore their own 'story' of Usher and are encouraged to identify their unique grieving process through role play and individual sharing within their peer group. The loss process is explored in relation to Usher syndrome, where an understanding emerges that the grieving may subside but the loss is exacerbated at times of readjustment and crisis demanded by the progressive nature of dual sensory loss within Usher syndrome.

A session on **genetics** outlines for mentors the mapping process of the Usher gene within families.

In choosing to help others, it is important for mentors to think of strengthening themselves. The **"care of self"** session allows mentors to identify their support networks and share coping strategies within the group.

Beginnings is another role-play where mentors are invited to rehearse the 'first' sessions with their mentee.

The second stage of training

The second stage is arranged around areas of interest which have specifically emerged for a peer group during the Stage 1 training. For example, family issues, research, mental health and BSL are areas we have introduced based on mentor need.

Originating from within humanistic psychology, our training is experiential and mentors are encouraged to share their thoughts and feelings and ideas with each other. Within role-play, everyone gives feedback to the trainee mentor. Such a training emphasis puts the 'learner' at the centre of the learning processes, where time is given for learning to take place as it arises within the group. Rogers' (1951) student-centred learning had a similar focus and, within our training, has provided a safe learning forum for mentors to grow in confidence in their work with their peers.

After the course

Post training, mentors are offered group supervision. Planned across 4-5 hours, mentors present their casework within their peer group. Again, everyone offers feedback to the mentor and issues are summarised by the facilitator – everyone is learning together within a rich and confidential framework.

References:

Rogers, C.R. (1951) *Client Centred Therapy*. Boston: Houghton Mifflin.

Chris Sherlock

Chris Sherlock is an integrative counsellor and supervisor and practices in East London.

She has four children and her daughter, Lindsey, 24, has Usher type I.

She is a Lecturer in Counselling in further education.

She is currently working for a Doctorate in Psychology which is entitled Living with Usher syndrome – what makes a difference?

She is a Consultant to the Mentor Programme and offers training and supervision to the mentors



Gloria Ward, Peer Mentor Co-ordinator



Through creative activities ... to communication and integration

Mária Podhájecká & Janka Šarišská

In this article the authors describe the communication projects that they have set up with partners focussing on pre-planned creative activities. Their aim was to create opportunities for communication and creativity, and encourage a process of inclusion for the children.

The projects were a partnership between the Evangelical Elementary Boarding School for Deafblind Children in Červenica, the Prešov University Pedagogical Faculty, a toy-producing company, VHV, and a Kindergarten in Prešov. It was carried out over a period of 30 months.

Starting with Social Communication

Communication happens in various areas of human activity. But our main concern is social communication, that is the connection between people and information transference between them. Pedagogical communication is a specific part of social communication.

Communication, following pedagogical aims, helps to increase the effectiveness of education. In pedagogical communication information is mediated by verbal and non-verbal means. Pedagogical communication has its space and time dimensions and is a multidimensional phenomenon. According to Gavora (et. al.), there are three basic levels; contextual, affective and regulative.

In every aspect of communication that was discussed as part of this project, there are three elementary components present:

1. the source – a communicator
2. destination – a communicant, receiver
3. the process of informing – communiqué.

A channel creates a way for information to pass between a sender and a receiver. In our projects the primary channels for interpersonal communication were; touch, looking, facial expression, mimicking, sound, signs, movement and gestures.

The Study

The study involved a partnership between the School, the toy company, a Kindergarten and Prešov University. The partners were all committed to building on communication, integration and socialisation to support deafblind children in a new and unknown environment. And the projects concentrated on the development of a deafblind child's personality through "work place" activities.

Our aim was to:

- enable deafblind (Db) children and young people to get to know new environments where activities took place
- enable Db children to meet new people in a occupational environment
- inform those who co-operated with us about Db realities
- encourage Db people to communicate and raise awareness
- enhance the vocabulary of Db people during creative working activities
- enhance and develop abilities, knowledge, communication and creative working skills.

In preparing for the project we undertook a huge amount of work to make sure that our aims were realistic and we would achieve our outcomes.

Mária Podhájecká & Janka Šarišská



The Projects

Part 1 – Producing wooden and fabric toys

With our partners in the Toy Company, colleagues in school and two of our senior pupils we began to take our plans forward!

Explaining the process

The toy company staff demonstrated how the work process was undertaken and we explained to students that after finishing produced toys we would show them at school, at home and then we would give them as presents for children in Kindergarten. During the school year we used toys in an educational process so that the students understood what the newly produced toys were used for. With this firmly understood, we proceeded to their production!

How we did it

Students visited VHV Company weekly at set days and times. They were led by a company's employee, with some background knowledge of teaching. Every week she would prepare work for two students and then they would participate in the production of toys – from start to finish! In making a teddy bear for example, the

production started with cutting out individual parts of paper shapes and placing them on fabric. First, they traced out a shape, and then they cut it out. Individual parts needed to be sewn together using a sewing machine. At this point students needed help from a company's machinist who sewed the pieces together for them. Natália and Peter, our students, watched the process. Then it was time for stuffing, hand sewing, gluing of eyes, nose, and mouth and finally tying a big ribbon round the teddy bear's neck! Aunt Jana, as the children started to call the company's employee, prepared individual working steps for Natália and Peter with great enthusiasm. And the students happily visited the company week by week to try out what they learned at school. Of course, there was always a deafblind school educator present who made sure that the students understood the entire working process and did not hurt themselves. The students brought finished products to school and showed them proudly to all the school's employees. They also took them home to show their parents and siblings. By the end of the school year they had made various kinds of toys: hand puppets, stuffed animals like a teddy-bear, a fox, a lamb, a frog; fabric fruities, wooden blocks, dominoes, matching games, that they were able to give away as presents.

Taking the Toys to the Kindergarten

The day came when Natália and Peter joined by their schoolmates went to visit the Kindergarten on Zemplinska Street in Prešov to give the toys to children.

There are 26 kindergartens in the city of Prešov, but the one we chose is a University Training Kindergarten of six classes with 22 children in each class. We visited the children and pre-school pedagogues in one of those classes. It was the first time that our students had done anything like this before!

The Kindergarten Director welcomed us and introduced the deafblind students to the young children. Our students use signs instead of words and each of them has a special sign for her/his name! This is how they introduced themselves by signing their names. Pre-school children followed them with great attention and interest, and some of them were even able to copy them. After they had "tested" the deafblind children's hearing by shouting at them they paid even more attention. The kindergarten children and Cervenica students got on very well!

Part 2 – Meeting the children and giving the toys

Natália and Peter explained to them by signing how they worked and produced the toys. They imitated cutting, sewing, stuffing, gluing and so on. Then they distributed all toys to children. The giving and taking of presents was very spontaneous and there was no communication barrier among the children. Natália, with Peter, were happy to give and did not hide their joy about having made these new toys. A lot of nursery school children used a sign for "Thank you", so that Natália and Peter would understand them. After the gifts the Cervenica students stepped in front of the audience and sang a traditional tune, but instead of singing with their voices they used their hands! A kindergarten teacher sang the song for them! The kindergarten children liked singing with their hands and they tried it too. Finally they all played a movement game consisting of dance and music in one big integrating circle accompanied by guitar. This was one, big and happy company that could stand as an example for all adults! There is no barrier that could not be overcome to reach a mutual joy and understanding. And those children managed to reach it.

Part 3 – Transferring skills

The final part of the project focussed on the application of skills and knowledge gained by students during their working activities. This time the children worked with students from the University and their teachers.

As before there was a preparation phase involving the students and staff of the University with some in-depth study of deafblindness and the concepts of working with deafblind students. We provided our book *A girl who saw with her touch and heard with her heart* (2000) to help to provide insights.

After this preparation the University staff worked out a plan of creative activities for Cervenica students.

To accomplish their aims they bought materials, tools, instruments and arranged a workshop studio at the university faculty. They planned to make leather key-holders, a wooden key-hanger, plaster pictures, wooden frames, designing flower pots with ceramics, making Christmas figures, Christmas decorations, drawing and engraving pictures. To come face to face with a deafblind child was not easy for the University students at the beginning. A deaf university student of Pedagogy studying learning disability also joined into the project. He communicated with students with the use of a sign language.

Every student adopted an individual approach to working together. The University students enjoyed it so much that they have gradually joined in activities in summer camps for deafblind children and their families.

Remembering and re-living success

There are video-recordings made to document the project and through using these video-recordings we enabled the children to recollect the activities they had undertaken as part of the project. Using the tapes, we discuss the individual steps of the working process and as a result, after some time, they re-live the joy from the done work all over again.

Conclusion

Everyone, who was a part of a project, entered into communication that brought a dimension of new light into his or her lives. This "communication light" was different for everyone. Everyone was enriched differently, but most of all in the human way!

Doc. PhDr. Mária Podhájecká, PhD.

Prešovská univerzita
Pedagogická fakulta
ul. 17. novembra 15
080 78 Prešov
Slovakia
e-mail: marpo@unipo.sk

Mgr. Janka Šarišská

Evanjelická špeciálna základná škola internátna
pre hluchoslepé deti
082 07 Cervenica 114
Slovakia
e-mail: evphsd@vadium.sk

Working Together: A Deaf Association and Deafblind People

Nataly Kremneva reports:

Five years ago a new independent charity was founded in Moscow – "Guardianship for Usher and deafblind people (children and adults)" – "Usher Forum". Deafblind and Usher adults, their family members, professionals and parents became co-founders of this charity. The main goal of the organisation is to create a network of services for deafblind people and their families. From the very first steps, Usher Forum has had very close relationships with Moscow Association of the Deaf.

We think that the experience of their special co-operation could be useful for those organisations that have only recently started supporting deafblind people. The achievements of these groups working together are described below in two ways: support for families and individuals and campaigning to national and local government.

Support of deafblind people and their families

What we offer:

◆ **Interpretation and guidance services:** Usher Forum trains communicator-guides who help deafblind people



**Nataly
Kremneva**

participate in the meetings of the Communication Club and other activities. Thanks to co-operation with Moscow Association of the Deaf, deafblind Moscovites – members of this Association – have the right to use the services of professional sign language interpreters free of charge;

◆ **Technical aids for rehabilitation:** Moscow Association of the Deaf provides deafblind members of this Association with technical aids – communication devices for deaf people – different vibrators and signal devices;

The main goal of the organisation is to create a network of services for deafblind people and their families.

◆ Information about Usher syndrome and deafblindness:

Usher Forum published a newsletter on the problems of deafblind and Usher people and other information materials on the problems of deafblindness. These materials are being disseminated to deaf activists of the Association;

◆ Partnership projects:

Usher Forum, together with activists from Moscow Association of the Deaf, have started to develop a new programme with "Mentors" – deafblind people supporting each other. The aim is to reduce the isolation felt by these people.

Informing society and governmental structures about the problems of deafblind people

What we offer:

◆ Working with the authorities of Moscow and Moscow region:

Moscow Association of the Deaf involves Usher Forum in the process of developing proposals to Moscow government on the problems of the rehabilitation of people with sight and hearing impairments;

◆ Joint activities:

Deafblind activists participate and present talks at conferences and seminars of Moscow Association of the Deaf and during Annual Moscow Deaf Week;

◆ Exchanging experiences with deafblind people from other Russian regions:

According to requests from the Usher Forum, leaders of the Moscow Association of the Deaf meet deafblind activists from other Russian regions, and tell them about the partnership of the Association with the Moscow government in the field of rehabilitation of people with sensory problems;

◆ International Projects:

Between 2001 and 2003 the Usher Forum has developed a Russian-British partnership aimed at the development of services for deafblind people in Russia. Within the framework of this project, Usher Forum worked in three Russian regions – Moscow, Ufa and St. Petersburg.



We need contact with our international colleagues, experience exchange and partnerships.

