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Review

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SORDEGUES



Yoga with deafblind children

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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 *Dbi*.

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Cover: Clarke School for the Deaf, Chennai

PRESIDENT'S MESSAGE

Negating the Fallout from Terrorism

During the past ten or fifteen years, we have seen remarkable progress in the expansion of our international community of people concerned with deafblindness. All of us in *Dbi* have witnessed an almost unbelievable growth of programs in the developing world, at a rate unprecedented in prior decades. We have seen our colleagues in developing countries finally able to realize their dreams for new programs, with the assistance of the international community of Non-Governmental Organizations. The selfless generosity of many of these organizations and the spirit of giving without geographic or cultural limitations has been marvellous to observe. The achievements in India, Peru, Eastern European countries, Africa, and many other places are due to the efforts, at least in part, of NGOs in Sweden, Denmark, the United Kingdom, Germany, Holland and the United States. It has been a source of great pride to me to observe this level of cooperation within our organization and also to participate in it as an international donor organization.

We have also witnessed the phenomenon of experienced people within a region assisting those with less experience. We have people in India providing training to other Asian

countries, Venezuelans and Argentinians providing training and support to new programs in Cuba and Guatemala, and South Africans training each other. Our international organization has become a field in which people truly have supported each other's work, with a level of cooperation not often found at a global level.

Each of us involved in such support has felt, at one time or another, tremendous self-satisfaction in being a member of an international community that works so well in spite of political differences between our countries, and despite social, cultural and religious differences between peoples. Our common denominator of caring for the welfare of deafblind people has been our bond, our unifying factor, and something that helps us to recognize our similarities and to minimize our differences. In our field, we have had the unusual privilege of working with some of the finest, most caring people our societies have to offer. For some of us, the successes experienced by our field have evoked, as well, our strongest hopes for international unity, cooperation, peace and brotherhood.

Then September 11, 2001 came and passed, having hit



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Dbi Review

us and left us like a destructive whirlwind. We all experienced the profound shock, anger and then sadness of this event, viewing it time and again with disbelief in the inhumanity and senseless savagery of the act. We all ached from that, and we all heard the testimony that the world as we know it has changed forever. That infamous day in our history did far more than cause us to grieve over the loss of life and property. It postponed, curtailed, and in some cases actually prevented an overwhelming amount of the good work being done across borders. In my own program, our work abroad was stopped altogether for a four-month period of time, and even now it has not resumed in some countries. Progress in our field, within many countries that truly need the assistance, has been terribly slowed down. Deafblind people who need programs and services are now delayed even further in receiving help.

All of the negative effects of the terrorists' activities have affected our field so negatively, and yet we are just a microcosm of the larger world picture. There exist even more dire consequences for international relations as a whole. It is so easy to let that

day dash our idealistic thinking about world unity and globalization in the best sense of the word. It is so tempting for wealthy nations to retrench, to question their giving and to become isolationist in their thinking. It is a climate in which donors and foundations might take the position of helping our own first and foremost, to the abandonment of international causes. The economies of wealthy countries have been effected negatively, resulting in diminished investment in poorer countries.

It is a responsibility for each of us individually to not let this happen. We must carry on with our international work, more determined than ever to foster an environment of mutual support. We need to resume our work abroad, with each other, wherever the dangers subside enough to make it possible. We must be outspoken at a local level in support of international collaboration and investment, with absolute confidence in the goodness we have experienced in our fellow humans everywhere. Above all, we cannot let senseless acts of terrorism demoralize us or dampen the spirit of the international family that is emerging in organizations like Deafblind International. Peace.

Michael T. Collins, President

EDITORIAL

Hello!

We have given way to Mike this time but this magazine is full to bursting. We lead on an intriguing yoga programme for young deafblind children which is proving successful in Chennai, India. We also have a focus on the developments in the East African countries of Kenya, Tanzania and Uganda, which are sharing expertise and gaining political and public support for their work.

We must draw your attention to a major announcement of the Dbl World Conference next year, hosted by the Canadians, and reach out to you all in this edition for your participation!

We have been very well supported this time by our regional news providers too – thank you all. Keep those stories and articles coming in!

Eileen and Frances

CONTENTS

- Practicing yoga with deafblind children
Dipti Karnad pages 4–6
- Deafblind culture in the UK
Susannah Barnett pages 7–11
- Prenatal genetic testing for deafness
Barbara Carmichael pages 12–14
- Person Centered Planning
Sheri Moore pages 15–18

CAMPAIGNING

- Social Inclusion in European Union page 19
- Social Exclusion – Croatia page 20

FOCUS ON AFRICA

- Finding our way – exciting developments in East Africa
Penny May Kamau pages 21–25
- Working in Uganda
Dorte Erikson pages 26–27
- East Africa Conference page 28

PEOPLE

- Yolanda Rodriguez page 29

NETWORK NEWS

pages 30–34

REGIONAL NEWS

- Australia page 35–36
- Czech Republic page 37
- Romania page 37
- Slovakia page 37
- Latin America page 37
- Russia page 38
- UK page 39
- Croatia page 39
- India page 40
- NUD page 40

CONFERENCE NEWS

- Canada pages 42–43
- Switzerland page 44
- Scotland page 44
- Italy page 45

MANAGEMENT NEWS

- Dbl Membership Form page 47

Practicing yoga with deafblind children

In this article Dipti Karnad describes the way in which the practice of yoga is making a real contribution to the lives of deafblind children at the Sadhana Unit for Deafblind Children at the Clarke School for the Deaf, Chennai, India

Yoga is a scientific system of physical and mental practices that originated in India more than three thousand years ago. Its purpose is to help each one of us achieve our highest potential and to experience enduring health and happiness. With yoga, we can extend our healthy, productive years far beyond the accepted norm and, at the same time, improve the quality of our lives.

Because yoga works on so many different levels, it has great potential as an effective therapy for chronic diseases and conditions that do not respond well to conventional treatment methods. For this reason, children with disabilities who practice yoga often surprise their parents and teachers with their quick mastery of basic motor, communicative, and cognitive skills. The same yoga routine can help children with learning disabilities develop greater concentration, balance, and composure in their daily lives.

Yoga requires quiet, consistent application. It does not require that we transform ourselves overnight into something beyond our capacity. Yoga begins by accepting our limitations, whatever they may be, and working with this self-acceptance as a base. In our daily practice, we gradually

In yoga, the body is looked upon as the primary instrument that enables us to work and evolve in the world.

learn to transcend our limitations, one by one, and in this way, real and lasting progress is possible.

Yoga helps one achieve a balanced state of mind, a healthy body and work efficiency through concentration, alertness and emotional stability. Yoga means "to join or yoke together thereby bringing the body and mind together in one harmonious experience." The whole system of yoga is built on three main structures: exercise, breathing and meditation. In yoga, the body is looked upon as the primary instrument that enables us to work and evolve in the world.

Hence the exercises of yoga are devised to put pressure on the glandular system of the body thereby increasing its efficiency and total health. Breathing techniques are based on the concept that breath is the source of life in the body and through yoga one increases breath control to improve the health and function of both body and mind.

Regular practice of all three parts of this structure of yoga produces a clear bright mind and a strong and capable body. An integrated series of balanced yoga poses increase body awareness, strength and flexibility. Specialized



Dipti Karnad

breathing exercises and relaxation techniques improve concentration and reduce hyperactivity.

Yoga and deafblind children

Just as normal children can benefit from yogasanas, disabled children too can derive many benefits from learning to practice yoga. However, teaching yoga to the disabled, especially to people who are deafblind, is a Herculean task, which when achieved pays rich dividends. Deafblindness is a sensory impairment where both vision and hearing are affected. Although the degree of impairment differs from child to child, it might be accompanied by other physical or mental anomalies. Some deafblind children may require assistive devices such as spectacles, hearing aids, mobility aids, as well as



augmentative and alternative communication like sign language, communication boards, Braille, or large print. Many may need these facilities throughout the day, all the seven days of the week, twelve months of the year; in fact all through their life. Parents, teachers and all concerned with the life of deafblind people require patience to work with such individuals.

While introducing yoga to the deafblind, multiply handicapped students of the "Sadhana" Unit for the Deafblind, at The Clarke School for the Deaf, Chennai, India, the staff had in mind the following aspects:

- ◆ to help children co-ordinate the activities of the mind and body.
- ◆ to reduce the distracted state of mind and help the mind to dwell on the present activity.
- ◆ to actively increase the ability to concentrate on the present activity.

Every morning the deafblind multihandicapped children meet together for Morning Assembly during which time incense is burnt and prayers

said. At the end of the assembly, children are told "time for yoga" and guided to take off their shoes and socks. Then they are led to their places in the yoga hall with two older children taking up their positions in front of the group. Four staff consisting of three special educators and one occupational therapist, take up their positions in front of, behind or alongside four totally blind children. Of these four children, one is totally deafblind and three are totally blind with auditory processing problems. The students with low vision follow the older children while the staff work with the totally blind students. As they do this they also monitor the others in the group.

Each yoga session starts with pranayama or breathing techniques. Due to individual differences, adaptations of pranayama, asana or exercises are made. Each asana consists of three sequences namely preparation, main pose and compensation or counterpose. After each asana, the students are given rest so that they do not become breathless or tired.

Each yoga session culminates with meditation in which the students sit cross-legged with their palms facing outwards, index finger folded to touch the thumb and eyes closed.

The special educators use various strategies suitable to each individual child. Some of the strategies are:

◆ Individual instruction

This has been found necessary due to the difference in degrees of dual sensory impairment, cognitive levels and physical abilities.

- ◆ **Modelling** This is being used in different ways. The totally deafblind child needs to work in close physical contact with the teacher, whereas the low vision child imitates his peer or the more able low vision child can follow photographs or cue cards.



◆ Peer tutoring and peer reinforcement

This has shown good results.

- ◆ Positive thinking on the part of the teachers has shown positive results. Objectives selected are within the capacity of each student, but not so low that they would be too easy to achieve. This, along with the physical ability of each student, has been the priority during planning.

- ◆ **Communication** This has been the key to the success of our yoga sessions. Teachers make sure that they use the most appropriate communication mode – either "on the body signs", total communication, signs, gestures or oral language.

- ◆ **Regular practice by the teachers themselves** This has enabled them to better understand the difficulties and given them an insight into planning strategies for teaching.

Yoga has become a popular part of the routine in the Sadhana Unit and no child wants to miss it. Parents report that their children have motivated them to do yoga and that they have enrolled themselves in yoga classes. We have noticed that that forty five minutes of yoga every morning has enhanced performance in the activities involving movement of our deafblind students. It has taught them sequencing and now they can understand vocabulary like "first, next, last". We have seen an improvement in their sequential memory. Most of them can tell which asanas follow one after the other. Our students have developed

spatial and body awareness, confidence and concentration. Our totally deafblind children have learnt that there is a world beyond their fingertips.

Our staff has endeavoured to prove that yoga can be taught to the deafblind and multihandicapped as well. Hard and challenging work but well worth it!

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Articles by Sumar Sonia, Sumar Renate – Courtesy Internet

A Special Educator's experiences in teaching yoga to a totally deafblind child. P.Srinivasan shares her thoughts on teaching Vijay

Vijay and Yoga

Teaching yoga to the deafblind has been a thrilling experience for a special educator like me. Vijay Krishna aged twelve is a totally deafblind boy to whom I have imparted yoga since June 2001. He has learnt six types of Asanas for which I have followed these steps.

- 1 Before starting the yoga class I sign to him, "Time for yoga" and make him stand straight in his place.
- 2 I stand behind him so that he feels the movements of my chest and stomach while breathing in and out.
- 3 Then I sign, "Start yoga".
- 4 In order to teach Asanas I stand just opposite him and perform the movements allowing him to touch me so that he can copy my body movements.
- 5 I have made him aware of certain cues like when I touch his elbow he raises his hand and when I touch his head he bends.

In this way I have successfully inducted Vijay into the beautiful art of yoga. Vijay makes use of his residual vision, as he can see the silhouette of others in a bright room at a distance of five feet, and his residual hearing, using his hearing aid, to listen to the drumbeats. By encouraging the use of residual vision and hearing I have faded physical prompting. My aim for Vijay is to make him proficient in yoga for developing concentration, attention, and relaxation.