Different seminars and training courses on the problems of deafblind people and campaigning took place during this period. Activists of deaf associations of these regions were invited to participate in all these activities. We are happy to inform you that as a result of the work, a new independent charity supporting deafblind people has been founded in Ufa. It's called OMAT – "Hope" in Bashkirian language;

◆ Informing society:

Usher Forum presents, on a regular basis, materials about its activities, Usher syndrome and the problems of deafblind people, in the newspaper "Deaf World", which is published by the Moscow Association of the Deaf.

Deafblind people in different regions of Russia are becoming more active. More people are getting involved in campaigns for the rights of deafblind people. Russian deaf people, who are losing sight, experience very many problems. First of all there is a problem of learning hands-

on-signing. In Russia this mode of communication is practically unknown. Besides, we need experience to create rehabilitational and educational centres for young people. We need experience in organising vocational and professional training and employment for deafblind people. That is why we need contact with our international colleagues, to experience exchange and partnerships.

A few words about myself: I have Usher syndrome. I lost sight and hearing gradually. I graduated from Moscow Lomonosov University and have a specialist qualification in history. Twelve years ago I became deaf and practically blind. For many years I worked for the Association, now I am a co-founder of the charity "Usher Forum" and a chairwoman for the local group of deafblind and Usher people in Moscow Association of the Deaf.

Nataly Kremneva

Usher Forum
Moscow, Russia
irv@child.ru
ivsai@mail.ru



Natural moral law and the right of deafblind people to the service of guide-interpreters

Why do deafblind people need the services of guide-interpreters?

The ability of people to live happily is determined by their ability to interact with their environment. In order to interact with their environment, people have to hear and see. As much as 94 per cent of all information a person receives concerning the environment is obtained through the senses of sight and hearing. However, a totally deafblind person cannot obtain this 94 per cent of information; only 6% of information is available, which is obtained by means of the remaining senses, particularly by means of touch. A deafblind person thus loses a chance to actively and efficiently interact with his or her environment. Such a significant loss can be partly alleviated with the help of another person, who can hear and see and who knows how to pass the obtained information to deafblind people. This person is the *guide-interpreter*.

Deafblind people are like strangers who find themselves in a strange, unknown country covered with fog. To survive, they need a guide and interpreter who knows the country well and who will help them to make themselves understood with the local people living there. The guide-interpreter's task is:

- to guide a deafblind person in the environment;
- to interpret and make a deafblind person familiar



By Jan Jakeš
(Chairman of VIA, The Association of the Deafblind, and an external part-time teacher in the Department of Special Education of the Charles University in Prague)

Deafblind people are like strangers who find themselves in a strange, unknown country covered with fog.

with the form and structure of the environment;

- to bring a deafblind person to the people sharing the environment with him/her;
- to interpret to a deafblind person the content of messages during communications with people from his/her environment.

Let us ask one particular question: what does the immediate world around us, which we call the environment and into which deafblind people venture with their reliable guide-interpreter, look like? And yet another question is connected with that: what must the guide-interpreter know, and be capable of, in order to be a good and reliable guide-interpreter?

The Environment

When talking about a person's environment, we take into account the complexity of all conditions which surround the person. At the same time, we distinguish between the natural world and the man-made world.

The natural world can be further subdivided into:

- a) the original environment of nature untouched by man; and
- b) the environment of the natural world changed and exploited by man.

The man-made world (environment artificially created by man) can be further subdivided into:

- a) the environment created by

material products of human activity, such as houses, cities, roads and other man-made and built things, and objects used for various purposes, e.g. living, working, and resting;

- b) the environment formed by ties (networks, systems) of personal and working relationships among people, such as friendship, marriage, family, education, ownership, working conditions, economy, culture, and the state; and
- c) the environment formed by spiritual and cultural products of human activity, such as language, philosophy, science, technology, art, ethics, law, politics, religion.

Based on this simple description of the environment, two things are obvious: how difficult it is for a deafblind person to orientate themselves when s/he cannot use the senses of sight and hearing, and how important and complex is the task of the deafblind person's guide-interpreter.

The deafblind person's claim to a guide-interpreter's service

The world surrounding us has many faces and many forms, which mutually permeate and overlap. It is varied, changeable, quite complex and difficult to grasp. That is why the world is interesting and entices people to explore it. It is a challenge for people to interact with their environment. The challenge

is addressed to all people. It concerns deafblind people as well! It is a challenge which is the task and the duty of a human being. Therefore we not only have a natural human right, but actually a duty, to get acquainted and interact with our environment.

And it is this human duty from which we, deafblind people, derive the right and entitlement to a guide-interpreter's service. In cases where the natural intrinsic abilities of an individual do not suffice for him to fulfil this duty, because they are limited or impaired, the natural social feelings of other people, and society, come to the forefront; it includes natural moral feelings and behaviour, the sense of responsibility, ability and the need to help. Thus, for example, parents help their children, adult sons and daughters help their elderly parents, and the healthy help the ill and the disabled.

The deafblind person's natural claim to a guide-interpreter's services is based on at least three reasons. Two of them are existential and one is ethical:

1. We are human beings.

We were born as individuals of the Homo sapiens species. We have to develop our individuality to become personalities. However, we can become "I" only with the assistance of some "You". For that we need to be accepted by other people, to be encouraged by them in our self-realization, to be educated and loved by them. In other words, we need to be communicated with. But most people communicate with each other on the basis of the fact that they can see and hear each other.

2. We are human beings.

It is our human duty to develop our own active existence in the world, take care of our

necessities of life, develop and complete our humanness in self-realization and self-actualisation. This can be done by activity, by interacting with the world and the people around us. But the contact of a person with his or her environment, i.e. with the world and other people, is based on information mostly obtained through seeing and hearing.

3. We are human beings with deafblindness.

We struggle with serious problems caused by the lack of auditory and visual information. We have permanent problems in interacting with the world and people, i.e. with our environment. This means that we have difficulty in getting acquainted with the world, orientating ourselves in the world, in responding to events around us, in adapting to the environment, in getting a response to our needs.

In connection with these three reasons, deafblind people's claim can also be expressed by these crucial questions:

1. Who will help the people surrounding us communicate with us, who are deafblind?
2. Who will help us to be in contact with our environment, when we are deafblind?
3. Who will help us overcome our difficulties, caused by deafblindness?

It is sad that we, deafblind people, have to remind the governments and law-makers of this natural principle. That is why we have to energetically speak of our needs and demands, and also about the requirement of the guide-interpreters' service. We must stress that the guide-interpreter is a person we need, because s/he makes it possible for us to interact directly with our

environment – that means that s/he helps us to live as a human being in the world and together with the people surrounding us.

This reasoning applies to all the services for deafblind people, not just to the service of a guide-interpreter, but also to the service of a personal assistant, intervenor and others!

Proposed Solution

The entitlement of deafblind people to a guide-interpreter service is based on the laws on human rights, i.e. on the personal right to live, the natural right to live a dignified human life, the right to education, the right of access to information, the right to freedom of movement and to be settled and the right to social aid. Generally formulated laws on human rights are nice but insufficient. It is necessary to establish such a legal environment with orders and regulations which will guarantee respect for the specific needs and demands of deafblind people.

Legislation must clearly and unconditionally comprise:

- a definition explaining deafblindness as a unique disability, which causes an adverse social situation for a deafblind person, and explains the need for specific social services.
- A law requiring:
 - a) social services to provide the services of a guide-interpreter, personal assistant, and other services;
 - b) a guarantee that technical aids for deafblind people are accessible; and
 - c) that communication shall be accessible in the format and language needed by each individual deafblind person.

Prague, October 30, 2003

We not only have a natural human right, but actually a duty, to get acquainted and interact with our environment.

Networks

ACQUIRED DEAFBLINDNESS NETWORK

c/o Ges Roelstone
Email: ges.roelstone@sonne-east.org.uk

CHARGE NETWORK

David Brown
California Deafblind Services
5016 Mission Street
San Francisco
CA 94112
USA
Email: dmbrown1@pacbell.net

COMMUNICATION NETWORK

c/o Jacques Szymanski
CRESAM
La Rivardière
62 rue de la Longe
95440 Migne-Auxances
FRANCE
Tel: +33 - 3 - 49 43 90 60
Fax: +33 - 3 - 49 43 80 51
Email: cresta.res@crecam.org

CONGENITAL DEAFBLINDNESS IN ADULTS NETWORK

c/o Dominique Spriet
30 Rue Barthelemy
F-93300 Aubry/Bois
FRANCE
Tel: +33 - 1 - 48 69 68 64
Fax: +33 - 1 - 48 69 68 64
Email: spriet.dominique@wanadoo.fr

EDBN

c/o Ursula Heinemann
Piazza Leopardi 7
60027
Osimo/AN
ITALY
Email: ursulaheinemann@tiscali.net

EUSN - EUROPEAN USHER SYNDROME NETWORK

Marilyn Kirby
c/o Sense
11-13 Clifton Terrace
London N4 3SR
UK
Tel: +44 - 20 - 7272 3862
Email: m.kirby@sense.org.uk

USHER SYNDROME STUDY GROUP (USSG)

c/o Mary Guest
Sense
11-13 Clifton Terrace
London N4 3SR
UK
Tel: +44 - 20 - 7272 7774
Fax: +44 - 20 - 7272 6012
Email: MGuest@sense.org.uk

INTERPRETING DEVELOPMENT NETWORK

c/o Kerstin Björk
AB Stockholmstolkarna
Horsögatan 74 A
116 21 Stockholm
SWEDEN
Tel: +46 - 8 - 658 39 00
Fax: +46 - 8 - 658 39 11

MULTIPLY DISABLED VISUALLY IMPAIRED EUROPEAN NETWORK

c/o Kent Lundqvist
Ekesvölans RC
Box 9024
S-70 000 Örebro
Tel: +46 - 18 - 676151
Fax: +46 - 18 - 6762210
Email: kent.lundqvist@rc.se

NORDIC CULTURE NETWORK

Lise Poggioni
Rørkvejsgade 47
DK-6700 Esbjerg
DENMARK
Email: enio@kve@post.tele.dk

TACTILE COMMUNICATION WORKING GROUP

Bernadette van den Tillam
15175 Prairie Road
South Salem
OH 43133
USA
Tel: +1 740 426 6728
Email: bernadettevandentillam@tactilemail.net

THE STAFF DEVELOPMENT NETWORK

Coordinator post: vacant

SIBLINGS NETWORK

Sabine Kersten
Email: siblingsnetwork@gmx.net

NETWORK NEWS

DBI Congenital Deafblind Network

Dominique Spriet, coordinator of the Network writes:

During the Canadian DBI conference we planned to try to get to know each other better! We felt that we needed to have more information about what others are doing. Recruiting staff to work in this area was an area of interest for all of us and the first question we discussed was how do we proceed to recruit our new members of staff? We started to debate this and different ideas were presented. So I am hoping that the readers of DBI Review will help us by joining in and answering this brief questionnaire. It will help us to get to know each other better!

Please contact Dominique at: spriet.dominique@wanadoo.fr

Name of the organisation: _____

Address: _____

Country: _____

Name of the responsible person: _____

How do you operate?

A day service: Yes ☐ No ☐

A residential service: Yes ☐ No ☐

A "home" for all year around: Yes ☐ No ☐

Have you a legal obligation of numbers of

days you provide the service, if yes how many: Yes ☐ No ☐

About the deafblind people

Number: _____

Sex: _____

Ages: _____

Levels of independence, communication, associated motor impairments associated psychological conditions, other associated impairments: _____

Activities

In the organisation: Yes ☐ No ☐

In the community: Yes ☐ No ☐

Rehabilitation

In the organisation: Yes ☐ No ☐

In the community: Yes ☐ No ☐

About the staff (Full time equivalents) (FTE)

Number of annual hours: _____

Total number of staff: _____

Number of persons in direct contact with the deafblind persons: _____

Number of administrative staff: _____

Number of maintenance staff: _____

Agency staff, if yes how many: Yes ☐ No ☐

Volunteers, if yes how many: Yes ☐ No ☐

Qualifications of the staff and number in each category: _____

Remarks and others questions: _____

The Usher Study Group

Highlights from the meeting held between 2-3 August 2003, Mississauga, Canada. Mary Guest reports:

The Usher Study Group (formerly known as the European Usher Study Group) met this year in Canada for two days just before the Dbl 13th World Conference on Deafblindness. The Group comes together every two or three years, to learn and to share experience on all aspects of Usher syndrome. To allow discussion and communication to flow easily numbers are kept to between 25-35. The Usher Study Group is open to anyone who is interested in deepening their understanding of the Usher syndromes.

During Day One, we looked at the future implications of scientific research for families with different forms of Usher. Advances in genetic science over the last decade have enhanced our understanding of Usher syndrome and other RP related conditions to the point where human clinical trials are imminent.

In his paper, Dr Bill Kimberling, Director of the Center for the Study and Treatment of Usher Syndrome, Boys Town National Research Hospital, Omaha confirmed that out of eleven genes known to cause Usher syndrome eight have been identified. The decoding of these genes has given scientists a much deeper insight into the real causes of Usher syndrome.

Medhi Sadeghi from the Department of Audiology at Sahlgrenska Academy, Gothenburg reported on two studies, one on hearing changes in Usher Type 2 and one comparing the functional state of vision between people with Usher Types 1, 2 and 3. He emphasised the importance that genotyping and phenotyping will play in understanding how a particular form may affect a person.

In her paper, 'Acadian Families and Usher Syndrome' Dr Bronya



Keats, Director and Head of the Department of Genetics at Louisiana State University described how history, the expulsion of the Acadians from French Canada in the 1750's and geography, living in the isolated bayous of Louisiana for nearly two centuries had led to a high incidence of Usher Type 1. Recent studies in Usher 1C gene mean that Usher syndrome can be diagnosed by genetic testing at an early stage in children with congenital deafness and Acadian ancestry which could lead to treatment for RP before the onset of symptoms.

Connie Miles, who organises meetings for Boys Town National Research Hospital for people with Usher to learn about informed choice, informed consent and scientific advances in Usher syndrome research, wound up our first day talking about ways of using scientific information to improve the quality of life for families. Children diagnosed early have specific information needs. As clinical trials become a reality for many families so will the information needs for families become even greater.

On our second day together Rebecca Atkinson shared her

personal transition from diagnosis to the reality of vision loss in her day-to-day life as a researcher in the broadcast media. This excellent and thoughtful provoking paper is reproduced in the Dbl Proceedings.

Anny Koppen, Director of the Nordic Staff Training Centre, Dronninglund made us a little envious as she spoke about the increasing sophistication and knowledge possessed by families receiving services. Professionals in Nordic countries are required to keep up-to-date with technology, legal changes and self-determination for people with Usher and need regular in-service training. Irina Salomatina, who heads up the Usher Forum Charity in Russia described the programme of social activities, visits to museums, restaurants, excursions to the country, which give deafblind people and guide/interpreters new experiences and lots of fun. All this achieved despite the political and economic upheavals over the last decade made us admire the tenacity of members of the Usher Forum in Russia.

People with Usher have a unique experience, which can be harnessed with training and support

to the benefit of others with Usher. In 2000 Sense launched the Peer Mentor Programme in the UK, which has shown how training people with Usher to be mentors can prevent unproductive lives, depression, give new direction and a sense of self worth both to the user of the service and to the mentor. The 'Training and Supervision of Peer Mentors', a paper by Chris Sherlock, is published in this issue of Dbl Review.

The results of a survey shared by Liz Cook on 67 people in six countries in Europe concluded that inspite of geographical and national differences the needs of Usher families were similar. As a result of meeting colleagues from four continents at this Usher Study Group we realized that people with Usher syndrome and their families face similar challenges wherever they lived.

Finally, Joseph Morrissey from Kenya challenged the whole group

with his description of the situation which faces deafblind people in Africa where Rubella is still a major cause. He asked that knowledge and expertise on Usher syndrome should be shared more actively in Africa, which is something that we are keen to respond to.

Post Script:

Mary Guest received the Dbl Distinguished Service Award for her outstanding contribution to the field (Editor)

The Siblings Network

Since the start of the Siblings Network in May of this year, the most frequent question I was asked was, why a Siblings Network? The answer in short is that siblings play a very important role in the lives of their deafblind brothers and sisters, but professionals who work with the deafblind and their families do not always recognise this. Sometimes even parents do not notice, as a lot of the things siblings do are regarded as "helping out whenever necessary". But growing up having a deafblind brother or sister is different and for most siblings it will

have a huge impact on their lives.

I am now in contact with a small group of siblings, all sisters, coming from Austria, Canada, Italy, The Netherlands, Poland, United Kingdom and the USA.

I went to the Dbl World Conference in Canada, where I was able to talk to a lot of professionals and parents. These discussions, all very positive, only confirmed the need for the Network and made clear that a lot of work still needs to be done. More awareness of the situation, which faces siblings, is needed.

Furthermore, I can announce a

National Siblings Evening in the Netherlands at the end of March 2004,

which will be organised together with Viataal. Based on this first meeting we will decide on how to proceed within the Netherlands.

For more information, I can be contacted by email: siblingsnetwork@gmx.net

Sabine Kersten



Acquired Deafblindness Network

Since the last edition of DBI Review the date for the next international seminar has been fixed for 6-10 October 2004 in London, UK. A prestigious venue has been secured in central London which satisfies all our requirements in terms of conference facilities for up to 200 people as well as considerations of access for deafblind and disabled people.

The seminar title is "Expectations, Opportunities and Possibilities" - exploring the relationships between people in

the World of Acquired Deafblindness.

The first announcement of the seminar was made, as planned, at the World Conference in Toronto in August. The ADBN ran a successful network day at the conference, attracting over 30 people. Discussion centred around feedback from the last seminar in Zurich in 2002 and links to the next event in 2004.

The ADBN co-ordinating group will meet in London at the end of October to commence detailed planning of the seminar programme.

We would be grateful to receive expressions of interest in presenting papers or workshops. Contact details appear in the first announcement of the October 2004 event later in the magazine.

Ges Roulstone



European Usher Syndrome Network

Following the Network sessions at the CAUSE conference in March and a presentation about the EUSN at the Dbl conference in August, we are pleased to announce that the total membership of the EUSN has expanded from 18 to 52. This includes people from Canada and Israel, as well as from several different European countries. The majority of the new members have Usher.

Peter Palmer has recently stood down as Chair of the EUSN because his family commitments have increased recently. On behalf of the EUSN, I would like to thank Peter for his interest in and work on behalf of the EUSN over the past six years.

The framework for the EUSN is currently being discussed. The new temporary Chair is Carol Brill Doran, who is also continuing as Secretary as well as being the

EUSN rep on Dbl Council. Marilyn Kilsby remains as temporary Treasurer. We hope to call elections within the next six months.

It's a time of change, so watch this space!

Marilyn Kilsby
National Usher Co-ordinator



EDbN: European Deafblind Network Report

The steering group of the European Deafblind Network met in London in March 2003. This was the first meeting to develop a new EDbN strategy to focus on key issues for the families as a priority.

Since then, all members have contributed to reaching the objectives that were agreed upon:

- Campaigning (led by Sense).
- Work is being done on two fronts:
 1. Recognition of Deafblindness at a European level: We intend to lobby members of the European Parliament during the first quarter of 2004. For more details please read the article by Lucy Drescher in this issue.
 2. Healthy Futures. To explore health issues associated with rare conditions that result in deafblindness, and to disseminate information that will lead to healthier futures for deafblind people. An application has been put in to the European Commission to fund this project.
- Network Co-ordination (by Ursula Heinemann). Co-ordination of areas of interest with Dbl, with the aim of disseminating information



and stimulating participation.

- Communication systems of the EDbN. The E-Group of the EDbN is functioning as a mail-list and allows members to access files and data. Several members were able to conduct surveys on different subjects of general interest. A new E-Group has been created and is open to everybody to receive the Newsletter and news. The official website remains www.edbn.org
- Liaisons (with the EDF and the WFDB): Wolfgang Angermann has been informing about all projects of the EDF. At the 13th Dbl Conference in

Canada, Ricard López was appointed as a member of the Dbl Council, representing the EDbN, and took part in the presentation meeting of the new Council, chaired by William Green, the new President. The Network takes this opportunity to congratulate our friends at the CDBRA for its excellent organization and friendship.

We look forward to the next meeting of the EDbN in June 2004, within the Family Event "Listen to Me 2", in Denmark.

Ricard López
Talking3@teleline.es
Catalonia & Spain

Launching the world-wide network for parents of deafblind persons

At the 13th Dbl World Conference in Canada, at the "Family Focus Group", I presented the paper "The World-wide Network for Parents and Families of Deafblind Persons". As a result of the subsequent conversations, the creation of a network for parents and families on a world-wide level was approved. The request for authorisation of such a network has already been made to Dbl, and at this time the supporting infrastructure is being created.

What are the reasons that convinced us of the necessity to take this step? Let me go through the motivations by summarizing the contents of my paper.

Our identity as parents and families of deafblind people

As parents, as families, we feel in our hearts the need to work for the present and the future of all children, our own and those of other families. Many of us have learnt that it is necessary to be present everywhere that discussions take place about our children and about

us. We must not leave this responsibility in the hands of others, but we have to accept it or share it, at any price. If we are not present at these meetings, the decisions that are taken do not respond to our real needs.

Families have to take care of all the needs of our children, but we are faced with a lack of resources of all kinds. It is necessary that all the programs designed to take care of a deafblind person include the support that the family needs. Often the family must assume excessive responsibilities to succeed in getting their deafblind son or daughter included in a school or social programme. It is especially hard to be the parents of a son or a daughter with congenital deafblindness and/or with added impairments. There are a lot of families facing this challenge. Problems of identification arise: is it deafblindness or is it not? In several countries persons are only identified as deafblind if the corresponding resources are available or the willingness exists to treat them as such. Otherwise they are classified as multiple-disabled or mentally challenged, and that's



Presenting the paper.

the end of the problem.

At times the professionals ask us questions about our needs and we do not know how to respond, because we are so used to forgetting about ourselves. Neither do we have the adequate training to address this subject.

For these reasons, among others, it is imperative that we parents and families accept our identity and work together to define the problems in all their dimensions, and work together with everybody involved to solve them. Personally I consider it desirable that this work be done in co-operation with the professionals and deafblind people who are willing to accept this challenge.



The audience.

The situation of the families of deafblind

The families with deafblind children (especially those congenitally deafblind or with added impairments) have leadership and representation problems. We find ourselves included in programmes designed by people who have only a partial or conditional view of our problems. We do not participate in the elaboration of the programmes; we only play a passive role in some services.

What are we doing?

Setting up a network with the purpose of:

- Sharing information.
- Co-ordinating activities across the network and lobbying.
- Training parent leaders with the capacity to co-operate with the professionals and to follow up on the programme implementation.
- Co-operating with Dbi. It is important that Dbi can dedicate part of its efforts in designing programmes for families and that at all Dbi Conferences families are present and our voice can be heard. We realise that the organisation of family camps associated with World Conferences is very complicated, but family participation is necessary, otherwise these conferences are primarily for the elite.
- Having the capacity for self-representation. The professionals have organisations and activities to represent them. A number of deafblind people have the capacity for self-representation and have, or are establishing, organisations and activities of their own. The only ones left out are us – parents and families, together with our children – without capacity of self-representation. It is necessary to become conscious that this tendency must change. The majority of families are not in a position to get together. Their lives do not give them this opportunity, but a few of us have



Above: Sheri and Debbie, President and Treasurer of the National Family Association for Deafblind of the USA.