My advice to everyone who wishes to teach yoga to the deafblind is:

- Fix realistic goals
- Reach the target
- Stick with the time
- Use appropriate reinforcement.
- Demonstrate to the student,
- Provide immediate feedback.
- Think positively.
- Communicate with the student appropriately.
- Practice yogasanas planned for the student, yourself.
- Never lose your patience.

These are the main steps to teach yoga to the deafblind.

Deafblind culture in the UK

This article was developed from a presentation given by Susannah Barnett at the national conference of Lega de Filo D'oro in Rome, November 2001. Susannah is Research and Practice Development Officer for Sense and is working on a Masters Degree at the University of Bristol, UK. Her research area explores the idea of Deafblind culture in Britain.



Deafblind culture in the UK

When I initially began my research, my concern was to identify whether a Deafblind culture exists in Britain. The subject has been considered in other countries but there is no substantial research in the UK.

My work so far

This article is based on the outcomes of the first of two studies. The findings indicate that, at this present time, there is no Deafblind culture in Britain with which the majority of Deafblind people can easily identify. However the findings do indicate that being Deafblind does produce a unique experience and those who have this experience have a common bond. The need to understand what it means to be Deafblind from the perspective of Deafblind people themselves is what is important.

I would like to discuss this in three parts:

- ◆ to consider what is meant by 'culture', and how this is defined;
- ◆ to highlight some of the difficulties for defining a Deafblind culture;
- ◆ to look at the research itself and some of the findings.

What is culture?

Within our world there are many different groups of people each with a culture that is unique to that group. Some cultures are determined by geographical location, people living in one area can be said to be part of one culture. Groups who follow certain religions may also be defined as having a unique culture. Different cultural groups may have similarities with other groups, but there are also certain aspects that remain unique to that particular group.

Culture can consist of many different areas. On one level culture guides the way individuals think and

behave through maintaining certain beliefs, language, rules and behaviour patterns. On another level culture provides us with roots, structure and understanding about ourselves. Culture leads individuals to an understanding of who they are and where they are from. It provides an identity, a sense of belonging. Culture gives meaning to life's experiences, but culture cannot exist in isolation. The rules, behaviour patterns, structure and meanings have to be agreed with others. Culture can only develop when people come together.

Defining a Deafblind culture – the problems

The fundamental problem with defining a culture based on the state of being Deafblind revolves around the fact a 'pure' Deafblind culture can only really be identified in people who are born Deafblind. This is the group whose total life experience results from the state of being Deafblind. Those with acquired deafblindness have the experience of being sighted or hearing or both hearing and sighted first before becoming Deafblind. These different experiences will have had influences on their cultural development and therefore people with acquired deafblindness cannot have access to a 'pure' Deafblind culture.

However, identifying a 'pure' Deafblind culture in people with congenital deafblindness is difficult because many people in this group also have other disabilities. Individuals with congenital deafblindness often do not have formal language skills and we can only guess at the extent of their awareness of themselves and of others around. This is a difficult situation from a research point of view, but also implies that without language skills or an awareness and contact with other people in a similar position, it becomes difficult for a group culture to develop in a conventional way.

It may be that there are people with congenital deafblindness who are able to participate in my

research, however, so far I have not been able to identify anyone with the necessary communication skills to act as a representative of a possible 'pure' Deafblind culture. Without such representation it is not possible to define a 'pure' Deafblind culture in any meaningful way.

Defining a model of Deafblind culture based on the experiences of those with acquired deafblindness has to be developed on a different basis. From the point of view of communication, research is possible. Although methods of communication are varied, individuals are able to express their own thoughts and ideas. However, individuals who acquire deafblindness come from Deaf, blind or hearing-sighted cultural backgrounds. These different cultural influences must be taken into account.

The key point here is that any research on what a Deafblind culture might mean for people with acquired deafblindness cannot immediately be assumed to also be representative of individuals with congenital deafblindness. We have no way of knowing.

The research findings

The research has been undertaken by making the most of modern technology and sending questionnaires by e-mail. The exploratory study involved ten Deafblind people with acquired deafblindness from all parts of the UK. As a group they were very diverse and included those with Deaf, blind or hearing-sighted cultural backgrounds. In the initial stages the question I was attempting to answer was whether there is a Deafblind culture in the UK. This was achieved by looking at four areas included in the definition of culture. These were:

- ◆ Associations and contacts
- ◆ Language choice
- ◆ Behaviour
- ◆ Identity.

The research findings were evaluated by asking the question: Is this evidence of a Deafblind culture or as part of a wider Deafblind experience?

Associations and contacts

It has been established that a culture can only develop where there are a group of people who share the same ideas, beliefs and established behaviour patterns. If a Deafblind culture is to develop there needs to be regular contact between Deafblind people. However, only three people who took part in the study had ever met another Deafblind person. Only one of these people had regular contact.

Deafblindness is a low incidence disability. The opportunities for meeting other Deafblind people are limited. For those who live away from the big towns and cities, this problem is intensified. It is also true that sometimes individuals make a decision not to meet with other Deafblind people, however, more often Deafblind people do not have the opportunity to make the choice.

It is also important to look at the times when

Deafblind people do come together. The three people involved in the study who had met other Deafblind people recorded that these meetings had been at conferences or other events run by either one of the two organisations in Britain for Deafblind people. As a result, opportunities for meeting are limited in that they may only happen once every six months.

The other factor, which needs considering, is the influence of 'outsiders'; people from another culture. All the individuals who took part in the study mentioned the use of professionals such as interpreters, guides, or communicator guides at some point. This is significant because all these people come from another culture - usually a hearing-sighted culture. The question is what influence do 'outsiders' have on the development of a Deafblind culture?

To some extent all cultures have to exist within the framework of wider society and therefore can never be truly independent. But most cultures do have times when members of the culture come together as a group and 'outsiders' are excluded, e.g. hearing people are not usually welcomed at Deaf clubs. A group of Deafblind people do not have this exclusiveness in the same way, 'outsider' influences from other cultures in the form of interpreters/guides are always present to enable communication and mobility.

The presence of 'outsiders' may suggest that Deafblind

To some extent all cultures have to exist within the framework of wider society and therefore can never be truly independent.

culture cannot develop because it can never be truly independent. Alternately a definition of Deafblind culture may simply have to include the dependency on interpreters/guides and other professionals as a necessary part of the culture itself.

Another opportunity for Deafblind people to communicate with each other is through technology. The setting up of the Internet and E mail systems has made access to information in the wider world much more accessible. Deafblind people alongside hearing-sighted peers have been able to benefit from new technology. Through the use of the e-mail system, Deafblind people can communicate directly with each other and also as groups on e-mail group lists. The ten people who took part in this study were identified through this source. For seven people in the study this was the only point of contact they had with other Deafblind people. Through e-mail Deafblind people as individuals and as a group have the opportunity to discuss issues, ideas and topics relevant to them, offer advice and support and also just experience general conversation. This method of communication is important because it is free from 'outsider' influences.

In one sense, it would be wrong to claim that a

culture can be established through contacts and relationships built up in cyberspace alone. This would be a very limited view of culture. It also has to be acknowledged that not every Deafblind person may have a computer. However, computers and associated technology are becoming a greater part of everyone's lives including the lives of Deafblind people. The benefits of computers for Deafblind people must be fully exploited.

Language choice

The argument has developed that Deafblind people must come together, if a culture is to develop. Equally important is the use of a common language as the unifying factor in the development and maintenance of a culture. A common language is the way experiences and beliefs are shared and reinforced and by which a culture is established and passed between its members. The use of a particular language also identifies individuals with a particular cultural group. Sign language is identified with Deaf culture; the use of spoken English reflects a British hearing culture. Braille is a communication method associated with blind people.

Deafblind people do not have a common language as a group but use different languages and communication methods. Individuals in the study group reflected a whole variety of communication preferences. This included sign language, deafblind manual, spoken English and Braille. As Deafblind people use a variety of communication methods, we have to ask the question, can a culture be developed and passed between its members in the same way? If there is a Deafblind culture it cannot be defined by the use of one particular identifiable language.

A common language is the way experiences and beliefs are shared and reinforced and by which a culture is established and passed between its members.

A second area to consider is how language preferences in people with acquired deafblindness were affected by the onset of vision and / or hearing loss. Again the results were mixed. An individual who came from a hearing-sighted background noted she was still able to use hearing and speech although she had also learnt Deafblind manual to use in noisy situations. Another individual had changed from using British Sign Language to hands-on signing as her vision deteriorated. A third individual who used spoken English and lip-reading recorded that she had not felt the need to change her communication although she acknowledged

that she might have to in the future if her vision/ hearing deteriorated.

The results indicate that changes to communication still reflected the background cultural roots. For example, Deaf people brought up using British Sign Language adapted to using hands-on or visual frame signing. Those who used English as a first language adapted to the use of the deafblind manual alphabet, as this is still based on the English language. The reason for this may be simply that people adapt to use a language that is most accessible to them based on what they already know. But, more fundamentally, this is linked to the reality that Deafblind people are isolated:

"People have asked me before if I want to learn sign language, but if I did, would I have anyone to communicate with?"

In general, other people who the Deafblind person is in contact with will continue to use the language that has always been used. On becoming Deafblind, the individual is unlikely to suddenly be transported to another culture in a way someone moving to another country might. The individual holds on to what they know and what is useful to them in their immediate surroundings. Any changes to communication made necessary by changes in vision/ hearing are still based on the background language and cultural roots. Language use is determined more strongly by the cultural environment in which the Deafblind person was brought up in rather than the later experience of being Deafblind.

So we know that a Deafblind culture cannot be defined on the basis of a unique language, and that the language choice of those who acquire deafblindness is still largely based on the language used by the community they associate with. On the reverse of this, we might also ask what language is used on the rare occasions when Deafblind people do come together? The point here is that just as there is no one defining language, it is also true that Deafblind people do not exclude others on the basis of language. Within the Deaf community, individuals who do not use sign language are largely excluded. Yet if a Deafblind person attends a conference it is noticeable that other Deafblind people will adapt their communication to try and meet different communication needs. The reason for this is that gatherings of Deafblind people cannot afford to be exclusive on the basis of language, because of the isolation that is experienced in everyday life.

Behaviour

Certain behaviour patterns are the outward actions of culture. The way individuals behave toward each other is agreed within a culture. Behaviour has to be conventional. The research has been conducted via e-mail. Establishing criteria for rules of behaviour has only been achieved as far as individuals have expressed their views, rather than by direct observation. However the study in general has highlighted some general points.

When Deafblind people meet each other, common ways of behaving begin to emerge. Consider how Deafblind people meet and greet each other? How do they start or finish a conversation in accepted way? How do Deafblind people attract attention? Within a cultural context, these sorts of behaviour patterns are important.

In meeting someone and beginning a conversation, the reliance on others continues to have an influence. One Deafblind person explained that when he went to a meeting, he always had to ask his communicator guide: "I need to go and talk to John, can you see him?"

When that conversation had finished he would then ask to see another person, and so it continued. This example highlights the Deafblind person's reliance on his guide to take him to the person he wants to see, and possibly also to interpret during the conversation. It also suggests that Deafblind people often have a specific reason for going to talk to someone rather than just as an opportunity for general conversation.

On the reverse of this, a second example:

"The problem with being Deafblind is that you often have to wait for people to come and talk to you first."

Through touch and the later use of the imagination, deafblind people cease to exist in a void. Touch is perceived, used and understood by deafblind people in very unique ways.

This person did not need to talk to specific people so she was left alone. If a Deafblind person does not have an awareness of other people in the room, they are left to stand alone to wait until someone else makes the first move. Conversation only happens on other peoples' terms. The question is then- what happens if other people do not make the approach? Deafblind people are again left isolated.

The whole area of interaction between Deafblind people is the subject of research in itself, and there are many other examples. However the key point is this. It has been established that physical mobility is a problem for Deafblind people; but when Deafblind people are part of larger gatherings, social mobility can also be a problem. The patterns by which conversations are initiated and take place still have the characteristic reliance on other people, both in directing the Deafblind person to the right person and interpreting the conversation. If this interaction does not happen, the Deafblind person is again left isolated.

Touch

A significant area not yet mentioned is the whole issue surrounding the way Deafblind people use the sense of touch. One man pointed out:

"If you talk about Deafblind culture, the most important thing is touch. Deafblind people use touch in ways that no one else does for feeling and communication, for letting someone know you are there."

The sense of touch is used by Deafblind people in a variety of ways: touch is used to explore objects and the general environment. It is an essential part of different communication methods such as Deafblind manual, hands-on signing, or Braille. Touch is used to access information. Touch is also used as a way of getting a person's attention and continued contact is a way of assuring someone they still have your attention.

The use of the sense of touch in such a wide variety of ways is something that is linked to Deafblind people in particular. Blind people also use touch to access information. Deaf people may use touch to attract someone's attention. However Deafblind people use touch to a much greater extent.

One example might be the role that touch has in communication. Through physical contact with the other person, as well as accessing conversation, Deafblind people, are able to perceive feelings about personality and mood. The act of reaching out and making physical contact becomes an extension of the individual's personality.

Touch also has a vital role to play in relation to the use of imagination. Deafblind people use touch to explore their immediate surroundings to enable them to build up a picture of their surroundings in their imagination. Touch is part of a process to provide meaning and context. Through touch, and later the use of the imagination, Deafblind people cease to exist in a void. Touch is perceived, used and understood by Deafblind people in very unique ways.

Identity

While behaviour patterns and language use are outward manifestations of defining a culture, there is also the important factor of identity. This refers to the extent to which an individual feels part of, and comfortable with, the practices and experiences of that culture. The concept of identity can be considered on two different levels. The first level may be described as 'group identity': the way individuals publicly describe themselves and the extent to which they take part in group activities. The second level of individual identity refers to the 'inner' experience: the feelings and experiences that are important to an individual.

'Group identity' refers to the way individuals publicly describe themselves. Individuals may describe themselves as being British, European or describe

themselves as following a certain religion. The terms individuals use to describe themselves suggest association and membership to a particular group. Within this it also suggests that individuals subscribe to a certain set of beliefs and follow a defined behaviour pattern. The terms people use to describe themselves indicate a particular cultural identity.

Those involved in the study were asked what terms they would use to describe themselves. Only one person described himself as being "Deafblind". Other responses included being "Deaf with a visual impairment", or being "Usher". One person stated she had never really thought about it.

If there is a defined Deafblind culture which people are familiar with, it is logical that people describe themselves as being "Deafblind." There are several possible reasons why this does not happen. Deafblindness creates an image of someone who is totally Deaf and totally blind. Individuals may choose to use other terms simply to give clear information about that nature of the hearing/ visual loss.

Individuals with acquired deafblindness may also want to retain their old associations. An individual with Usher (type 1) described herself as being "Deaf with a visual impairment." This individual had a Deaf cultural background and was brought up by Deaf parents within the Deaf Community. The self-identification of being "deaf with visual problems" may be a way of securing ties to the Deaf Community and maintaining a Deaf cultural identity. Individuals with a strong cultural background are reluctant to move to what appears to be the unknown territory of the world of deafblindness.

It may also be true that, within the UK, deafblindness is still seen within a disability framework, rather than from a cultural perspective. As a comparison, within a Deaf culture perspective, the term "Deaf" is seen as a positive term. The cultural roots instil pride in its members that it is good to be Deaf. However deafblindness is still predominately seen as negative, within a disability framework. People, who may otherwise be categorised as Deafblind, chose not to use this term because of its associated negative implications.

The second level of the inner identity refers to the way people understand themselves and their relationships to others. This inner identity may be described as a sense of closeness to others, the removal of barriers and the feeling of shared experience of the world. This feeling of inner identity is hinted at:

"It was the first Deafblind conference I had been to, I would go again but my communication would need to improve, then maybe I would really feel I had come home"

It is this feeling of 'coming home' which is the real inner identity. It is the situation where Deafblind people are equal - having the same experiences and understanding of one another and those around them.

Uniqueness of the experience of deafblindness

So, the centre of my whole argument is that people who have both a vision and hearing loss have a unique experience of the world in a way which only those who have this experience can fully appreciate. It is the Deafblind experience that binds Deafblind people together, rather than identifying with a cultural group. In one sense the factors of association, language, group identity and behaviour are part of that experience but they are also the result of that experience. The way people act and relate to the people around them is the result of the total Deafblind experience. This is the sense of "coming home" which is referred to above.

Deafblind culture or Deafblind experience?

My research suggests that there is no established Deafblind culture in Britain.

The reasons for this include:

- ◆ Deafblind people do not meet regularly enough - the basic principle of community life as a location for the sharing and transmission of culture cannot be realised.
- ◆ The absence of a unique language associated with Deafblind people.
- ◆ The aspect of touch is possibly the nearest we have come to defining an aspect of a Deafblind Culture, but this alone is not enough.
- ◆ The fact that many Deafblind people do not see themselves as "Deafblind" suggests their cultural identities lie elsewhere.

The Deafblind experience

However, I believe there is a common experience shared by Deafblind people and it is this that we need to understand in more detail. The questions we need to ask are:

- ◆ What does it mean to be Deafblind from the perspective of Deafblind people themselves?
- ◆ How do Deafblind people perceive the world around them?
- ◆ What are the means attached to these experiences?

It is these questions which have formed the basis of my second study which is now almost completed.

Conclusion

By definition culture gives meaning to life experiences. Therefore it is the experiences that become the foundation of a culture. It may be in the future that an understanding of the Deafblind experience and growing opportunities for the sharing of ideas amongst Deafblind people themselves will be the foundation of a unique Deafblind culture.

Prenatal genetic testing for deafness – do families want it?



Barbara Carmichael is a Clinical Nurse Specialist in Genetics and this study was undertaken as part of a Masters degree in Human Molecular Genetics with Counselling.

At the European Usher Syndrome Study Group meeting last summer in the Netherlands one of the participants, Dr Maria Bitner, from Great Ormond Street Hospital in London, described the work that Barbara has done with families. Barbara has kindly agreed to let us print this paper in full.

Introduction

Advances in genetic testing, and in the understanding of the genetic causes of deafness, mean that prenatal diagnosis for deafness has become a possibility for some families and is likely to become more widely available in the future. Although there is some anecdotal evidence that families might wish to use prenatal testing to avoid the birth of a child with deafness, there is limited objective information about families' views. A study was carried out asking hearing parents of deaf children about their views on prenatal testing in general, and on prenatal testing specifically for deafness. The families were also asked for their views on a new method of prenatal diagnosis, called pre-implantation genetic diagnosis (PGD).

Until recently there were two methods of prenatal testing available;

amniocentesis and chorionic villus sampling (CVS). Amniocentesis cannot be carried out until around 16 weeks of pregnancy. CVS can be done sooner at around 11 weeks, but carries a greater risk of causing miscarriage.

Prenatal diagnosis with amniocentesis has been available for over thirty years, and CVS has been in use for about twenty years. The number of conditions that could be detected using these methods was limited at first. Initially prenatal testing was used to detect conditions caused by a chromosomal abnormality, for example Down Syndrome. As technology improved, more conditions could be identified, but the real expansion in testing has come in the last decade, since we began to understand the underlying genetic causes of different conditions, and to identify the gene changes responsible.

Both amniocentesis and CVS require a pregnancy to

As technology improved, more conditions could be identified, but the real expansion in testing has come in the last decade, since we began to understand the underlying genetic causes of different conditions, and to identify the gene changes responsible.

have started before testing can take place. Parents who find their baby is affected have to decide whether to continue or to terminate the pregnancy.

More recently a different method of prenatal diagnosis has been developed. Preimplantation genetic diagnosis (PGD) combines in-vitro fertilisation (IVF) techniques with genetic diagnosis. Embryos are created outside the womb, and tested for the genetic condition before they are implanted. In this way parents can choose only to have unaffected embryos implanted, avoiding the need for invasive testing on the pregnancy later on. This method of diagnosis is theoretically possible for some families, but it is not yet widely available and success rates are low.

A study was carried out to gauge the level of interest in PGD, and to determine the views of hearing parents of deaf children about prenatal

testing in general, and on prenatal testing specifically for deafness.

The study

Thirty-two families were approached to take part in the study. They were identified from the records of patients who had attended a department of clinical genetics for genetic counselling. The criteria for inclusion were that the parents should be hearing; that they should have at least one deaf child, and that they should have undergone genetic testing for a common genetic cause of isolated non-syndromic deafness. The families were sent an initial information sheet, and an opt-out form to return if they did not wish to be contacted further. Families who did not return the opt-out form received fuller information about the different methods of prenatal diagnosis, and a questionnaire. One questionnaire was sent for each parent so that both had a chance to give their view. Seventeen completed questionnaires were returned, representing a 30% response rate.

The questionnaire

The questionnaire consisted of a number of questions requiring a Yes/No answer, and respondents were given space to explain why they answered as they did. A series of questions was asked about attitudes to prenatal testing specifically for deafness, and also for other conditions. The same questions were then asked in relation to preimplantation genetic diagnosis. Finally parents were asked which of a number of options they

would choose if they were planning another pregnancy.

Attitudes to prenatal testing

Parents were asked if they would consider prenatal diagnosis for deafness, with termination of an affected pregnancy. They were also asked whether they thought this should be available to others, even if they would not choose it for themselves. Most respondents (15/17) felt this was an unacceptable option for them, and 13/17 said it should not be available to anyone. Comments from these parents included

"Deafness is not a reason to abort the pregnancy. It is not life-threatening"

"Deafness in a baby is certainly not a reason for termination. A deaf child has as much right to life as a hearing one and can have an equally fulfilling life"

"Having a deaf child does put extra pressures on a family but that would never be a justifiable reason for termination."

One parent said she would consider prenatal diagnosis without termination of pregnancy in order to be prepared for her child's needs, should it be deaf. Of the two respondents, both female, who said they would consider prenatal diagnosis for themselves, with termination of an affected pregnancy, one commented

"I would not want the struggles in our lives, the heartache we have experienced, and the worry"

Those who felt prenatal diagnosis should be available made comments suggesting that it should be an individual

choice and recognised that some people might feel they could not cope with a deaf child

"If a person felt that having a deaf child would be an insurmountable problem for them, I would not wish to prevent them from having prenatal diagnosis"

Most parents (16/17) felt that prenatal diagnosis should be available for some conditions. Parents were asked to specify what sort of conditions they thought testing should be available for. The replies indicated that these parents felt it should only be available for "serious" conditions.

"Severe brain damage or very severe physical disability"

"For babies who would die young or be in constant pain ... needing medical support 24 hours a day"

Some parents took a broader view, recognising that "the answer is not black and white. It depends on the severity of the disability and then it's a very personal choice and depends on many circumstances"

Fourteen parents said that if they were at risk of having a baby affected with a serious genetic condition, they would consider prenatal testing with termination of an affected pregnancy. Parents who made further comments were generally concerned with the quality of life of the affected child, and also the effect on the rest of the family.

"To risk having a child with severe disabilities would be of great concern as it would affect the time I need to give to my current family"

"You must consider the quality of life the baby would have."

Those who felt prenatal diagnosis should be available made comments suggesting that it should be an individual choice ...

Attitudes to preimplantation genetic diagnosis

Parents were generally much more positive about this option, with 11/17 saying that they would consider it for themselves, and 15/17 saying they felt it should be available for others. PGD was clearly regarded as ethically more acceptable than prenatal diagnosis and termination of pregnancy.

"The moral dilemma of whether to terminate an affected pregnancy is much greater and more complex than the decision whether to implant an embryo"

"This appears a good solution – ethically acceptable"

Another parent (who would not choose prenatal diagnosis) stated: *"If I could eliminate the risk (of having another deaf child) I would"*

Without exception, parents felt that PGD should be available for other conditions. A wider range of conditions were seen as being suitable for PGD than for prenatal diagnosis, although generally parents gave examples of conditions which would be regarded as serious. When asked if they would choose PGD themselves to avoid the birth of a child with one of these conditions, 16/17 parents felt this was an acceptable option, with the one parent who disagreed stating her unwillingness to undergo IVF to achieve a pregnancy as her reason.

Although it is difficult to draw any firm conclusions from this small sample it does provide some indication of families views on the issues of prenatal testing for deafness.

Options for managing a future pregnancy

Parents were asked to give an order of preference to different options if they were planning a further pregnancy assuming all options were available to them. The choices were: no testing in pregnancy; prenatal testing and termination of an affected pregnancy; or preimplantation genetic diagnosis. PGD was the most frequent first choice, followed by no testing in pregnancy.