Below: Nandita of the National Association for the Blind of India.



been able to get some training and we are aware of the needs and the opportunities.

How are we planning to take it forward?

Everyone interested can register to join this network, applying to talking3@teleline.es.

We need all parents and representatives of deafblind children and adults to register as contact parents.

1. The contact parents will communicate among themselves by e-mail (within the frame of a specific mail list).
2. The people signed up will be the link between themselves and other parents and representatives.
3. Everybody signed up will have access to all working documents



Above: Leanne of Sense UK.

Below: With Marjan van Kemenade of the Netherlands after the workshop.



- from an internet website.
4. A 3-monthly newsletter will be sent to comment on the work done during this period.
5. The official languages will be English and Spanish.

Ricard López, Father of Clara (11 years, congenitally deafblind)
talking3@teleline.es

APSOCECAT Catalan Association for Deafblind Persons
www.xarxabcn.net/apsocecat

APASCIDE Spanish Parents Association for the Deafblind
www.apascide.org

EDbN European Deafblind Network
www.edbn.org

Dbi Deafblind International
www.deafblindinternational.org

The CHARGE Network

The CHARGE meeting at the World Dbl Conference in Toronto was very well supported, with the room full to overflowing and with many families present. The day opened with a wonderfully clear and compassionate introduction from Nancy Hartshorne, herself a parent.



Nancy Hartshorne

From then on the discussion and questions flowed freely with everyone in the room taking an active part.

David Brown, Tim Hartshorne, Ann Gloyn and Dr Kim Blake were present, and as an extra bonus, they were all making presentations as part of the main conference programme.

At the business part of the meeting the resignation of David Levey as Network Co-ordinator was discussed. After several years in this post David felt it was time for a change but he will remain an active member of the Network.

The decision was taken to put together a small core group to administer the Network.

Most importantly, there will be an email listserv for the Network with David Brown as Secretary. The main thrust will be information and

questions about practice and research. It will have a more 'professional' orientated direction.

This is quite different from the support function of the existing CHARGE listserv, which is more 'parent sharing'. But anyone interested in knowing more about CHARGE will be able to subscribe. The listserv membership will also help in the planning of CHARGE events and meetings to be held at upcoming Dbl European and World Conferences.



David Brown

Tactile Communication Network

Bernadette van den Tillaart reports:

The Network members have been very active. During the last year we met 3 times. In December 2002 we met in Norway where Knut Johansen, Director of the Andebu Dovblindesenter in Norway, hosted our Network.

The main question (which had been set before) was: "How do congenital deafblind persons develop social concepts by the tactile mode?"

In August 2003 at the Dbl conference in Toronto we shared our first ideas and videos with many participants at a well-visited Network Meeting. Their contributions were very fruitful. Last October the Network was hosted by Erika Steiger, Director of Zentrum Tanne of Die Zweierische Stiftung für Taubblinde. The last year's processes led to the following thoughts:

We are interested in how deafblind persons build social concepts in a tactile way. We hope that this understanding will help us

to broaden our social concepts through the enrichment of the deafblind persons. On the other hand it may help us to share our social concepts with deafblind persons, so that our concepts will enrich and support their lives.

We hypothesize that mutual tactile attention – touching and exploring things together and experiencing shared bodily movements – affects a deafblind child's concepts of the physical and social world around him, and vice versa: the physical world in which we find ourselves with the deafblind person (and/or which we create with him) affects our shared social experiences.

We invite Dbl members to share your ideas and experiences that might be relevant to this effort to map a deafblind person's tactile world. Here are some questions which might inspire your thinking:

- Have you made maps (either drawn or mental) of what a particular deafblind person's

experience of their physical and social (narrative, story) world might look like from their perspective? Or – if you are a deafblind person – can you draw such a map of your own experience in your near world?

- For an individual young child, do he/she have a mental map of how large his/her (bodily, social) tactile world is or how far it extends beyond his/her own body? Can this be represented on a map that may be meaningful to others?

We are grateful for any thoughts, drawings, maps, photos, videos that might help us in our thinking.

The Tactile Communication Network hopes to meet again in Spring 2003.

Email: bernadettevandentillaart@tiscali.nl





Slovakia and Ukraine

Partnership with Ukraine!



Janka Šarišská and Mária Podhájecká relate the start of an exciting partnership across national boundaries.

The Boarding School for Deafblind Children in Cervencia, Slovakia has created a new project with the Boarding School for Deaf Children in Uzhgorod in the Ukraine. The title of the project is *Partnership for enhancement of services for the deafblind population in Ukraine*. The people behind the project are Mária Podhájecká from Prešov University and Janka

Šarišská, Director of Deafblind School in Cervencia.

The project will develop:

- ◆ through an exchange of information and good practice and the transfer of experience. Its aim will be to improve the services to the deafblind and their families as well as to improve their social integration. The work from Slovakia will be applied to all deafblind people, but youth in particular, parents, local and country authorities etc. Special attention will be paid to equal opportunities and gender equality for the multi-handicapped deafblind. The project's objective is also to initiate a parents organisation.
- ◆ through enhancing its experience with deafblind people by establishing links with other professionals in CE, CEECs, CIS and, if possible, anywhere else in the world. The sustainability of the project will develop as the Deaf School of Uzhgorod becomes part of an international network, dealing with deafblind issues. This will enable the institution to benefit from

all available information and experience developed abroad.

We started to realize this project in August. On our first visit to Ukraine we found that there are really no services for deafblind children and adults. We prepared a seminar with the topic *The Upbringing and Education of Deafblind Children*. The participants were the professionals from the Deaf School in Uzhgorod and professionals from deaf and blind schools from the Ruthenia Region in Ukraine. Also in attendance were the parents of deafblind children, representatives of the local authorities and professionals who work with multi-handicapped children, youth and adults.

The presentations covered a wide area including an introduction to deafblindness, developing service provision, considering the family and working with multi-disabled children. We have now established that:

- ◆ there is a group of deafblind people and families in the Ukraine who need services;
- ◆ it would be useful to do a survey in the Ukraine to find how many deafblind people there are; and
- ◆ we need to find out what their lives are like and what kind of services they require.



**Poland**

Justyna Korzeniewska from the Association for the Welfare of the Deafblind in Poland gives us just a taste of the fantastic time the holiday participants had when they were guests in this welcoming country

Welcome to Poland!**European holiday destination – 2003!**

This year the Holidays for the Deafblind took place in Poland between 16-23 August 2003. We had great pleasure in inviting deafblind people from other European countries, such as Belgium, the Czech Republic, Finland, France, Holland, Italy, Russia, Sweden and Switzerland. There were 20 deafblind people with 21 guide-interpreters and, in addition, 16 deafblind people from Poland.

The initial idea behind these holidays for deafblind people was to provide an opportunity to exchange personal and professional experiences, to introduce different cultures and people as well as enjoying a chance



for active recreation. We focused on this when we organized the holiday. We planned to show our guests the culture and history of Poland. Therefore, we offered sightseeing tours to Old Towns in Warsaw, Torun and Kolobrzeg as well as guided tours around these cities. We also wanted to present traditional Polish art (during workshops) and typical Polish food.

The integral part of the Holidays for the Deafblind 2003 was active recreation. This included walks on the beach, a visit to the "Indian Village & Small Zoo," water sports, a trip to the "Gallery of Gardens", and even driving military vehicles!



Following the keynote theme of the International Holidays for the Deafblind, we learned a lot about different cultures, countries and nations. We got this knowledge from everyday contacts as well as from the "Evening of National Presentations", prepared by each country. The biggest surprise for us was that we also learned a lot about our own culture, country and our Polish deafblind people! Most of them do not speak English very well and do not have much experience of international contacts. We were worried that they would be too shy to initiate the first contact with the foreign guests. We were so impressed when they asked





kasza) were their favourites!

What about professional experience? We observed many various styles of guiding by guide-interpreters of deafblind persons. Every helper presented a high level of professional skills, and used similar methods, but with different styles! We can say that each country has its own guide-interpreters school. Another major discovery of this holiday was finding out how popular "LORM" is with deafblind people! Some of the participants learned this method during a few days when they spent time with others who knew it very well.

We had a wonderful time and we wish the countries



which will be organizing the International Holidays for the Deafblind in the future, a lot of good days and a very special time!

Justyna Korzeniewska
Association for the Welfare of
the Deafblind
ul. Konwiktorska 9
00 - 216 Warsaw
Poland

for extra time for meetings with the international group; they were so open and really interested in making new friendships across nations and languages. We were also surprised by the amount of new information and experience about our own country we got from contacts with people from different countries. We learned from them that our country is big and traveling through a half of it in one day (it was one of the points of the program) can really be a big adventure. We also changed our mind about Polish food. Actually, it was not the most famous and typical Polish meals which got top approval from our guests. Some of our every day meals (like for example



**Kazakhstan****Timur
Timirkhanov**

In the last edition I was able to announce that the Kazakh Foundation "Meyrim" was starting its own newsletter. It's called "Gleam". If you would like to receive a copy in pdf format please get in touch!

I would like to ask for advice from the readers of Dbl Review as I am interested in finding out more information about deafblindness and deafblind people. I would like to be pointed to sources, like

the Internet and mailing lists that operate in English. I would particularly like to hear about excellent sites, where I can find the information I am seeking.

timirkhanovs@nursat.kz

Russia**Irena
Salomatina****'Hope' at the very edge of Europe – 'Omat' is launched!**

There is a Russian city called Ufa at the very edge of Europe, in the southern Urals. Ufa is the capital of the national republic – Bashkiria. In April 2003, thanks to the active work of Bashkirian deafblind people and their families, another independent charity supporting deafblind people in Russia was born. In Bashkirian it is called 'Omat' which is 'Hope' in English.

"Our organisation was born by parents of deafblind children and deafblind adults" says Nina Urlova, Deputy Director of 'Omat'. "People who know everything about pain, ignorance and pressure became the leaders of the charity. They can feel others' problems better and know how to say the most supportive words". 'Omat' was founded by 11 people: 3 parents of deafblind children and 9 deafblind people. The mother of a deafblind girl – Svetlana Vavilova – became



the Director of the charity.

'Omat' outlined two priorities for the near future. The first is to identify deafblind people in the city of Ufa and the Republic of Bashkiria and create a database, and secondly to develop medical services for deafblind children.

Meanwhile, deafblind people and their families celebrated the foundation of the organisation. A birthday party gathered together deaf, deafblind and blind friends,

their family members and supporters. Women baked cakes and biscuits and men prepared a music and dance programme! Champagne was sparkling to mark the event... people even joked: "Could those people be deafblind? – they danced and sang so happily!"

We are happy to say that this extraordinary event took place thanks to partnership from Sense International and Usher Forum (Russia). It was funded by CAF and DFID.

**The
Philippines****Dr Yolanda
Capulong
writes:**

The deafblind programme is based at the Philippine School for the Deaf and is one of a number of programmes for children who are deaf with additional disabilities. The school is working on the curriculum to include a transition programme to prepare the children for their post-school lives.

We are also looking at ways of developing an intervenors group and more

advocacy to advance the cause of deafblind people in the Philippines. The Hilton Perkins International Program and the Perkins School for the Blind are supporting us in the areas of teacher training and information.

They have a wonderful facility which the deafblind children share with deaf children which was built and equipped by the HSBC Bank.

**Dr Yolanda Capulong**



School of Sign Language for Parents

Since several years ago, we began organizing "classrooms" for teaching Sign Language to parents of deafblind people. Classes are taken usually weekly during the school calendar, and we have a lot of fun and communication. In this way, families are helped to communicate with their deafblind sons and daughters without too much effort. Simultaneously, links among families are tightened. We encourage families to participate in these particular "schools".