Impact of deafness on the family

To try to determine whether parents' decisions about prenatal diagnosis were affected by their experience of having a deaf child, they were asked whether they felt deafness had had an impact on the family. Their answers were categorised as being "positive" or "negative". Six parents felt that there was a significant impact which was generally negative

"incredible strain on the whole family."

"increase in general stress and anxiety. Less time for other children"

"sadly I feel it has had a very negative effect"

Three parents felt the impact had been positive

"It has totally changed the way I think about deafness. It has greatly enriched our lives"

"Our deaf child is so brilliant. We as a family are closer and support each other more"

Three parents felt that the impact on the family had been both positive and negative.

Summary

In this small study of a selected group of hearing parents of deaf children, there was low interest in prenatal diagnosis for deafness, with termination of an affected pregnancy. Although a significant proportion of parents felt that having a deaf child had affected their lives in a negative way, they did not feel that prenatal diagnosis and termination of pregnancy is an acceptable means of avoiding the birth of further affected children. Some parents felt the choice should be available for others. There was considerable interest in preventing the birth of further deaf children without undergoing termination of pregnancy. Although it is difficult to draw any firm conclusions from this small sample it does provide some indication of families views on the issues of prenatal testing for deafness.



Person Centered Planning

Dr Sheri Moore is an assistant professor in the Department of Special Education in the School of Education at the University of Louisville, Louisville, Kentucky USA. Sheri has experience of working with families to develop ongoing and flexible "futures plans" and in this article shares some of her ideas and tools for design!

A person centered planning process, Personal Futures Planning, has been presented in the literature for about 20 years. Personal Futures Planning /Person Centered Planning, "is an approach to designing support that is guided by the individual with disabilities that receives support, builds from personal strengths and vision, and results in practical action plans" (Flannery, Newton, Horner, Slovic, Blumberg, & Ard, 2000). It is a promising concept that has been underutilized within the educational and vocational professions. Wells (1994) details important characteristics of Personal Futures Planning as follows:

Personal Futures Planning is a process that focuses on the capacities and strengths of an individual in order to create a vision of a desirable future. Personal Futures Planning involves much more than the development of a written plan; it is an *ongoing problem solving process*. Desired changes come about through the efforts of a small group of people who voluntarily agree to meet over time for mutual support, brainstorming and strategizing. This circle of support is committed to taking action to ensure that changes will be accomplished for the individual. Personal Futures Planning differs radically from typical human service planning. Traditional planning

meetings tend to focus on deficits and problems. Personal Futures Planning, however, is a process that builds on capacity rather than on deficits; people who have participated describe it not only as "fun" but also as "empowering, exciting, and life-changing." People participating in Futures Planning come together to discover an individual's gifts, talents, and interests in order to create a shared vision of a more desirable future.

Personal Futures Planning is a process built on inclusion, and special care is taken to include the person whose life is being focused upon. The process is guided by a skilled facilitator who works to ensure that each participant is given an equal opportunity to contribute. People participate as equals; each person's contribution is valued and an important part of the process.

Mount (1994) has developed and conceptualized a number of important values and underpinnings of the Personal Futures Planning Process. Following on pages 16 and 17 is a chart summarizing important principles and tenets of the Personal Futures Planning Process and their relationship to supporting the transition process and the development of self-determination capabilities.

The chart illustrates how the development of a person centered futures planning

approach can maximize and contribute to the transition process and the development of self-determination skills and abilities. All three processes are interrelated and offer opportunities for developing and supporting the capacities of individuals with disabilities. The sooner these processes begin, preferably during the preschool years, the more time and effort can be directed to making a more optimal future happen. The Personal Futures Planning Process incorporates numerous steps to develop the future vision or dream, including: developing a personal profile; reviewing/incorporating trends in the environment; developing desirable images of the future; identifying obstacles as well as opportunities; developing strategies and action plans; determining individual responsibilities and team collaborative responsibilities for implementing the Personal Futures Plan (Mount, 1994).

A publication of the Minnesota Governor's Planning Council on Developmental Disabilities (1992) summarizes well the benefits of Personal Futures Planning:

Personal Futures Planning looks for doors and opportunities. It creates visions and captures dreams. It continually strives to be both visionary and extremely practical. The planning

The process is guided by a skilled facilitator who works to ensure that each participant is given an equal opportunity to contribute.

PERSON CENTRED PLANNING

PERSONAL FUTURES PLANNING PRINCIPLE

Personal Futures Planning Principle	Relationship to Supporting Transition Process	Relevance to Self-Determination
A creative process designed to help individuals with disabilities design a life of meaning and contribution.	Transition focuses on a meaningful life as a contributing member of society, as a major outcome. Obtaining meaningful and satisfying work as well as a full life in the community are basic to successful transition.	Individuals have opportunities for input and defining a life of meaning and contribution, based on their values and priorities.
Ongoing process of mutual discovery and education, culminating in an individualized plan for an optimal future.	Transition process should be fluid and ongoing, allowing for modifications as needed. The transition product, the Individualized Transition Plan (ITP), is highly individualized and specific.	Ongoing process of determining one's future direction based on individual preferences. Opportunity for "mutual support and discovery" during the self-determination process.
A team of people work together collaboratively for social change for the focus person with disabilities. Team members include the focus person, family, friends, peers, and professionals/service providers. The goals and values of the focus person drive the development of a Futures Plan.	Transition process is a team approach and collaborative. A good Personal Futures Plan incorporates the goals of the transition process. The planning team, from futures planning, would support the transition process.	The person with the disability has a collaborative team of support people to help them realize their goals related to self-determination. Values inherent in self-determination are "core values" of the Personal Futures Planning Process.
The team makes a commitment to work together to change the quality of life for the focus person.	Team commitment is essential to realize the successful school to work transition. An "in-place" Personal Futures Planning team forms the core or basis of the transition team, with additional team members added.	The focus person determines, defines and shapes their own "quality of life". They are supported by a team of people who are committed to helping them realize an enhanced quality of life.
A facilitator guides the process, and works to assure its implementation. The facilitator also keeps the goals and visions focused, with the assistance of the focus person.	The transition process needs the commitment of a "key" person, who maintains accountability for overall success of transition process. Overlap of some future planning team members in the transition process is desirable.	The focus person has a primary contact/support person/mentor to assist in their realization of self-determination goals.
The focus person is included as an active and valued participant. The person with the disability is the cornerstone of the work of the Personal Futures Planning team.	The satisfaction of the focus person is the ultimate measure of the transition plan's success. The person's values and choices need to be the basis of the transition plan. The person with the disability needs to be involved throughout the transition process.	The focus person is valued and largely determines their own future, based on their priorities, needs, dreams, etc.
The focus person, and often his/her family, invite/select the team members, including peers, family friends and relatives, professionals and service providers, etc. This team develops the Personal Futures Plan in a collaborative process.	The choice of transition plan "members" or team is determined by choices of the focus person and their family. This group becomes the "core" of the Transition Planning Team, with service provider's and professionals added as the situation dictates.	The focus person's personal preferences and choices are highly valued in defining and developing the collaborative team.

PERSON CENTRED PLANNING

Personal Futures Planning Principle	Relationship to Supporting Transition Process	Relevance to Self-Determination
<p>The team members collaborate to build a shared appreciation of the focus person's gifts, strengths, abilities, interests, and challenges. The Future Planning Process is highly individualized to showcase the focus person's unique talents, abilities, and challenges.</p>	<p>A collaborative effort guides the transition process, building on personal abilities and strengths. A capacity-oriented view of the focus person results in a more appropriate, positive, and often more successful transition plan.</p>	<p>The focus person actively participates in articulating their gifts, strengths, abilities, interests, and challenges. This process is "key" to working toward a shared vision of the future and the realization of self-determination goals.</p>
<p>The process is based on a capacity approach. Realistic but optimistic perspectives in the planning process are encouraged and supported. Challenges are addressed in creative and new ways.</p>	<p>Abilities, not disabilities, are emphasized. Capabilities are incorporated to develop a meaningful transition plan, which includes the individual's strengths. The plan is directed toward meaningful and satisfying work and community life.</p>	<p>Abilities and strengths are valued and intentionally "highlighted" as potential building blocks in the future. The preferences of the focus person are valued and critical to the process.</p>
<p>A life rich in community experiences and meaningful community membership is valued. This community membership is an underlying premise and goal of the Personal Futures Planning Process.</p>	<p>The ultimate purpose of the transition plan and process is to assure a positive and meaningful transfer to the world of work, and to a meaningful community life.</p>	<p>Individual preferences such as type of housing, location, job preferences, and recreation opportunities, are determined by focus person.</p>
<p>Creative thinking and creative solutions are encouraged. Creative solutions are found "outside" the established service system. "Dreaming" in new and different ways is encouraged and supported.</p>	<p>Developing a full life in the community, including employment, often calls for creative solutions to "barriers". The Person Centered Planning Process is designed to foster and encourage creative solutions, often outside of the existing service systems. This philosophy would be useful in developing an optimal transition process and plan.</p>	<p>The focus person makes choices and preferences, possibly incorporating and considering suggestions from team brainstorming sessions. Creative thinking from the focus person and on behalf of the focus person is valued as part of the self-determination process.</p>
<p>Options for the present and the future are not linked or dependent upon current or existing services.</p>	<p>The transition process sometimes needs to go beyond existing and available service options. Sometimes existing options are inadequate, inappropriate, or possibly not available.</p>	<p>The focus person can dream, without the limiting factor of existing service options/programs. The focus person's options can more truly be self-directed and self-determined, if not linked to existing services.</p>
<p>The team commits to becoming an ongoing source of support for the focus person and their family.</p>	<p>Transition team members will likely need to "revisit" the transition process at various life change/transition points. An ongoing team who knows the focus person well, would be the "core" of the "revisited" transition plan.</p>	<p>The focus person has ongoing support to make their choices/preferences/dreams become reality.</p>
<p>Team members work to both develop an optimal futures plan, and then to take responsibility for developing an action plan to make the plan a reality. Futures planning involves a commitment to ongoing implementation of the futures plan.</p>	<p>Successful transition plans require the collaboration and coordination of team members working together, to make the plan a reality.</p>	<p>The focus person determines what is an optimal future for themselves. Team members share responsibility to "make it happen" with the focus person in the "driver's seat" of the plan.</p>

process develops a true picture of the person, and describes the best possible future of the person in community. It then identifies problems blocking that future, and opportunities for progress.

Personal Futures Planning can make a difference in three ways: in the effect of being vision focused and person-centered; through the changes in the person's life which result from actions taken; and by changes in services and the system in response to the plan.

Working together, in collaborative teams, is important for people with disabilities, their families, support persons in their lives, and for professionals and service providers. Combining the process of person centered planning with transition planning, and incorporating self-determination values, will likely significantly enhance the lives of children and youth with disabilities. Beginning the person centered planning process in the early years of a child's life will enhance the opportunities for a more optimal future. Person centered planning can provide the framework for developing an appropriate and meaningful transition plan. Combining the values inherent in person centered planning, transition to work and community, and self-determination should result in richer lives in the community, and more optimal futures for our children and youth with disabilities. Person centered

planning should increasingly form the cornerstone and support for the transition process; person centered planning can also play a significant role as a support for the actualization of self-determination.

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The social inclusion of deafblind people within the European Union

How does the European Union impact on the lives of deafblind people? How do deafblind peoples' lives in Portugal compare to those living in Italy? These are just two of the many questions raised at a seminar in Brussels which took place towards the end of May, hosted by Sense International and its transnational partners, Casa Pia de Lisboa (Portugal), Lega Del Filo D'Oro (Italy), Sense (UK) and representatives of the European Deafblind Network.

66 delegates from 15 European countries attended, including 15 deafblind people, and heard keynote speeches from Richard Howitt MEP, Chair of the European Parliamentary Intergroup on Disability and Stefan Trömel, Director of the European Disability Forum.



Richard Howitt MEP strongly welcomed the Charter, describing it as an

excellent tool to use to pursue the rights of deafblind people within Europe, and telling delegates of his passion for the cause of deafblindness. He undertook to circulate this amongst MEPs and to promote a discussion on the issue of deafblindness at a forthcoming meeting of the European Parliament.

Delegates discussed in detail a series of recommendations flowing



Ove Bejsnap, Belgium delegate

from 18-months of research into the lives of deafblind people in Italy, Portugal and the UK. The result is a Charter, outlining the rights deafblind people are entitled to as citizens of the European Union, and a report entitled *Combating the Social Exclusion of Deafblind People in Europe* which is being made available to policy and decision-makers at European and national levels.

In his closing remarks the seminar Chair, Lex Grandia, Secretary General of the World Deafblind Union, captured the spirit of the meeting when he called on deafblind people to take a more active role in the politics of their countries and at a European level: "I wish that deafblind people would express their anger more in a political way. If you feel attracted to be a member of a

political party, do it. I want to see deafblind Members of Parliament. Unfortunately we have the responsibility to tell the story, hundreds and hundreds of times.

Unfortunately, we are getting tired of that from time to time, and that's the moment we need a conference like this: to meet together, and give each other the courage to campaign and campaign and campaign."

Copies of all materials, including a Guide to *Working with Europe for deafblind people*, are available in English, French, German, Italian, Portuguese and Spanish from Sense International, the transnational coordinators on si@sense.org.uk 11-13 Clifton Terrace London N6 3SR Tel: 020 7272 7774.



Antonio Pires and his interpreter at the meeting

Social exclusion campaign in Croatia: Moving towards rights of deafblind people

From July 2001 until April 2002 a campaign on the rights of deafblind people in Croatia was conducted with the title, 'Moving towards rights of deafblind persons'. The campaign was supported by Sense International, as part of a European-wide initiative on social exclusion.

At the UN Conference which was held in 1995 in Copenhagen, social exclusion was identified as one of the major problems of society, together with poverty and unemployment. Since then many examples of social exclusion have been recorded but none about the levels of social exclusion of deafblind persons living in Croatia. Never until now have deafblind people, themselves, had the right say what they really need.

The campaign

The Campaign, organised by DODIR, consisted of a survey about social exclusion. People were consulted at a

series of Round Table events that were held in 5 Croatian cities: Varadin, Osijek, Rijeka, Split and Zagreb. During the campaign many materials were produced, including brochures and leaflets about the specific rights of deafblind people. One of the most important outcomes was that the report was submitted to the government.

The survey:

Who took part:
50 deafblind people from all around Croatia, 27 family members and 27 social work centres.

The main findings:

- ◆ Social workers that are dealing with fulfilling rights of deafblind people in Croatia are not aware of definition of deafblindness and deafblind people.

- ◆ There is a discrepancy in the number of people identified: DODIR says 150 but social work centres have only identified 271
- ◆ The education of deafblind people is poor: 63% of people finished some kind of secondary schooling, but there are no highly educated deafblind people
- ◆ Half of the people expressed their discontent with treatment in schools
- ◆ 43% were discriminated against in access to employment and 70% of them had to leave their jobs because of their double impairment
- ◆ 77% are discontented with their treatment in stores, banks, coffee places, and restaurants
- ◆ 70% are discontented with treatment in ambulances and hospitals and in 53% say they cannot communicate with their doctor
- ◆ There are no services for deafblind people except those run by DODIR

Equal rights?

According to Croatian laws deafblind people have the same rights as other people with disabilities, but they do not have the services to match. However, DODIR concludes from this survey that there are serious levels of social exclusion in Croatia where 42 percent of the deafblind people who took part said they were virtual prisoners in their own home without any support, even from their families.



Colleagues at DODIR

Finding Our Way – exciting developments in East Africa

Deafblind work in East Africa has been growing steadily since its humble beginnings in the early eighties. Kenya, for the obvious reason that work started there first, has the bulk of deafblind programmes but as you will notice the other two countries Uganda and Tanzania are quickly catching up.

In a way Uganda and Tanzania are lucky. The pioneering work in Kenya was difficult because there was hardly anything already established to give a lead. We noticed early in the programme that due to cultural, economic and some other variants it would not be possible to simply replicate work done in the developed countries but it would be necessary to create a new way. For example we realised that the group home concept, which works well in Sweden, would not work in poor African countries. In its place community based rehabilitation was embraced and it was a wise decision!

The work already done here is the result of selfless endeavour between the donor communities, parents and government departments. We hope the co-operation will continue as the work expands.

Penny May Kamau sends this report from her Newsletter

The background to development

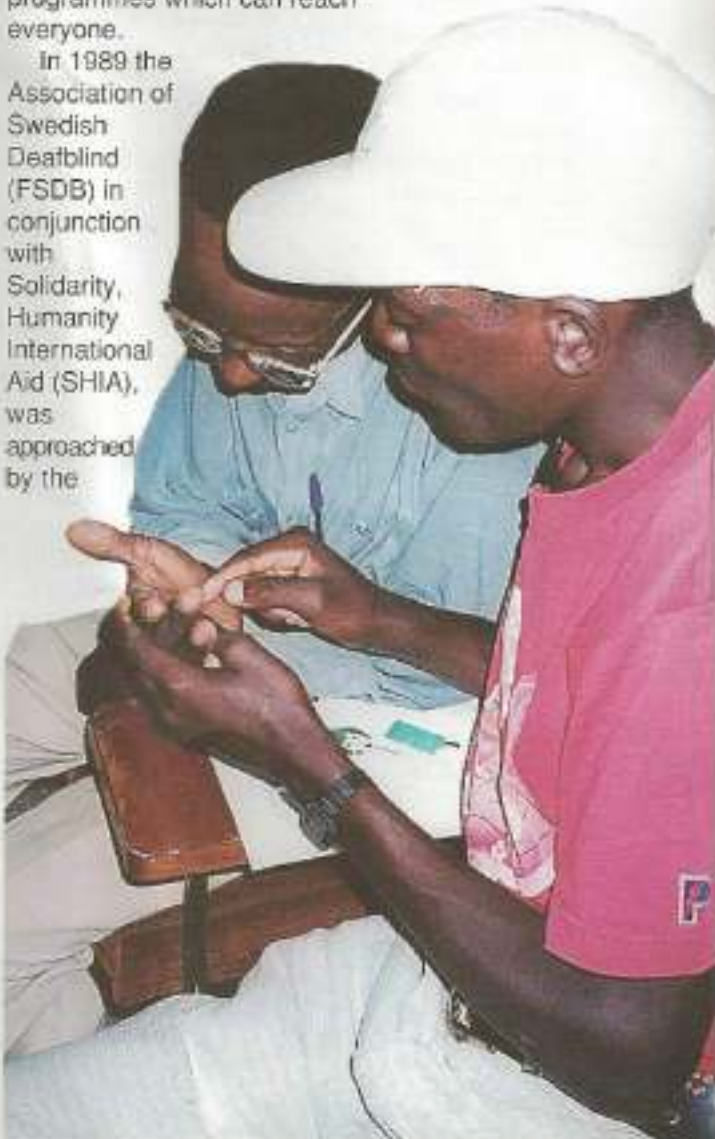
In 1985 the first education programme for deafblind children in East Africa was initiated by the Christoffel Blinden Mission (CBM) and started at Kuja School for the Deaf in South Nyanza, Kenya. Today the region can boast of seven primary school programmes and three vocational programmes for the deafblind, more than the whole of the rest of Africa together.

How did this development come about?

The deafblind population in the world is relatively small. In Africa we do not have any reliable statistics of the number of deafblind persons in the population, but it is possible that the figure could be much higher than in developed countries. This could be due to the high incidence of diseases such as malaria, measles, meningitis etc, and also due to the lack of good health care. However, it may also be the case that many children born deafblind and with complicated conditions do not survive beyond the early years.

As the deafblind population is relatively small and widely dispersed, it is very important to pool all available resources in order to provide the best quality programmes which can reach everyone.

In 1989 the Association of Swedish Deafblind (FSDB) in conjunction with Solidarity, Humanity International Aid (SHIA), was approached by the



Viktor Wafula (in white cap) and John Ngaira at the seminar for deafblind adults in Kakamega last November. Viktor and John are both former students of Sikri. Viktor is interpreting for John. John became deafblind as an adult and Viktor was born deaf and has very low vision.

Kenya government to assist in training teachers and support staff to work with deafblind children. This work began at Kabarnet School for Deafblind Children in Kenya, and at the Kenya Institute of Special Education (KISE). FSDB then started working in co-operation with CBM who all along had been sponsoring the education of the deafblind children both at Kuja and at Kabarnet.

As awareness on deafblindness grew and more children and adults were identified, a steering committee comprising of professionals from various fields was set up to oversee the development of the work in Kenya.

In 1991 FSDB started co-operation with the Hilton Perkins Foundation from the USA who have extensive experience in developing programmes for deafblind people around the world.

Together with the Kenya deafblind services committee, FSDB and Perkins decided to reach out to the neighbouring countries and help them develop programmes of their own and this marked the beginning of a very fruitful regional and donor co-operation in developing services for deafblind people in East Africa.

Teacher training

In co-operation with the Ministry of Education in Kenya, Uganda and Tanzania, the donors have been able to help train teachers of the deafblind. Much of the training has been done in the programmes directly as this has proved to be the most effective method. In addition to this several workshops for teachers have been held where teachers from all programmes in the region have had the opportunity to sit together and learn.

At present only Kenya and Uganda have developed programmes for vocational training of the deafblind.

A teacher exchange programme has also allowed teachers of the deafblind to visit other deafblind programmes in the region and share ideas, experience and knowledge with each other. Both the regional workshops and the exchange programme have given many teachers their first opportunity of travelling outside their own country which in itself has also helped them gain much valuable experience and confidence.

Teachers Networks

A strong network of teachers has now emerged in the region and the quality of teaching has been greatly improved.

Vocational Training

At present only Kenya and Uganda have developed programmes for vocational training of the deafblind. Through regional co-operation it has been relatively easy for Tanzania to benefit from existing programmes in Kenya and they have sent one student vocational training at Sikri Training Centre in Oyugis where there are courses for the blind, the deaf and also the deafblind.

Involving and working with parents as partners

The same approach has been taken in regard to the parents of the deafblind. Previously parents were not directly involved in the education of their deafblind children, but now they have been encouraged to play a more active role in their children's education. This has helped to ensure continuity even when schools are closed and the children are home.



Matthew Ochieng from Nyangoma in the Western part of Kenya. He is attending the meeting of deafblind adults and his interpreter is a deaf man. Ochieng has Usher and has almost totally lost his vision. He works at Nyangoma Primary School for the Deaf.

Getting together

Parents have now joined hands not only locally and nationally but also regionally. Every year parents representing every school programme as well as parents of those who have already completed school are given the opportunity to come together for a week during the regional seminar for the deafblind.

For many parents, the possibility of joining hands has helped them to accept and overcome the problems their situation presents.

Having the opportunity to visit other parts of the region is an education for the parents and many feel very proud of their deafblind children who have given them the opportunity to travel outside the country for the first time.

An extensive rehabilitation programme for deafblind young people and adults has been in place in Kenya for the last 5 years and much progress has been made. This is, however, an area where there is great challenge for everyone. There has been considerable success in the work but there are also many problems still to be solved. It is hoped that as the young children in the programmes mature, a similar programme can be established in the neighbouring countries to serve the children as they grow into adults.

Here is a just a flavour of all the activities happening in East Africa!

Sikri Deafblind Unit

There are currently 8 deafblind students at Sikri Agricultural Training Centre who follow courses in farming and animal husbandry as well as some handicrafts.



Alphonse John, 10 years old, totally deafblind and a student at Uhura Deafblind Unit in Dar es Salaam, Tanzania. In the picture he is washing his clothes - one of their daily activities.



Stakeholders in the newly launched Nairobi Deafblind Unit which will start at Kilimani Primary School.

Four of the students at the unit present a great challenge to the staff at the school as they are unable to cope in a group situation and need training on a one-to-one basis. This way of working was new to most teachers and therefore they have taken courses in how to work with these students, including special communication training, and preparation of individual education programmes.

There has been a lot of follow up on these students and parents have also been encouraged to be more actively involved.

Seminar for Deafblind Adults

As part of the support to young deafblind adults, a seminar was arranged to bring everyone together.

Parents were encouraged to attend the seminar to so that they may be more

actively involved in the welfare of their children.