Spain

Juan Carlos
García,
APASCIDE,
writes:

Apascide Aragón

Apascide Aragón was founded in 1996 as an association to provide resources to individuals, families, friends, and communities affected by deafblindness. As an association of family and friends of deafblind people, all are welcome to participate in Apascide Aragón's endeavours. The association's project, entitled "Proyecto para la integración y desarrollo del sordociego" (Project of integration and development of the deafblind individual), aims not only to help those in Aragón but also intends to serve as a reference for associations established in other regions in Spain. One of the project's main initiatives includes the establishment of a professional course and continued education for those working with deafblind

individuals. Apascide Aragón also looks to provide a library of resources about therapeutic, educational, and medical options available in Spain and internationally.

Additionally, the association aims to provide individuals and their families with counselling services, assistance with various types of residential and daily living requirements, and rehabilitation and recreational activities that emphasize tactile and communication skills. One of the association's central goals is to provide trained mediators who can guide the family in practices that continue the education and the social integration of the deafblind individual. By continuing to expand its efforts, Apascide Aragón hopes to be able to specially prepare community volunteers to be able to work

with deafblind people.

More than fifty professionals have participated in the association's initiatives, and it has maintained contacts with local, regional, national, and international organizations for deafblindness as well as with associations representing cochlear implantation.

A public organization, Apascide Aragón is currently looking to strengthen the structural and economical base for its initiatives. In this developmental stage, the association would appreciate any support or advice that peer organizations in other parts of Spain or elsewhere in the world might be able to offer.

Emails are welcome and may be sent directly to the association using the address apascide-aragon@wanadoo.es.



Latin America

Graciela Ferioli writes:



Celebrations in Argentina

On November 8, 2003, the Instituto "Fátima" in Buenos Aires celebrated its fifteenth birthday. The staff and families developed several activities with the children, families and friends. It was a great and enjoyable day!

A new CD in Spanish!

A new CD with materials produced in or translated into Spanish has been launched! This CD has articles covering topics on Curriculum, Assessment, Communication, Sexual Education, Research and others. It will be distributed all over Latin America to programs to provide updated information to professionals and parents who are interested in the field of deafblindness and multi disability education. This CD was made with support from the Hilton/Perkins Program through a grant from the Conrad N. Hilton Foundation.



Anniversary of the Argentinian Parents for Deafblind people Association.



10th Anniversary!

November 9, 2003 was the 10th Anniversary of the formation of the Argentinian Parents for Deafblind People Association. The Association celebrated with a range of different fun activities. Mrs. Clara Berg from the National Family Association for Deaf-Blind, USA, was guest-of-honour and hosted the ceremony. She made a presentation on "What parents of young adults who are deafblind want to know about their future?"



India

**Dr Bushan
Punani of BPA
writes:**



As you know BPA and Spandan started working jointly immediately after the devastating earthquake of 26th January, 2001 to provide a variety of services to people of Kutch District affected by the earthquake. Both of these organizations decided to set up a permanent rehabilitation unit named "Kutch Comprehensive Rehabilitation Centre" to provide services like

physiotherapy, provision of ortho-prosthetic devices and other support services to persons with disabilities on a permanent basis.

Thanks to numerous donors, supporters and well-wishers the construction of the building has been completed and all the departments have started working from our new campus. It is our proud privilege to say that the technology being used at the

centre will provide high quality services to earthquake-affected people.

Blind People's Association

Jagdish Patel Chowk
Surdas Marg
Ahmedabad 380 015
India

Tele: +91 79 630 3346

Fax: +91 79 630 0106

Website: www.bpaindia.org

Venezuela

**Maria Luz Neri
deTroconis**



SOCIEVEN Sordociegos de Venezuela was set up in 1995 to support deafblind people and their families as well as multiply disabled people who would also benefit from their programmes. The people they serve all experience severe communication difficulties, and their work is dedicated chiefly to the congenitally deafblind.

SOCIEVEN also supports and works with the Center for Integral Attention of the Deafblind (CAIS) set up in 1995 by the Department of Education, Culture and Sports, and ORVES the Venezuelan organisation for older deafblind people, also established in 1995. SOCIEVEN obtains technical

support from the Hilton Perkins International Program and financial support from the Mayor's Office of Chacao.

SOCIEVEN is part of ULAC, the Latin American Union for the Blind, and is linked with ONCE the National Organisation for the Blind of Spain and is also supported by the Mayor's office in Baruta.

Demography

They estimate that in Venezuela there are approximately 4,000 children, youngsters and adults who have congenital or acquired deafblindness. So far around 300 deafblind people have been located. During the seven years since

SOCIEVEN began much has been achieved to advance the cause of deafblindness, but they are conscious of how much more remains to be done.

The state of the country's economy has had a great impact on the work of the Association.

Mission

"To build, with deafblind and multiply disabled people, their families, professionals, members, national and international organisations, and the general community, the place that deafblind and multiply disabled people deserve in Venezuelan society, striving to improve their quality of life and that of their families."

Canada

**Stan Monroe
reports:**



Deafblindness Demographic Study

The Canadian Deafblind and Rubella Association (CDBRA) and the Canadian National Society of the Deaf-Blind (CNSDB) are partnering on A Study of Deaf-Blind Demographics and Services in Canada. This project is funded through Human Resources Development, Canada and will be completed by June 2004.

The purpose of this project is to produce a report which is essentially a directory of resources containing detailed information about the demographics of persons who are Deafblind in Canada, a list of accessible services and resources, commentaries on the current status of this disability and future directions. Research

Assistants are being located across Canada to collect demographic information and to conduct Focus Group meetings. An important component of this project is public awareness. Media activities will be implemented to create better national awareness of deafblindness and to promote the project in advance of the field research.



Colombia

A job from the heart



Deafblind young people are living more fulfilled lives thanks to volunteers. Marcela Forero tells us all about an exciting new project.

In Colombia, the volunteer programme of Sense International (Latin America), created to support the rehabilitation process and fulfil the needs of the deafblind people, is successfully being developed.

To wake up one day with the sun in your face and not to be able to see or feel the wonderful things that are happening around you, is something that cannot be easy to cope with. This is why one hundred and five Colombian volunteers from varied backgrounds give their time, effort and skills to act as



the eyes and ears of those who, due to varying acts of fate, are deprived of the opportunity to enjoy the privileges that many of us just take for granted.

But, what is the motivation that drives these men and women who, without any economical benefit, give their time in the same way that a mother would do, and be there to share the little steps taken day by day by these young adults during the process of rehabilitation? The answer, although it seems quite complex, can be found

in the most fundamental part of the human being: namely, the heart. This is the engine which seems to compel these volunteers! The power from the heart may be represented by a pleasant smile, one word of gratitude, or simply, the silence of a look on completion of an arduous joint task.

Thanks to the tireless effort of these volunteers, the Centre of Integration for Deaf-Blind Young-Adults, called "Yolanda Rodriguez", was officially opened on 22nd May 2003. This centre is managed by the Colombian Deafblind People Association (SURCOE) with the support of Sense International (Latin America). From day one, they exclusively focussed on the achievement of social integration of deafblind people and their functional independence. Additionally, a group of 32 volunteers support the Educational Programme CELIVIA in which they contribute to the development of almost 20 deafblind and multidisabled children.

The union of these hearts was the result of the dream of a few people. After





overcoming a number of initial difficulties, they managed to bring together various individuals – young people, adults, professionals and housewives – and worked to raise their awareness as well as equipping them with the necessary tools to carry out this noble endeavour.

Of the 180 people who applied to work as volunteers, 105 managed to finish the training process successfully. The successful volunteers received the coveted volunteer qualification (junior class) in February and 9th August this year. This will feed the flame leading them to the path of a special world inhabited by people who will benefit from their work.

At the present time, the group is stronger thanks to the seeds that have been planted in different committees and projects, which have been useful in not only directing this boat towards efficiency, but also in acquiring the necessary human resources in a country where the people and the international community are



crying out for a change.

And because good things are worth emulating, another initiative has been launched to bring in new recruits wanting to contribute to the building of our continent, and likewise, wanting to defend the rights of the deafblind children, young people and adults at other institutions in Colombia. Shortly, this centre will push back the frontiers when the programmes of Peru and Brazil join with it. It is envisaged that this collaborative venture will adopt this new way of working, which simply involves individuals committing themselves with all their hearts to work for the benefit of others, forgetting

the differences or limitations that may exist between human beings, and in unity overcome all the difficulties that are currently overwhelming Latin America.



For more information please contact Marcela Forero, Development Manager, Sense International (Latin America), mforero@senseintla.org





Slovakia

Group Home For Deafblind Adults in Slovakia



Peter Fasung,
President of
the
Association of
Parents and
Friends of
Deafblind
Children in
Slovakia
reports:

There isn't any project that deals with the complex care that deafblind adult in Slovakia require. The kind of care we are talking about includes the educational element for deafblind children. The results of 10 years educational work with deafblind children in Cervenica proves that they can be educated as well as anyone else. At this time there are 12 students at school.

In 1998 The Association of Parents and Friends of Deafblind children in Slovakia was established. One of its main priorities from the start was to create dignified conditions for deafblind people as they grew from children to adults.

Nowadays the school provides our children with a good standard of education but nobody has solved the situation of what will happen to the children when they reach the age of 18 years. The big question is where to go after school leaving age. Deafblind adults have two choices – to live with their parents or to live in the huge homes run by the social welfare department in

Slovakia. Both choices are unsatisfactory as the children will inevitably lose the knowledge and skills acquired at school because of the lack of the meaningful activities. We know that our children will continue to need communication support otherwise behaviour problems will arise. We don't want to let that happen!

In 2001, in co-operation with the parents association and school in Cervenica a pilot project was created, which is designed to establish a support programme for community living for deafblind and multi-disabled adults as they leave school. Assistance will be provided to each deafblind individual in order that they can use community services to ensure maximum development of independence skills, so they can live their lives as a full-value member of the community. All parts of their home will be adjusted to the needs of these individuals and full or partial assistance will be provided with respect to the intensity and extent of the disability.

So, I am happy to say that

we are making progress! We are really excited about it but we had no idea how much effort and labour would be needed to realize this excellent idea! We have started to look for a proper house and we have succeeded! It is large house with the garden and is suitable for 6 – 10 people.

The hardest part of our work was to get money to purchase house. In spite of a huge effort from all involved people we could not to put together the whole sum of money. We still are still looking for 25,000 Euros.

The parents association and the school cooperate very closely with the Blind and Partially Sighted Union in Kosice and local government. Our foreign partners are Hilton / Perkins International, Sense International and DbI.

We are at the beginning of the realization of our project, but I believe that we will be successful, because we are determined to create the conditions for a great life and educational development of all our deafblind children in Slovakia.

Peter Fasung

New Zealand

Great news from New Zealand! Jan Scahill, a founder member of Deafblind NZ Inc, has been awarded the Queen's Service Order in the birthday honours list. Only a very few people each year receive recognition in this way and this is well deserved. Jan edits the See Hear! magazine – which shares the news about the many activities which happen across New

Zealand, courtesy of Deafblind NZ.

Meetings are held all over New Zealand. Deafblind and vision/hearing impaired people meet together for social activities which include chat sessions, guest speakers and visits to places of interest. Have a look at the web site!

www.deafblind.org.nz

European deafblind people form their own Union!

Denmark was the host to 32 deafblind people from 18 European countries in October 2003 when the founding meeting of the European DeafBlind Union – EDbU – was held. The event took place at the training centre of The Danish Association of the Blind in Fredericia.

It all began in 1999 when the Nordic deafblind associations got the idea of starting a union, and with the Danish chairman, Ové Bejsnap leading, they have been working on the project since then. Working together this group of deafblind developed the constitution for EDbU.