The seminar was held near Kakamega in Western Kenya in November and was attended by 25 adult deafblind people, 27 parents and 8 facilitators. The weekend, which was a follow up of the seminar held last year, was a great success!

For part of the time both parents and the deafblind people were together sharing experiences and keeping each other up to date on their situation.

The main activities for parents were to have sign-language training and also to hold a formal meeting of the National Parent Organisation.

Parents were very positive about learning sign language as for many this was their first chance to learn the basics. It is hoped that there will be more opportunities for parents to develop their communication skills.

Deafblind people had their own forum where they were taught some basics of running a small business. There were a lot of healthy discussions and it is hoped that this will help them succeed in their own ventures.

They also shared a lot with each other concerning relationships. This arose as one participant had recently married and was experiencing difficulties in communication with his wife. Two of the participants who are happily married were asked to listen and then advise the young man accordingly.

A great challenge to the organisers of the seminar was the provision of interpreters to cater for all needs. Interpreting for the deafblind was a new experience for most of the interpreters. In spite of this they did a commendable job and their efforts were really appreciated.

As programmes for deafblind people develop in the neighbouring countries, it is hoped that the models used in Kenya for adult rehabilitation and for parental involvement can be applied there too.

Tanzania Uhuru Deafblind Unit

The unit for the deafblind is housed at Uhuru Mchanganyiko School in Dar es Salaam. There are currently seven pupils and two full time teachers in the unit who are assisted by three housemothers.

The unit has a new dormitory building which can house up to thirty children and great efforts are now being

made to identify more pupils.

Uhuru Unit has been host to several teachers of the deafblind from Kenya during the last year. These visits are very important as it helps teachers to plan appropriate programmes for their students and helps parents understand their role.

Uganda Ngora School for the Deaf

Ngora School for the Deaf offers both primary and vocational training for the deaf. Recently they accepted the first deafblind students and their progress has been remarkable.

Under the supervision of Mr Joe Morrissey, Director of the School, the two young

deafblind men have learned many new skills including agriculture, weaving, handicrafts and daily living skills. One of the students, Stephen has also begun to learn Braille.

The two deafblind students are taught by deaf teachers who have been able to concentrate a lot on their signing skills and this has greatly improved their communication and social skills.

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Stephen Imalingat, 19 years old and a student at Ngora School for the Deaf in Uganda where there is a vocational training for the deafblind. In the picture Imalingat is demonstrating his recently acquired weaving skills at the Regional conference in Jinja Uganda. During the time he was there he managed to sell all his products!

Working in Uganda

Dorte Eriksen, herself a deafblind person, has been to Uganda several times to meet deafblind people in this huge country. One of her tasks is to make them aware that they are not alone in their disability and that there are ways of communicating. In this article Dorte describes some of her experiences from her last visit ...

The Association of Danish Deafblind people is involved in a project in a Uganda. The aim of the project is to support deafblind people in Uganda. In the first place, this involves finding and teaching deafblind people sign language and giving

It is a great pleasure and challenge to work with this project. It means a lot to me. We really do make a difference in the area.

them knowledge about their disability. This can create the foundation of a feeling of togetherness.

In a democratic country, like Denmark, with an advanced social system we feel an obligation to help countries who are less developed. And the best way to do that is to share our experiences and show deafblind people in less well developed countries how we have managed to create a well functioning deafblind organization.

On the road and meeting people...

Along with our local co-ordinator, who is deaf, we had planned a trip to different areas of the country. It turned out to be a pretty hard one because of the bad condition of the roads and the huge distances in the country. Also, many of the deafblind people live in rural areas. Among others, we visited a



Dorte Eriksen (second from right)



In Arua, about 10 hours drive north of the capital, we met a deafblind man who lived in this village (pictured opposite) with his wife and 3 children. He was born with normal sight and hearing, but has become deafblind after a disease. He knows only very little sign language, so all communication with him is by shouting. He and his family expressed a great wish to learn sign language and guiding techniques.

15-year-old boy. He was working in the field when we arrived, but his uncle went out to get him. He was very interested in my fair skin – so different from those familiar to him!

Another day, we had planned a trip to Gulu about 450 kilometres north of the capital, Kampala. There turned out to be trouble in the area. Along the road, we saw many soldiers gathered with machine guns. And in Gulu we ended up spending the night at a hotel with two armed guards outside our door. But we managed to meet with a deafblind man anyway. He expressed a great wish for education in tactile sign language.

Close to Arua lived a young man born deaf who had gone to deaf school. He was selling bananas in spite of his very bad sight. He expressed great interest in the project and wanted to keep in contact with us.

I gave him a piece of paper with all our data, but he couldn't read it. I then gave him a magnifying glass, which he got completely carried away by – suddenly he could read the letters!

I also met a 12-year-old girl who because of her impairment had never gone to school. She communicated with her family by pointing at things, but it was very limited communication.

A different quality of life...

What counts for most of my experiences is that I have met people in Uganda who with few and simple "helping aids" or educational programmes would be able to experience a completely different quality of life than they do now. These are people who mostly feel totally alone with their disability, who are isolated and in the

best cases have very limited communication with their surroundings. That is why I will return to Uganda for a 3-months period in 2002. The aim of my travels will be to inform and educate people in sign language, tactile sign language and guiding techniques. Hopefully, many of the people that I met at my last trip will be there.

How the project has challenged me...

My own challenge is to learn the local sign language, so that I can speak directly with the people that I meet in the area. It is a great pleasure and challenge to work with this project. It means a lot to me. We really do make a difference in the area. It is a small difference, but the small waves on the surface can be felt too. And it is good for a beginning!



9th East Africa Conference for the Deafblind

16th to 20th March 2002 – Jinja, Uganda

"Mothers and fathers of deafblind children are now smiling" said Esther Sande, a mother of a deafblind child and regional representative for parents of the deafblind in the East Africa region.

Mrs Sande made these remarks when she delivered her speech during the opening ceremony of the 9th East Africa Deafblind Conference held in Jinja, Uganda from 16th to 20th March 2002.

The conference which was officially opened by the Minister for Disability, The Hon Florence Nayiga Ssekabira and drew 75 participants from the East Africa region. Heads of schools, teachers in charge of deafblind programmes, district education officers and

senior officers from Ministry of Education headquarters, interacted freely and worked together to discuss and improve their programmes. Representatives from FSDB and CBM also attended the conference.

Through the efforts of the Ministries of Education in the three East African countries of Kenya, Uganda and Tanzania and with support from The Association of the Swedish Deafblind (FSDB), Hilton Perkins, and The Christoffel Blinden Mission (CBM), the region can now boast 10 full time school programmes, a transition and rehabilitation programme for school leavers and adults. There is also a well-developed parent network.

During the conference parents had a two-day

meeting first where they were able to come up with issues to be forwarded to the administrators who joined the conference on the third day.

Each programme had the opportunity to report on their activities and any problems they may be facing and then to plan for the coming year.

The main issues that arose in the conference was the provision of enough trained teachers, salaries for support staff and how to organise more home visits and follow up for teachers.

Through the participation of representatives from the ministries of Education in the three countries many of these issues were discussed and new strategies formed to cater for the increasing demand for teachers and support staff.

Conference participants had the opportunity to visit to a new deafblind unit at the Uganda School for the Deaf in Kampala where they saw the programme in action and interacted with children and teachers at the school. The school had prepared a wonderful lunch for the whole group and deaf students at the school provided some excellent entertainment.

After the main conference a meeting of the East Africa Deafblind Committee took place at the same venue. Members heard reports from activities of organisations for deafblind people in the three countries and discussed ways forward.



Opening of Regional conference in Jinja Uganda. The Minister of State for Disability, Mrs Florence Nayiga Ssekabira, speaking. On her left is Sven Sjoberg, Director of the Association of Swedish Deafblind.

Yolanda Rodriguez – a truly exceptional woman

Yolanda Rodriguez studied modern languages and by the age of 36 she was a bilingual secretary working for the large, multi-national company Phillips. She had been married for 5 years and was expecting her first child. Unfortunately and tragically, due to medical negligence during the birth, Yolanda left the delivery room in a coma after an injection was wrongly administered in her spine. Consequently, she is deafblind and is paralysed, with some use of her arms only. As she began to recover Yolanda communicated by writing things down from her hospital bed. She said, "I could not hear, see or move my legs. I had lost my young life, my dreams, my home."

The only motivation was the support of the family and friends and especially her husband, Juan José. He also told her that she had a beautiful baby girl.

Yolanda found it very difficult emotionally to come to terms with what had happened. She was furious and desperate about it. But, typical of the woman we now know, she directed all this energy into studying and, after a time, she took a lifeskills course in Arkansas, USA. In time she learned Braille in Spanish and English and took correspondence courses from Hadley School in USA in world history and other areas of study. Laterly, she became involved with the National Institute for the Deaf and became an advisor on deafblindness and a translator in both English and Spanish. At the 4th Helen Conference in Sweden she presented a paper. At the 5th DB conference she met Stig Olson and this led her to write a



Yolanda Rogríquez and Juan José

proposal to set up POSCAL project. As a result she has been involved in conferences and training sessions.

Recognition of Yolanda's achievements have come from many countries: she received an award in 97 – out of 32 candidates – called the CAFAM award. In 2000 she received the Lady of America award from Puerto Rico and most recently the Richard Kidney award

at the Helen Keller Conference. As Yolanda says about her own life "with courage and love I have learned to be happy with my husband and my daughter and the rest of the world ... and mainly my own"

She has put deafblind people on the map and inspired other people to think 'it's not just me.'

Ximena Serpa

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Communication Network

The bad news first ...

Over recent years, the Communication Network collaborated very closely with the CNEFEI, a teacher training centre based near Paris in Suresnes. At the moment, our main partners in this centre are Alain BONY and Nathalie LEWI-DUMONT who succeeded Monique SIROS (who has now retired) and Josiane BRACHET.

We also have had a lot of contact with Jacotte DUPLENNE another CNEFEI staff member who was in charge of international programs. Maybe some of the participants in the courses remember her? Jacotte was a nice and very active colleague. She was also the Deputy Mayor of a town near Paris. On the 27th of March, at one o'clock in the morning, at the end of the meeting of the town council, a mad man drew a gun and killed 8 members of the council. She was one of them. There was no reason for that crime except madness. We will miss her ...

Progress and plans ...

After the successful European Seminar which took place in May 2001 in Paris and the participation in the Network Day during the Dbl European conference in The Netherlands, the Communication Network is now working at planning further developments for ongoing research. In most of the European countries, research activities developed in relation with the topics that the Communication Network has initiated, are in full swing. Now we can say now that this network has really expanded a lot, which means that the future tasks consist of sustaining the development of these national and transnational activities and to develop further research.



A meeting of the core-group will take place in Paris from 29th to 31st of May. During this meeting we will address the definition of our research topic eg. to identify how, within the process of communication, the fluent use of body language (mimetics), sign language and possibly speech in the case of C.I., can help a child develop language skills that are complex in nature and coherently part of the flow of exchanges between the child and his worldly and social environment.

Activities and Events

Nothing is planned so far, but possibilities exist for using events organised by Dbl (Toronto Conference) or NUD (Gatherings, Aug 29-31: Sensation, Perception and Meaning-making) to help clarify concepts and produce material.

We think also of having an expert seminar as a way to prepare another big event in 2005.

We also think of developing exchanges with our colleagues in Russia or America.

We hope that we will be able to give more precise information in next issue.

European Usher Study Group

Advances in genetic science raise ethical issues that confront all of us especially, families with genetic conditions such as the Usher syndromes.

At the 10th European Usher Study Group in Holland, July 2001 Maria Bitner from Great Ormond Street Hospital for Children in London in her paper raised the subject of prenatal testing or pre-implantation genetic diagnosis (PGD). Her paper was based on an investigation carried out by Barbara Carmichael a Clinical Nurse Specialist in Genetics with families of deaf children to find out parents views on prenatal genetic testing for deafness. 'Prenatal genetic testing for deafness- do families want it?', undertaken by Barbara Carmichael, is reproduced in full in this issue of Dbl Review. It is thought provoking and we would like to thank Barbara and Maria Bitner for sharing the results of this study.