The aim for the union is to improve conditions for the deafblind people all across Europe. At present, deafblind people have different services in each country. In some countries deafblind people don't have their own association, but belong either to an association of the deaf or the blind or organizations run by professionals, rather than deafblind people themselves. This means that deafblind people are not part of the decision making process that relates to their own needs.

Naturally, it is difficult for



William with Stig Ohlson

deafblind people to have a powerful voice and as a result, it is also difficult for them to raise money for their activities. For example, deafblind people from several countries were not able to attend the historic meeting in Denmark either because they do not have the money for the travelling expenses or because they cannot get interpreters or practical assistants.

Deafblind people from Bulgaria,

Turkey and Netherlands among others were not able to join in, even though they do support the establishment of EDbU.

Denmark's achievements!

In Denmark deafblind people can get a personal assistant to help with practical things which they find difficult to do for themselves. The latest news is that a pilot project, providing free interpreter services to deafblind people in social occasions like family parties and meetings at school, will be made permanent.

Legislation about support for deafblind people is very different from one country to another, and with the help from the new union deafblind people should expect to be able to influence the politicians to improve conditions.

Audit of Services

One of the first tasks for the European Deafblind Union will be to get an overview of the services available in each country.

After such a successful first meeting the EDbU is off to a fine start!



Ové Bejsnap (right)

Helen Keller International Award 2004

Presented for the best submission of artwork in any medium, on the subject of deafblindness



Sense Scotland invites submissions from artists working in any medium for the 2004 Helen Keller International Art Award. The competition is open to any artist, with the only criteria being that work submitted must be on the subject of deafblindness. A panel of independent judges will carry out

judging and the identity of artists will remain undisclosed until judging is complete.

The winner of the 2004 Helen Keller International Art Award will receive a trophy and a cheque for £1000. Two highly commended entries will each receive a certificate and cheque for £200. Further commendations may be made at the discretion of the judges.

How to enter:

Artists wishing to submit a piece of work to the competition must complete an entry form and return this to Sense Scotland. Alternatively, you may enter the competition online at www.sensescotland.org.uk/helenkeller

- The closing date for entries is 30th January 2004.
- Sense Scotland must receive finished artwork by 30th July 2004.
- All artwork should be sent to:

**Sense Scotland, 5th Floor,
45 Finnieston Street,
Glasgow G3 8JU**

For entry forms or further details about the award contact

Lindsay Mitchell
Arts Development Officer

Phone 0141 564 2444

Email arts@sensescotland.org.uk

Further information/images contact

Graeme Thomson,
Communications Officer:

Phone 0141 564 2444

Fax 0141 564 2443

Mobile 07717 133538

Email
gthomson@sensescotland.org.uk

Website
www.sensescotland.org.uk

Sense Scotland is a Company Limited by Guarantee.

Registered in Scotland No: 147570.
Scottish Charity No. SCO22097.

Scottish Patron: Mary, Countess of Strathmore.

ENTRY FORM AND RULES

Sense Scotland presents

Helen Keller International Award 2004

for the most inspiring submission in any art medium on the subject of deafblindness

"The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart."

Helen Keller

CONFERENCE NOTICE

FIRST ANNOUNCEMENT

5th European Seminar of the Acquired Deafblindness Network

“Expectations, Opportunities and Possibilities”

Exploring the relationships between people within
the world of acquired deafblindness

6 – 10 October 2004 in London, UK

Theme: This seminar will review the relationships between people in the world of acquired deafblindness. We will be exploring ways to improve services to people with acquired deafblindness.

As part of this process we will discuss the expectations of deafblind people, what opportunities can be created and how together we can turn possibilities into realities.

The Acquired Deafblindness Network: The Acquired Deafblindness Network is recognised by Deafblind International (DbI) and was established in 1989. Its aim is to create and support a network of people who are involved in the world of acquired deafblindness. For this reason, a seminar about “Acquired Deafblindness” has been held every two years in a different European country since 1994.

Sense: Sense is the national deafblind charity that supports people who have both hearing and sight difficulties. Sense offers a wide range of support and services across the UK to help deafblind people of all ages to reach their potential. This includes advice, support and information for people who have developed hearing and sight loss in later life.

The complete seminar programme and registration form will be available in April 2004

Sense East
72 Church Street
Market Deeping,
Peterborough
Cambs, PE6 8AL, UK

If you require this information
in another format or further
details please contact:

Tracey Cook
tracey.cook@sense-
east.org.uk

Telephone:
+44 (0) 1778 382230

Textphone:
+44 (0) 1778 382266



NUD Conference

Developing communication in congenitally deafblind children with cochlear implants

8-11th September

This conference is organised to present and discuss both the theoretical and experience-based knowledge on the development of communication in congenitally deafblind children who have cochlear implants.

Target participants are staff in pre-school and school programmes, as well as supervisors and consultants.

For details please contact:

The Nordic Staff Training Centre for Deafblind Services (NUD)
Slotsgade 8, DK-9330, Dronninglund, Denmark
Nud@nud.dk
www.nud.dk

NUD Courses

Basic rehabilitation for persons with acquired deafblindness

1-6th March 2004

The training course will provide knowledge about combined severe hearing and vision loss and its consequences for a person's communication access to information and orientation and mobility. This course is suitable for workers in direct services and will include a variety of simulation exercises and concrete examples.

Children with hearing and vision impairments in pre-school and school programmes

12-15th May

This is a conference planned to present and discuss information about how to adapt the learning situation for children in pre-schools and schools who are becoming deafblind. Target participants are staff working in schools and kindergartens, as well as their supervisors.

CONFERENCES

2nd European Family Conference Slettestrand, Northern Jutland Denmark 20th - 26th June 2004

A Family Event: "Listen to Me 2 - in Denmark"

Communication through Danish Culture and Nature

The Dbi Networks: Nordic Culture and Edbn members, as well as Sense International and the Hilton/Perkins Programme are pleased to invite you to another international gathering of families.

The conference is for parents and their children from Western, Central and Eastern European countries.

As with other conferences in the past this conference will allow parents to discuss and exchange experiences and information on a wide range of issues concerning family life. The scientific planning committee is:

Lone Poggioni (Dk)
Gill Morbey (UK)
Ursula Heinemann, (A)
Klaus Vilhelmsen (Dk)
Preben Gundersen (Dk)
William Green (I)
Frank Ulmer (Dk)
Ricard Lopez (E)

This group are in the process of finalising the programme, which promises to create an exciting basis for discussion, and follow up the thoughts originating from the family event in Italy last year. The group are also looking for a new design for a Logo to represent the theme of "Listen to Me" as it is an event planned to take place every two years.

Dates

The arrival date is 20th June and departure on the 26th June 2004

Venue

Slettestrand holiday centre is in a beautiful part of Jutland and is only 250 metres from the sea. Travel is normally via Aalborg which is easily accessible by train, plane or car.

The centre offers a wide range of activities catering for many tastes. Accommodation can be in rooms for up to 4-5 people overlooking the sea. There are areas designed for children to play games. For further information about the centre can be found at www.slettestrand.dk

Participants

For the purposes of registration a "family" is up to four members: parents, their sensory impaired family member and one assistant of the families choice.

Programme outline

In fact there will be many parts to the programme:

- ◆ Parents meetings and conferences
- ◆ During these meetings their children and assistants will be able to participate in artistic/musical activities designed for

them and led by experienced artists in areas such as sculpture, music and dance, drama or handcrafts and much more according to needs and choice.

- ◆ Programme for siblings
- ◆ Visits to services for deafblind children and adults

There will be time for sight-seeing excursions, artistic activities or just simply having a break and relaxing all together.

Excursions can include shopping, boat trips etc.

Costs

The Planning Committee is in the process of examining funding possibilities to keep the price accessible for everyone and to ensure the participation of families from central and eastern European countries.

For more information, to suggest a logo design or to announce your interest please contact as soon as possible

Lone Poggioni
enrico-lone@post.tele.dk

13th Deafblind International (DbI) World Conference Update

Canadians reflect on their success!

Stan Monroe

The 13th Deafblind International (DbI) World Conference was a huge success. Conference organizers were thrilled to host 557 delegates from 48 countries at the Delta Meadowvale Hotel in Mississauga, Ontario from August 5 to 10, 2003. This was the first time in two decades that North America has hosted this international event and the first time in Canada. The theme of the conference was

"Communication is the Key to Opening Doors Worldwide for Persons who are Deafblind".

There were so many activities throughout the week that it is difficult to describe them all in a small article. But just a few highlights for those who were not there:

- ◆ The Conference Opening was a memorable affair which began with the National Anthem sung in Canada's two official languages,

English and French. This was followed by the Flag Ceremony, with a flag representing each country carried in by a flag bearer, reminiscent of the Olympic Games.

- ◆ Conference delegates were welcomed by Hazel MacCallion, the eminent mayor of Mississauga Ontario.
- ◆ The Founding Members of CDBRA were recognized and those in attendance were presented with a certificate.



The vast array of foods from Canada served at the reception.



- ◆ The book 'Perceptions of Light – Canada', a photographic documentary of Canadians who are deafblind produced by Natalie Schonfeld was launched and Natalie made a video presentation of some of the contents of the book.

Following the Official Opening Ceremonies, delegates were treated to a vast array of Foods from Canada as part of the successful meet and great reception!

Plenary sessions

"Communication plays a critical role in opening doors to Deafblind people in everyday life," says Michael T. Collins, President, Deafblind International in his opening address at the initial Plenary Session. "This conference gives us an opportunity to promote cooperation, add to our knowledge and open doors to the future for Deafblind individuals around the world." Michael's plenary session entitled "Celebrating Communication Around the World" featured presenters and short films from Slovakia, Costa Rica, India, Kenya and Canada to indicate the progress made in providing services for persons with deafblindness in all corners of the world.

Highlights

The collaboration of CDBRA Chapters from British Columbia and New Brunswick/PEI promised a very rewarding family social event one evening. Parents and siblings from Canada, USA, England, Wales, India, Netherlands, Poland, Spain, Brazil and Argentina had an



The Conference Opening Ceremony

CONFERENCE NEWS



opportunity to socialize with refreshments and music.

Another of the many highlights included Stephen Lewis speaking on *The Global Fight Against Disease: The Impact of Quality Services*. Mr. Lewis is the former Canadian ambassador to the United Nations and he currently is the UN Envoy to HIV/AIDS in Africa. He spoke about the need for organizations to be advocating for the rights and needs of people who are deafblind on a world wide basis especially since deafblindness as a very low

incidence disability, it often does not get the attention it requires.

Workshop sessions

The conference delegates had the opportunity to attend 130 Workshop sessions, 32 poster sessions, 21 program displays, numerous commercial exhibitor and vendor displays, "Ask an Expert" consultations and creative exhibits from artists who are deafblind.

Audio and video tapes were made of the sessions and are

available for sale at the following website: www.cmcgc.com/030806.

Presenters were from both the developing countries and developed countries, each sharing their own unique cultural expertise. Some of the presenters included: Dr. Jude Nicholas, from Norway, who is a leading researcher on neurophysiological issues related to deafblindness, especially congenital rubella syndrome.

Time to unwind

Conference attendees had the opportunity to unwind and choose one of three tours: a visit to Niagara Falls, a tour of Toronto or attend a dinner theatre by the Famous People Players, a theatre production company that has traveled around the world and consists of many persons with disabilities. Listening to some of the stories the following day all appeared to have a great time.

At the Closing Banquet, two Canadians received prestigious awards. Cherry Bulmer won the Annie Sullivan Medal for her many years of volunteer work on the National Board of Directors of CDBRA, as a co-author on *WINGS: A Model of an Integrated Lifestyle*, a book about her adult daughter who was born deafblind and as the long-time editor of *Intervention*, the newsmagazine of CDBRA. Stan Munroe won the Distinguished Service Award for his many years as president of CDBRA, and as the chief researcher of two projects – *The Late Emerging Manifestations of Congenital Rubella* and *Results of a Volunteer Registry of Persons who are Deafblind, 1999–2001*.