One of the other outcomes from the EUSG is that some of the scientists present got together with Sense to work on a proposal to carry a National Collaborative Study on Usher in the UK. The proposed study will take 3 years and involve 200 Usher families. We are waiting to hear about the funding, of course. If the funds are granted we are sure that such an in depth study could have positive outcomes for

people with the Usher syndromes worldwide.

Lastly, I have been approached by the Canadian Deafblind and Rubella Association to hold an Usher Study Group just before the 13th Dbl World Conference (5th-10th August 2003) in Mississauga, Ontario. The proposed dates for the Usher Study Group are Sat 2nd-Sun 3rd Aug. I am working with Connie Miles from the USA in trying to put a programme together. More details will appear in the December issue of Dbl Review.

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Charge Network

New Member

The CHARGE Network is pleased to welcome Corinne Blouin to the Development Group. Corinne is a colleague of Jacques Souriau works for CRESAM, France.

CAUSE

The CAUSE Project (CHARGE and Usher Syndrome in Europe) is gaining momentum and a report of the trans-national meeting is on page 32.

A date for your diary

The Cause Conference will take place at The Hanover International Hotel, Hinckley, Leicestershire, UK on 27th-30th March 2003.

New Email Address

Please note that my new address is as follows:
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David Levey
CHARGE Network Coordinator
CAUSE Project Coordinator
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David Levey



Liz Cook reports...

Charge and Usher Syndrome in Europe

Poitiers in France was the venue for the 2nd meeting of the CAUSE project partners, which was held over a weekend in May.

CAUSE is a project funded by the European Union Rare Diseases programme, which aims to promote work with Usher Syndrome and CHARGE across Europe.

This will be done through the production of leaflets and information packs; the development of a CAUSE website and through undertaking surveys across the partner nations. Additionally, the project will hold a conference, bringing together the European Usher and CHARGE Networks.

Problems with the air traffic control computer in the UK on our morning of travel delayed the UK group and unfortunately meant that our colleagues from Ireland were unable to get to Poitiers for the weekend.

David Levey (the CAUSE project Co-ordinator) and Liz Cook from Sense opened the meeting, on the Saturday morning, with an overview of developments on the project since the last partners meeting held in London last December. This included the preliminary planning work for the conference; setting up a website for the project and developing sub-groups within the project partners meetings to advise on aspects of the project specifically relating to Usher and CHARGE.

Representatives had been asked to bring to the meeting examples of resources, such as leaflets, videos and information folders, produced by their organisation on Usher and Charge. We spent some time on the first morning looking at these to develop an impression of what was available across the partner nations; to identify resources that

could be shared under the umbrella of CAUSE and to highlight gaps in the information currently available.

Later, discussions continued in the sub-groups; with the focus on the Saturday being the development of a structure and theme for the conference. On the Sunday we talked about the information to be produced by the project and survey's that could be undertaken across the partner countries.

Although much of the weekend was spent in intensive discussion, we also found time to enjoy the sights of Poitiers; together with the local cuisine and to informally learn more about the work of the other partner organisations.

By Sunday lunchtime we agreed that the meeting had been extremely productive and provided us with the momentum to develop the project further. In summary the



project partners agreed on the following:

- ◆ The CAUSE conference will take place at the Hanover Hotel, Hinckley, Leicestershire from 27-30 March 2003. The conference will be an event for families and people with Usher and CHARGE, together with professionals. The organisers plan to provide a leisure club for children and deafblind people who will not be taking part in the main conference programme.
- ◆ The conference will include plenary sessions on "Adapting to Change" and "Identity and Being"

- ◆ The project will produce a CAUSE information folder, with information about Usher and CHARGE and the respective European Networks, together with an extensive bibliography of materials available throughout Europe on the two conditions. An editorial committee has been formed from the project partners to oversee this work.
- ◆ The project will undertake two surveys. The first will be a behavioural survey of children with CHARGE: an extension of work that has been initiated in France and the USA. The second will be a lifestyle survey of adults

with Usher, which will possibly be presented in the form of video interviews with individuals from the partner nations.

For further information on the CAUSE project, please refer to the Deafblind International website (CAUSE pages will soon be added) or contact the Project Co-ordinator David Levey LEVEY2000@aol.com. David may be contacted by post c/o Sense, 11-13 Clifton Terrace, London N4 3SR.

Liz Cook
Groups and Membership
Manager, Sense

MDVI Euronet

**Meeting in Lisbon,
14-16 March 2002**

**Report from Kent
Lundkvist**



Last March, coordinators of MDVI Euronet, the recently formed European network of professionals from organizations involved in the education of children and youth with multiple disabilities including visual impairments, met in Lisbon to discuss projects and activities to be developed by the Network. The meeting was attended by members from Italy, Sweden, Ireland, Portugal, Czech Republic, United Kingdom and Germany.

The group had already identified nine working targets during an initial meeting in Dublin, warmly hosted by St. Joseph's School for the Visually Impaired in April 2001. These targets are:

- 1 Assessment and visual assessment,
- 2 Early intervention & family support,
- 3 Mobility for visually disabled children and youth with additional disabilities,
- 4 Changing from school to resource center. Inclusion
- 5 Teacher/staff training. Pedagogical materials.
- 6 Prevocational training
- 7 Visually impaired children with emotional disturbances
- 8 Communication
- 9 Implications of change in the population in assessing models, education strategy, etc.

The goal of Lisbon's meeting was to give MDVI's activities an official start by deciding on specific topics

to address in the near future, as well as identifying tasks to be achieved and discussing applications for European Funds.

The group also decided on a logo to identify MDVI Euronet, and worked on a poster to be used at the ICEVI Conference in Amsterdam as a visual illustration of the network's main concerns. The poster identifies four of MDVI's priority areas, i.e., Resource Centres, Independent Living, Staff Training and Changing Needs.

Each coordinator attending the meeting selected and discussed with the whole group aims and methodologies to be used in the development of projects based around the 9 targets.

Getting in touch

The Coordinators of each of area will contact group members interested in the subject to inform them about projects and motivate their participation. Groups welcome professionals interested in the area who want to share and discuss their knowledge and practice. Anyone interested in a particular topic is encouraged to contact the group coordinator or the MDVI Euronet chairperson, kent.lundkvist@sit.se

The group also decided to apply for European funds to support four main projects:

- 1 Early Intervention and Family support
- 2 Implications of change in population in assessing models and education strategies
- 3 Access to the environment through mobility and communication.
- 4 Changing from school to resource center. Inclusion

MDVI Euronet is a three-year project, working mainly through the use of internet services.

Coordinators of each of the nine topics will meet once a year to assess progress and define new directions for the Network.

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Visually impaired children with emotional disturbances
Pauline Carmichael
pauline.carmichael@rnib.org.uk

Group 8
Communication
Kevin Tansley
kevin.tansley@ukgateway.net

Group 9
Implications of change in population in assessing models, education strategy, etc.
Patrizia Ceccarani
ceccarani.p@legadelfilodoro.it

Staff Development Network

We reported in the last issue that following the European Conference in Holland the Network had opened up to invite all individuals who were interested in aspects of staff development to join. The network session had concluded with a wish to bring people together to share focused aspects of staff development across national boundaries. Three interests emerged from those present. It was proposed that people would share ideas and information via email and one person volunteered to chair each group.

The 3 groups that emerged were:

- ◆ Staff development for those working in services for congenitally deafblind people – this group is chaired by Paul Hart of Sense Scotland on Phart@sensescotland.org.uk
- ◆ Use of technology for learning – this group is chaired by John Mascia from the Helen Keller Centre NY on HKNCFIELD@aol.com
- ◆ Practice Development with staff – this group is chaired by Maarten Vegting from Sense on mvegtin@sense.org.uk

Further exploration of whether there is the possibility of setting up formal egroups or having access to the DBI website to enable people to exchange ideas is still to be explored.



Virginia von Malachowski

Virginia von Malachowski on vvonmal@aol.com



Australia Political activity

Regional news
from Mike Steer



1 A National Forum on Deafblindness was held in Sydney on 5 and 6 July 2001. The event resulted from letters written by the Australian DeafBlind Council (ADBC) to the Commonwealth Minister for Family and Community Services and brought together some 50 participants from all over Australia. Hosted by the Royal Blind Society of NSW, recommendations from the Forum were framed as a package to be presented to the National Disability Advisory Council for inclusion in on-going negotiations over the Commonwealth-State Disability Agreements. The Agreements are the periodic vehicles for determining national and state-level services' funding priorities.

2 Blind Citizens Australia (BCA) is Australia's large and influential special interest group representing the needs of some 280,000 Australians who are blind or significantly vision impaired. Its mission is to achieve equity and equality for its members through empowerment, by promoting positive attitudes and by striving for high quality and accessible services. At its impressive, highly organised National Convention in North Sydney in September last year, the unique needs of Australians who are deafblind received much discussion. As a result, the following resolution was passed:

'This Convention recommends to Blind Citizens Australia that in order to address the needs

of people who are deaf-blind, it work with the Australian DeafBlind Council and the National Disability Advisory Council to have deaf-blindness recognised as a specific disability in the Commonwealth-State Disability Agreements which are currently being negotiated, and to have specific funds allocated for deaf-blind services under these agreements.'

This development was a direct result of the participation of several of the BCA's national leadership personnel in the National Forum some months earlier.

National Council News

Irene McMinn of New South Wales has again been elected President of the Australian DeafBlind Council for 2002. Other office-bearers include Michelle Stevens of Victoria (Vice-President), Sharon Barrey Grassick of Western Australia (Secretary) and John Finch of the Victorian DeafBlind Association (Treasurer).

The ADBC committee has overcome the "tyranny of distance" and is now meeting over the Internet rather than by teleconference as it has in the past. For the first time, all committee members now have email accounts, so that meeting agendas and comments are circulated by email. This has a number of advantages. There is no longer the expense of interpreters and telephone links, and committee members can respond to agenda items at their own pace.

Some of the topics currently being considered by

national committee members include:

- a) ADBC funding issues
- b) differences in service provision between the states
- c) the cost of adaptive technology and aids
- d) outcomes from the National Forum and
- e) national organisational issues related to Deafblindness Awareness Week.

Bob Segrave, who retired in July of 2001, is now back in harness as part-time administration officer of the ADBC. Bob's can be contacted at bob@segrave.net.

ADBC

THE AUSTRALIAN DEAFBLIND COUNCIL

The ADBC Web site

More than 11,500 visits have been made to the ADBC Web site since it was initiated in 1999.

The site is at <http://internex.net.au/dba>.

New definition

The New South Wales Department of Education and Training (DET) has recently taken steps to redefine those it will accept as deafblind for purposes of receiving additional resources. In order to be considered deafblind in the public schools of New South Wales, as of February 2001, the new definition is as follows:

'Students must have a hearing and vision impairment, both at levels that severely impact on their ability to learn and which result in unique educational needs. In particular, these

**Australia**

continued

students will require an alternative means of communication (generally a tactile system) and/or highly specialised technology to facilitate their communication.

There must also be evidence that the combined impact of the dual sensory impairment requires an intensive educational provision beyond that provided for students solely with hearing or vision impairment, or severe intellectual disability.

In order to qualify for additional assistance at school, the approval of a Coordinator of Student Counselling and Welfare is required, together with a Coordinator of Special Education (both are positions at senior specialists in the DET system), before a student can be confirmed as having met the criteria.

Australian National Conference 2002

The Sixth Australian National DeafBlind Conference "Touching the world"

will be held at the

Francis Lloyd Function Centre
24 John Street
Lidcombe

New South Wales

from Friday 12 to Monday 15 July 2002

More information from:

DeafBlind Association (NSW) Inc.

PO Box 1295

STRATHFIELD NSW 2135

Fax 001 61 2 9745 6714 or

001 61 2 9642 7734

Australia

New Premises to offer a world of opportunities



Celestine Hare
from the
Deafblind Association
reports...

In 1967 The Deafblind Association was founded by a small group of parents who believed that collectively they could help children with deafblindness and other disabilities achieve skills and options for life. Since then we have overcome many of the real and tangible barriers to achievement for people who have deafblindness.

However, many deafblind children and adults have limited opportunity to improve life skills and options due to the difficulty in accessing services and carers. That's one of the key reasons why we have purchased the new building in Riversdale Road, Camberwell. This location is centrally situated and the

area is well serviced with public transport. The building is designed to help people with restricted mobility to move freely in an open and safe environment.