Linda Mamer

Greetings from John and Jacquie McInnes!

We have just received our *Dbl* review, *Talking Sense and Intervention* magazines and have had a chance to do a quick read through all three. It's so exciting to be able to keep abreast of all the wonderful things that are happening around the world. We will have many hours of reading and imagining in our hearts and minds what it would be like to be able to travel and personally share these happenings with each of you. Thank you to you all who take the time to send in reports. It is a means of "caring and sharing" which lifts the spirits when things get difficult and gives us all a chance to feel good about what they are doing right.

We were unable to attend the latest World Conference, but have been assured by good sources that it enabled many people to renew their strength and head back home to fight on.



Our love and admiration goes out to you all who are taking up the challenge and ensuring that deafblind individuals in your part of

the world are receiving a chance to reach their potential.

Many thanks for taking time to care and share!"

Living with CHARGE

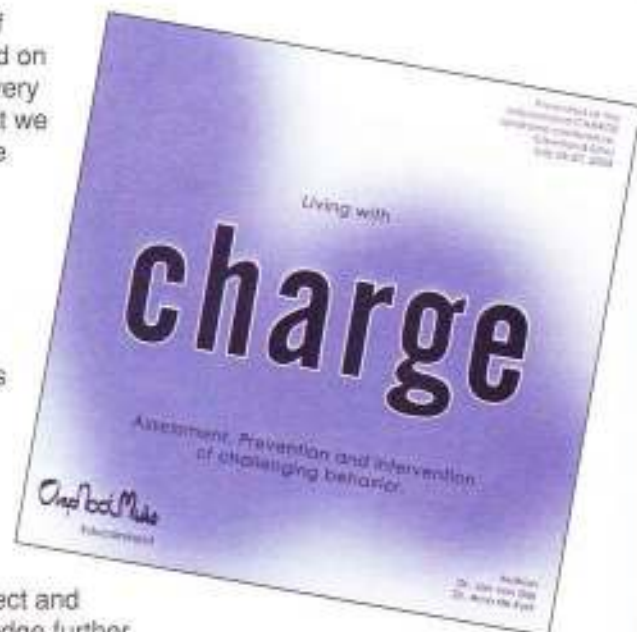
Dr Jan van Dijk and Dr Arno de Kort have brought out a CDROM entitled "Living with CHARGE". It provides information and ideas around assessment and discusses fully, using a range of child studies, some of the challenging behaviours that these children can experience.

The reader/viewer can navigate through the material at their own pace and have the opportunity to see video clips of the children, their teachers and families. The way the CDROM is set out provides a mini-tutorial in developing observational skills- so important when supporting children with complex needs like those seen here.

Questions are asked of the viewer throughout which ensure

that the key points of thinking are focussed on and absorbed. The very different children that we meet here also make this CDROM very interesting and as representative as it can be when all children are unique.

As well as the child studies, there is a good section of further reading and additional video material that is available for those wanting to dig deeper into the subject and develop their knowledge further.



To order a copy email: info@aapnootmuis.com

Management Committee News

The Management Committee met on 4th August 2003 at the 13th World Conference in Mississauga, Canada. Many issues were discussed including details of the European Conference in Cervenica, Slovakia in August 2005 and the possible location of the next World Conference in 2007 which the Council would decide upon by ballot.

The General Assembly also met during the World Conference and ratified constitutional changes including a few additions to the Dbl Awards and the appointment of two Vice-Presidents, one of whom must be from outside Europe and North America.

Mike Collins stepped down as President having led the organisation through a very successful period over the past four years. Dbl has been involved in many major events and activities during this time. We all thank Mike for his tremendous contribution and commitment to Dbl and look forward to his continuing involvement with Dbl as Immediate past President.

Incoming Dbl Officers and Council members

William Green was elected to be our new Dbl President and Bernadette Kappen and Graciela Ferioli were elected as our two Vice-Presidents. In addition to these changes, Richard Hawkes, Anny Koppen and Ton Visser were

appointed as members of the Management Committee and Malcolm Matthews continues as co-opted Information Officer.

William said he was honoured to be elected Dbl President and to lead such a wonderful international organisation. He said that he would strive to pursue the objectives of Dbl. Looking to the future, he emphasised the importance of strategic planning, as well as the further development and expansion of the Dbl networks as a focus for his term in office.

The new Council also had their first meeting at the Canada Conference. The new Council members are:

William Green (Italy)
Bernadette Kappen (USA)
Graciela Ferioli (Argentina)
Ton Visser (The Netherlands)
Richard Hawkes (UK)
Michael Collins (USA)
Dominique Spriet (France)
Wolfgang Angermann (Germany)
Rossano Bartoli (Italy)
Daniel Alvarez Reyes (Spain)
Sergei Sorokin (Sweden)
Tony Best (UK)
Barbara Mason (USA)
Celestine Hare (Australia)
Stan Monroe (Canada)
Anny Koppen (Denmark)
Bhushan Punani (India)
Koh Poh Kwang (Singapore)
Gill Morbey (UK)
Ges Roulstone (UK)
Jacques Souriau (France)
Ricard Lopez (Spain)
Carol Brill-Doran (Ireland)
Mary Guest (UK)
Lone Poggioni (Denmark)

World Conference 2007 – Host Announcement!

We are very pleased to announce that the next world conference will be held in Western Australia. Further details will be announced next year.

If you would like a full copy of any of the minutes or of the changes to the Dbl Constitution, please contact us at: dbi@senseinternational.org.uk



Bernadette Kappen and Graciela Ferioli

13th World Conference News

This was a very successful and enjoyable conference and, on behalf of Dbl, our thanks go to Stan Munroe, Linda Mamer and staff at the Canadian Deafblind and Rubella Association, for their fantastic job of organising this conference. 561 people, representing 48 countries, attended the World Conference this year.

At the Conference, Dbl presented a new award for persons who have made outstanding contributions to our field over a lifetime. The very first recipient of the Lifetime Achievement award was Peggy Freeman OBE. This is a well-deserved honour for Peggy, marking years of great achievement and contributions to the field of deafblindness.

Distinguished Service Awards were presented to Mary Guest (UK), Stan Munroe (Canada) and Inger Rodbroe (Denmark).

The major Dbl events for the next four years are:

2004

Family Conference in Denmark in June organised by the Nordic Culture Network
Acquired Deafblind Network Conference in London in October
Dbl Asia Conference

2005

Dbl European Conference in Slovakia (August)

2007

Dbl World Conference in Australia



William Green and Mike Collins

Membership Update

DbI would like to express its appreciation for the continued support of the large and small corporate members. We strongly encourage individuals to join DbI in order to contribute to, and widen further, our global community in the field of deafblindness.

We currently have 611 members from 78 countries recorded on our database. It is very important that all

members renew their membership for this year as we will be updating our database and your details will be removed if we do not hear from you by the end of the year. If you have any queries regarding the status of your membership, please do not hesitate to contact us on dbi@senseinternational.org.uk.

DbI Website

For all the very latest news and information on DbI, visit www.deafblindinternational.org.uk.

international.org. We welcome new submissions to the website so if you would like to contribute or advertise an event or recent success, please send details to Malcolm Matthews at mmatthe@senseinternational.org.uk.

The DbI Secretariat

If you have any queries regarding DbI, please forward them to dbi@senseinternational.org.uk.

DbI is a vital network for all involved in the field of deafblindness. In order to best serve our members, it is crucial that we raise sufficient funds through fees to finance our basic activities. With this in mind, there is a Corporate as well as an Individual membership form for you to fill in. Please encourage as many people as possible to join.

Non-Voting Members consist of individuals, national networks and non-subscribing Corporates. Non-voting members can contribute to the decision making process of DbI through either a corporate member or an international network. Non-voting members will receive a copy of DbI Review and other relevant DbI information. Non-voting membership costs US \$30 a year or a discounted US \$100 for 4 years.

Voting Members are the representatives of **corporate members** who have paid their subscription fees, and the representatives of recognised DbI networks.

There are now two tiers of **Corporate Membership**:

Large Corporates:

Annual Fees between US\$3,000 and US\$5,000

Small Corporates:

Annual Fees between US\$300 and US\$1,500

Corporate Members can be nominated to sit on the Council.



With deep sadness I have to inform you that our friend, colleague, and headmaster of the educational department of the German Rehabilitation Centre for the Deafblind in Hanover (Germany)

Dietrich Bunck

unexpectedly died on September 30th 2003. We are shocked by his sudden death.

Dietrich Bunck was one of the great educators of our time in the field of deafblindness. His advice and expertise were welcomed inside our country as well as abroad. His stirring energy, his sharp view for essentials, and his talent for organisation made him a well-appreciated participant of many national and international steering groups, commissions and councils.

Beside many other activities on an international level, for many years he was the representative of our rehab centre in the bodies of Deafblind International and the European Deafblind Network, where he was one of the authors of the constitution. He was among the initiators of the European Usher syndrome Study Group, and took part in the preparation and organisation of many international conferences and seminars.

During the 5th European conference of DbI in July 2001 Dietrich Bunck received the "DbI Distinguished Service Award" in recognition of his outstanding and lasting contribution to services for deafblind people.

We shall always remember Dietrich Bunck with deep respect and gratitude: his ideas and overall concepts will stay alive in our work.

Wolfgang Angermann

Executive Director
Deutsches Taubblindenwerk gGmbH
Albert-Schweitzer-Hof 27
D-30559 Hannover
Phone: +49-511-5100515
w.angermann@taubblindenwerk.de

Non-Voting Membership

I would like to join/re-join DbI as an individual non-voting member (*please delete as appropriate*)

I wish to pay an annual fee of US\$30
or £20 (payment attached)

I wish to pay for 4 years' membership at the **discounted rate** of US\$100 / £65
(payment attached)

Please waive my membership fee as I am unable to pay it at present

Please debit my ☐ Visa ☐ American Express
☐ Mastercard

Expiry Date

Please note that credit card payments are made to Sense who then credits DbI.

Please find enclosed my Postal Order ☐

Title (Mr., Mrs., Dr. etc.)

Surname

First name

Organisation

Job Title

Address

Town/City

County/State

Post/Zip code

Country

Tel: (please include country & area codes)

Fax: (please include country & area codes)

Email:

DbI Review (tick one box in each category)

I would prefer to receive DbI Review in:
☐ English ☐ Spanish

I would prefer to receive DbI Review on:
☐ paper ☐ disk

Please return to:

DbI Secretariat
c/o 11-13 Clifton Terrace,
Finsbury Park, London N4 3SR, UK.



Corporate Membership

There are now two tiers of **Corporate Membership**:

Large corporates:

Annual fees between \$US3,000 and US\$5,000

Small corporates:

Annual fees between US\$300 and US\$1,500

We would like to join DbI as a Large/Small
Corporate Member (*please delete as appropriate*)

We submit an annual fee of US\$

Corporate members are entitled to receive up to 25
copies of DbI Review. We would like
copies in English/Spanish (*delete as appropriate*).

Method of payment (must be made in US dollars)

☐ Cheque or international postal order

☐ Bank Transfer

Name of Bank: RABOBANK

Address of Bank: Sint-Michielsgestel, Netherlands

Account Name: Instituut voor Doven: INZAKE DBI

Account Number: 11.29.09.825

Member Details:

Organisation

Representative

Date of Bank Transfer

Address

Tel: (please include country & area codes)

Fax: (please include country & area codes)

Email:

URGENT NOTICE: Please fax your completed form
through to Ton Visser, DbI Treasurer,
on +31 73 55 12 157,
or post to Ton Visser, DbI Treasurer,
c/o Viataal, Theerestraat 42,
5271 GD Sint-Michielsgestel, the Netherlands.



The World Association Promoting Services for Deafblind People

Honorary Officers

President

William Green
Lega del Fila D'Oro
Via Martecorno 1
60027 Daino (AN)
ITALY
Tel: +39-071-72451
Fax: +39-071-717102
Email: green.italy@usa.net

Vice-President

Bernadette Kappen
Overbrook School for the Blind
6333 Malvern Avenue
Philadelphia
PA 19151
USA
Tel: +1-215-877-8913
Fax: +1-215-877-2466
Email: brk@bsb.org

Treasurer

Graciela Ferick
Hilary Perkins
Independencia 376
Planta Baja Apt. D
5000 Carleba
ARGENTINA
Tel: +54-251-423-4741
Fax: +54-251-423-4741
Email: A.Visser@victual.nl

Secretary

Richard Hawkes
Sense International
11-13 Clifton Terrace
Finsbury Park
London N4 3SR, UK
Tel: +44-20-7272-2881
Fax: +44-20-7272-6012
Email: rhawkes@senseinternational.org.uk

Information Officer

Malcolm Matthews, Sense

Deafblind Officer

Eileen Boothroyd & Frances Hampton, Sense

Management Committee

William Green, President DbI
Lega del Fila D'Oro

Mike Collins, Immediate Past
President, Perkins School
for the Blind

Arny Kappen, Nordic Staff
Training Centre for Deafblind
Services

Bernadette Kappen, Vice-
President DbI, Overbrook
School for the Blind

Richard Hawkes, Secretary
DbI, Sense International

Malcolm Matthews,
Information Officer DbI,
Sense

Graciela Ferick, Vice-President
DbI, Hilary Perkins
Programme for Latin
America

Ton Visser, Treasurer DbI,
Victual

Networks

ACQUIRED DEAFBLINDNESS NETWORK

c/o Ges Roudstone
Email: ges.roudstone@sense-
east.org.uk

CHARGE NETWORK

David Brown
California Deafblind Services
5010 Mission Street
San Francisco
CA 94112
USA
Email: ddbrown1@pacbell.net

COMMUNICATION NETWORK

c/o Jacques Sourias
CRESAM
La Rivardière
62 rue de la Longeaise
86440 MIGNIE-AUX-VALS
FRANCE
Tel: +33-5-49-43-89-30
Fax: +33-5-49-43-89-51
Email: centre.cre@cream.net

CONGENITAL DEAFBLINDNESS IN ADULTS NETWORK

c/o Dominique Spriet
30 Rue Barbes
F-93600 Aubervilliers
France
Tel: +33-1-48-68-68-64
Fax: +33-1-48-68-68-64
Email: spriet.dominique@univ-paris.fr

EDbN

Ulrich Hennemann
Piazza Leopardi 7
60027
Osimo/AN
Italy
Email: unshel@comuneosimo.net

EUROPEAN USHER SYNDROME NETWORK (EUSN)

c/o Marilyn Kirby
11-13 Clifton Terrace
Finsbury Park
London N4 3SR
UK
Tel: +44-20-7272-7774
Fax: +44-20-7272-6012
Email: mkirby@sense.org.uk

USHER SYNDROME STUDY GROUP (USSG)

c/o Mary Gault
Sense
11-13 Clifton Terrace
Finsbury Park
London N4 3SR
UK
Tel: +44-20-7272-7774
Fax: +44-20-7272-6012
Email: MGault@sense.org.uk

INTERPRETING DEVELOPMENT NETWORK

c/o Rainer Bjork
AB Stockholmskärns
Hornsgatan 74 A
118 21 Stockholm
SWEDEN
Tel: +46-8-638-39-03
Fax: +46-8-638-39-11
Email: rainer.bjork@stockholmstockholm.se

MULTIPLY DISABLED VISUALLY IMPAIRED

EUROPEAN NETWORK
c/o Kert Lundkvist
Eskolan RC
Tel: +46-19-6762-151
Fax: +46-19-6762-210
Email: kurt.lundkvist@tel.se

NORDIC CULTURE NETWORK

Lone Poggens
Roerkaasgade 47
DK-6700 Esbjerg
DENMARK
Email: lonerica.jose@post.tele.dk

TACTILE COMMUNICATION WORKING GROUP

Bernadette van den Tilhof
15175 Prairie Road
South Salem
OH 43153
USA
Email: bernadette.vanden-
tilhof@usa.net

THE STAFF DEVELOPMENT NETWORK

Co-ordinator post vacant
C/o Sabine Kirsten
Email: s.kirsten@post.vatant

SIBLINGS NETWORK

C/o Sabine Kirsten
Email: s.kirsten@post.vatant

Large Corporate Members

FRANCE

Jean-Marc Chert
French Deafblind Consortium
Tel: +33-1-4627-4810
Fax: +33-1-4627-5801

GERMANY

Wolfgang Angermann
German Deafblind Consortium
Tel: +49-011-510090
Fax: +49-011-5100857
Email: dwalt@tspiral.de

Christoffel-Blindenmission

Tel: +49-6251-131 130
Fax: +49-6251-131 165
Email: p.werses@cbm-bonn.de

ITALY

Rossana Barbi
Lega del Fila D'Oro
Tel: +39-071-72451
Fax: +39-071-717102

NETHERLANDS

Ton Visser
Instituut voor Dooven
Tel: +31-73-65 88 111
Fax: +31-73-65 12 157
Email: A.Visser@victual.nl

PORTUGAL

Antonio Rebelo
Casa Pia de Lisboa
Tel: +351-1-391 0959
Fax: +351-1-391 34 48
Email: cpl.aduza@mail.telepac.pt

SPAIN

Daniel Alvarez Reyes
ONCE
Tel: +34-1-245 3097
Fax: +34-1-245 4157
Email: daniel@once.es

SWEDEN

Sergei Sorokin
Resurscenter No Gerd
Tel: +46-122-23950
Fax: +46-122-23959
Email: sergei.sorokin@rogard.se

UK

Tony Best
Sense
Tel: +44-20-7272-7774
Fax: +44-20-7272-6012
Email: abest@sense.org.uk

USA

Barbara Mason
Perkins School for the Blind
Tel: +1-617-572-7221
Fax: +1-617-523-8076
Email: mason@perkins.psk.k12.ma.us

Bernadette Kappen
Overbrook School for the
Blind

Tel: +1-215-877-8913
Fax: +1-215-877-2466
Email: brk@bsb.org

Small Corporate Members

AUSTRALIA

Celestine Hare
The Deafblind Association
Tel: +61-3-9882 7055
Fax: +61-3-9882 9210
Email: c.hare@daa.asn.au

Kyle Watt

Regal Institute for Deaf and
Blind Children
Tel: +61-2-9872 0316
Fax: +61-2-9872 3879
Email: kwatt@regal.org.au

Irène McKinn

Australian Deafblind Council
(ADBC)
Tel: +61-3-8892 7055
Fax: +61-3-8882 9210
Email: dabb@adbc.net.au

Sandy Joint

Deafblind Association of
Queensland
Email: mail@deafblind.org.au
sandy.joint@qld.gov.au

Sharon Grassick

Senses Foundation Inc
Tel: +61-8-9272 1123
Fax: +61-8-9272 6800
Email: sharon@senses.asn.au

AUSTRIA

Christa Heilmann
Osteur, Hilfswerk für
Taubeblinde
Tel: +43-1-602 6612 0
Fax: +43-1-602 6612 17

BELGIUM

Marlene Daelman
MPI Spierma
Tel: +32-50-340 341
Fax: +32-50-337 306
Email: Marlene.Daelman@mpi-
spierma.be

CANADA

Edward Abels
Independent Living
Residences for the Deafblind
in Ontario
Tel: +1-905-770 4948
Fax: +1-905-770 6598
Email: ed@ed@sympatico.ca

Stan Munro

Canadian Deafblind and
Hearing Association
Tel: +1-519-372 0867
Fax: +1-519-372 0312
Email: stan.munro@sympatico.ca

Jose Brindley

The Lions McInnes House
170 Henry Street
Branford
Ontario
Tel: +51-9-702 6450
Fax: +51-9-752 9049
Email: mcinnes@lions.org

DENMARK

Birte Laurrup
National Centre for
Congenital Deafblind
Tel: +45-98-155313
Fax: +45-98-155323
Email: laurstrup@vestf.nja.dk

Arny Kappen

Nordic Staff Training Centre
for Deafblind Services
Tel: +45-96-47 16 03
Fax: +45-96-47 16 16
Email: arny@nordic.dk

Henrik Østergaard

Videosentral for
Dovblindhed
Tel: +45-44580000
Fax: +45-44580000
Email: dcentral@dcnet.dk

Preben Gundersen

Dovblindesentral
Tel: +45-99-31 89 00
Fax: +45-99-31 73 44
Email: preben@dcnet.nja.dk

FINLAND

Heikki Mäkelä
The Finnish Deafblind
Association
Tel: +358-9-54 95 35 18
Fax: +358-9-54 95 35 17
Email: kuusokse@helsinki.fi
heikki.makela@kuusokse.fi

Maria-Lena Sjöström

The Service Foundation for
the Deaf
Tel: +358-9-68 031
Fax: +358-9-585 3837
Email: kuusokse@kuusokse.fi
kuusokse@kuusokse.fi

INDIA

Brishan Puri
Blind People's Association
Tel: +91-79-630 3346
Fax: +91-79-630 0108
Email: brishan1@sancharnet.in

NETHERLANDS

Bernard de Vries
Vlaar-Het Loo Fila, LSSB
Tel: +31-35-68 85 711
Fax: +31-35-68 38 456
Email: info@vlaar.nl

NORWAY

Evafrid Andreassen
Regional Resource Centre for
Deafblind/VKS
Tel: 0047-55-92 34 86
Fax: 0047-55-92 34 91
Email: evafrid@andreassen-
@stetnet.no

Torodd Strand Hauge

Skandinaviske Ressurssenter
Tel: +47-22-703 700
Fax: +47-22-703 701
Email: skandinaviske@resurssenter.no

Krist Johansen

Andebu Dovblindesenter
Tel: +47-33-435700
Fax: +47-33-435720
Email: krist.johansen@signo.no

SINGAPORE

Koh Poh Kheng
Singapore School for the
Visually Handicapped
Tel: +65-2503755
Fax: +65-2503348
Email: kohpohkheng@ssvh.edu.sg

SOUTH AFRICA

Dr Petrus Botes
Institute for the Blind -
Worcester
Tel: +27-231-22313
Fax: +27-231-23959
Email: gionewschost@ibw-
institute.org.za

Dr Willem Roodenrys

South African National
Council for the Blind
Tel: +27-12-3461171
Fax: +27-12-3461177
Email: roodenrys@sa-nb.org.za

SPAIN

Dolores Romero Chacón
APASCIIDE
Tel: +34-91-733 52 06
Telfax: +34-91-733 43 17
Email: apasciide@ampl.es

SWEDEN

Sven Sjöberg
Association of the Swedish
Deafblind (FSDB)
Tel: +46-8-3599033
Fax: +46-8-5550042
Email: sven@fsdb.org

Anne-Marie Sjögren

SPMDA Communication
Centre
Tel: +46-18-602 4249
Fax: +46-18-330 724
Email: anne-marie.sjogren@
stortel.se

SWITZERLAND

Barbara Bettmann
Schweizerische Stiftung für
Taubeblinde, Heim Tanne
Tel: +41-1-714 71 00
Fax: +41-1-714 71 10
Email: barbara.bettmann@
stiftung.ch

UNITED KINGDOM

Ges Roudstone
Sense East
Tel: +44-1779-340021
Fax: +44-1779-380078
Email: ges.roudstone@sense-
east.org.uk

Gillian Marbury

Sense Scotland
Tel: +44-141-364 2444
Fax: +44-141-364 2443