The internal hydrotherapy pool is one of the most exciting features in the new building offering new experiences in mobility, training and movement therapy for people living with disabilities. The pool will also be well utilised by community groups for rehabilitation therapy. This will help to build awareness of our organisation in complementary areas of health care.

The purchase of the Camberwell facility will release the Association from

paying heavy costs on rental properties. This secure investment will achieve significant capital growth in the years ahead and provide a solid foundation on which future plans can be made. It is timely that the Association is able to make this commitment to our future and to show strong fiscal management and stringent governance of the fund we receive from donors.



Czech Republic



Jan Jakes writes that he is very busy with his work at the University but he is the organiser of a general meeting of the Czech self-help association of deafblind persons. In this group they are always looking for new ways to promote and develop better interaction between deafblind people and their environment. To contact him: jajakes@volny.cz

Romania



Andrea Hathazi, a teacher at the Unit for deafblind pupils in Cluj, has started to extend her work into the area of acquired deafblindness. She has developed a questionnaire and goes to the school for deaf children where, with the help of a teacher, she is assessing children. Although to date no children with Usher have been identified, some children have been identified with low vision and as a result have visited the ophthalmologist to have spectacles fitted.

Slovakia

Janka Sarisska reports a major breakthrough in Slovakia...



The school for deafblind children in Garvenica will celebrate its 10th anniversary this year. During the entire 10 year period we had to advocate for the right conditions for the education and upbringing of deafblind children and then we had to fight for them to be accepted. The main problem was to persuade the decision makers in the government that the ratio one teacher to one student in deafblind population is appropriate. I achieved this, with the support of my staff by inviting the officials from the local authorities and from the Ministry of Education to visit our school. The most important breakthrough came

when I wrote the Ministry of Education to ask for this problem to be solved by creating the legislation to include deafblind children. As a result we received an inspection and two professionals verified the whole process of education and upbringing in our school. The result of this inspection came out very well. After that, in the cooperation with the official from the Ministry of Education, we worked out the proposed legislation. I am very happy that after 10 years from the establishment of the deafblind school we achieved the following: "On the 6th of March 2002 was approved by the Ministry of Education of Slovak Republic no. 293/2002-9, by which is determined the number of pedagogical employees and other employees at schools. The normative number of the teachers for deafblind children is one teacher for one student."

Latin America

Ximena Serpa

POSCAL

POSCAL comprises of 14 countries; Argentina, Chile, Uruguay, Brazil, Bolivia, Ecuador, Colombia, Venezuela, Dominican Republic, Cuba, Nicaragua,



Guatemala, Honduras, Peru. 13 of these have associations for deafblindness and are affiliated to the Latin American Federation of the Deafblind, an umbrella organisation that emerged from Poscal.

POSCAL has completed its first aim of creating the Latin American Federation of the Deafblind. Every country has now completed a training course to bring them up to the same standard.

Columbia has now completed a 'strengthening' course that was developed by the National Federation of the Deaf in Columbia who took the principles of their deaf course and modelled it to be

used with the deafblind. This course was very successful in Columbia and it is hoped that the people who completed the course will be able to train others in the course in the future and multiply their knowledge in that way.

POSCAL is now selecting another country to receive the same course. Countries have applied and are trying to prove they are active and working hard – the best candidate will be selected to receive the course!

Aims for the year are to provide the 'strengthening course' to one country and to keep improving the way that the organisations are working.



RUSSIA

Irene Solomatina (pictured) and Olga Kuzmicheva from the Usher Forum in Moscow tell us about an exciting new project they are planning...

In February this year, Irene Solomatina from Usher Forum in Moscow, Marjena Zaorska from Poland, Tatjana Basilova from the Teaching Institute in Moscow, and Lydia Dymisky from Belarus met together and discussed the idea of a student conference on sensory impairment. There is currently no educational institution in Russia able to develop training for teachers of deafblind/msi children. The project proposal is for 3 countries (Poland, Russia and Belarus) to hold student conferences for students who have been working for less than 3 years in the MSI field. These one-day conferences will be open to undergraduates and post-graduates from a number of different disciplines including medical, psychological and sociological. The language of the conference will be Russian and participants will be encouraged to exchange materials and broaden their awareness of and interest in

MSI issues in a language that they are comfortable with. The aim is to allow students and young professionals within the field to have fun together as specialists and thereby increase their self-confidence. The financial arrangements have yet to be confirmed but it is hoped that the first conference will take place as planned.

Usher Forum

The work is continuing in two geographical areas: St Petersburg and Ufa. The work in St Petersburg is coordinated by Audrey Markov who is congenitally blind with a progressive acquired hearing loss. There are currently no services for deafblind people in St Petersburg. However, Audrey has found 5 families in the area who have children with single sensory loss and additional disabilities and has given a presentation to the group about his own experience of living with sensory loss. It is hoped that this group will continue to meet and offer support to its members.

The work in Ufa is coordinated by Nina Markov who has Usher Type 2 and works as a guide communicator and advocate for deafblind people. Nina has already made contact with 30 individuals in the area who are deafblind. Following a visit from Irene in February this year, Nina has held 3 networking meetings for deafblind people with approximately 10/15 people attending each meeting.

Usher Forum are excited about the developments in both these regions. Their aim for the future is for the Usher Forum to remain in Moscow

and to have smaller independent, affiliated groups in other cities. It is hoped that if these groups can remain independent and autonomous then hierarchy and bureaucracy can be avoided. Usher Forum would like to be in a position to offer advice and support to its groups but not govern them. Usher Forum itself now encompasses not only people with Usher Syndrome but also other deafblind people, both with congenital and acquired deafblindness. It is planning a series of seminars in the Autumn in Moscow and will invite all of its deafblind members. Other events planned include: speaking to teachers about teaching deafblind/Usher children; holding a parents seminar to encourage them to get together; running a seminar for campaigning and lobbying activists from other disability organisations to find common ground; leading a training course for Guide Interpreters. The Guide Interpreter course will be run twice a week in the evenings in Moscow from October 02 - April 03.

It has also recently received a grant from Humanitarian Aid to give out vitamins to the families of the deafblind children that they work with.



UK

The 4th Professional Development Programme

Emma Fisher reports:

During the months of September and October 2001, Sense International hosted its 4th Professional Development Programme (PDP). Established in 1996, the PDP provides professionals in countries, where specialised training is not available, the opportunity to develop their skills in the field of deafblindness. In total, 22 professionals from 13 different countries have benefited from the PDP.



On September 10th 2001, 5 participants from India, Kenya and Romania came together for the start of their 6 week training programme. They were:

Sumitra Mishra, National Training Co-ordinator with Sense International (India);
Leela Agnes, Programme Officer for the Community Based Rehabilitation programmes of the Holy Cross Service Society in Tiruchirapalli, Tamil Nadu;
Stella Kamau, Teacher at the Nairobi Parents of Deafblind Childrens Unit;
Andrea Hathazi, Teacher at the deafblind unit in Cluj; and
Monica Marin, Teacher at the deafblind unit in Bucharest.

During their 6 week stay, participants took part in a mixed programme of formal and informal training, with visits to deafblind

programmes and placements involving more than 20 centres and 50 trainers throughout the UK.

Now back in their respective countries, participants are working on a follow-up programme with support from Sense International. These include the development of a Teachers' Network in India, developing the Community Based Rehabilitation (CBR) programmes in Southern India, developing a training course for undergraduates in Romania, creating a multi-sensory stimulation room for children in Bucharest and establishing a deafblind unit in Nairobi.

Sense International will be running its next PDP in autumn 2003 and if you would like to find out more about the programme, please contact Sense International at sl@sense.org.uk

Croatia

Another Award to DODIR



Martina Stabi from DODIR writes:

After receiving the prestigious City of Zagreb award, which we won in 1999, and the Award for Young Businessman in Year 2000 we have, yet again, had recognition for our work with another award!

To celebrate the International Year of Volunteers, the Government of the Republic of Croatia's Office for NGOs recognised the achievements of 12 NGOs and 12 individuals who have promoted the development and systematic evaluation of volunteering. The Premier, Ivica Racan, personally presented "DODIR" with their prize for

this work. President of DODIR, Mrs Sanja Tarozay, used this occasion to highlight the fact that volunteers come from all groups in society and that DODIR places importance on including elderly volunteers and those with special needs. DODIR is particularly proud of its volunteers who are deaf and who are giving a huge amount to improve the quality of life of deaf and deafblind people.

Special guest of the evening was UN Ambassador of Goodwill, Heather Mills, who came with Paul McCartney. The Premier, Ivica Racan, acknowledged her work to improve the quality of life of disabled people and presented her with the special sculpture

"DODIR", work of deafblind artist Mr Dusan Dosenovic. Heather Mills said that in her life she had received many awards, but this one was very special indeed.

At the cocktail party afterwards DODIR's deafblind members and volunteers were very excited at the chance to meet the President and a famous Beatle at the same time!

"DODIR" will also benefit from the events organised by the Board of the American Chambers of Commerce in Croatia as part of a charity week as it will be the main beneficiary. The money will help DODIR to equip educational and rehabilitation spaces and with this important support, raise its profile

**India**

Subhash Datrangé, a Member of the World Blind Union task force on Low vision and Member of the Consultative Group on Low Vision, Government of India writes:

The idea has been in the air for some time now that an Institute of Low Vision Rehabilitation and Research be established in India with an International or Regional status. The brief concept note on ILVRR below explains the broad vision behind the project.

The idea may interest Corporate citizens, leading Foundations and Charities, Individuals with celebrity status and makers of Low Vision aids, ophthalmic equipment world-wide.

International Institute for Low-Vision Rehabilitation and Research

There are 140 million people with low vision in the world and 28 million in India alone. They are neither blind nor

fully sighted. The problems of low vision care, education and rehabilitation have largely gone unnoticed because their disability is disguised.

The world over, greater emphasis is currently being placed on finding solutions to the difficulties people with low vision experience. Strategies are being developed to impart skills and for empowerment.

India has a large pool of technical, scientific and ophthalmic personnel. The country is in a unique position to give a professional lead for promoting low vision rehabilitation, world-wide.

She is eminently suited to set up a Global Institute of Low Vision Rehabilitation & Research for developing new tools for evolving effective solutions to problems.

The proposed Institute will have state of the art facilities, including a library, for

carrying out research, field studies, investigation and experimentation, besides conducting training programs for low vision professionals. The Institute will also have R&D workshop for developing low vision devices & production facilities, and a resource centre.

A centre of such or comparable magnitude and scope is not to be found anywhere in developing countries. Setting up such an Institute will therefore place India on the low vision map of the world. We will therefore do well to establish such an Institute of excellence.

Responses, feedback and comments in general may be mailed to subhashdatrange@yahoo.com or faxed on (91)(22) 5244017. Subhash Datrangé would be happy to assist in the planning & execution of this prestigious project

NUD

Elin Ostli reports

- Lea Hyvärinen, the well-known medical specialist from Finland published a CD-rom on Assessment of Vision last year. It can be ordered at Lea-test. Her homepage contains LOTS of information and has pages in English, German

and French in addition to Finnish and Swedish.
<http://www.leva-test.sgi.fi/>

- Mr. Stig Ohlson, a former chairman of the Swedish Deafblind Association, was elected president of the

World Federation of Deafblind People. He gave an inaugural speech at the Helen Keller Conference in New Zealand.
<http://www.deafblind.org.nz/hkstig.html>

Apology

DbI Review no. 27 (June 2001)

Deafblind Education: a case study in Mampong-Akuapim – Mrs Grace Gadagbul

We have received correspondence from Mrs Agnes Akapo, Headteacher of the Demonstration School for the Deaf in Mampong-Akuapim about some of the factual information contained in this article. We have extended an invitation to Mrs Akapo to write about the school to set the record straight.

Researchers identify Alström syndrome gene

Sandra Surette, from Alström Syndrome International reports:

When our daughter, Cheryl, was diagnosed with a rare, genetic condition in 1990, we were told never to expect research into the disease that plagued her.

Today, we are very pleased to inform you that researchers of the Jackson Laboratory in Bar Harbor, Maine (USA) and the Division of Human Genetics at Southampton University (Britain) have identified the gene that causes Alström Syndrome. Beyond this discovery, we now have hope that further medical research may eventually bring forth treatments and perhaps, even a cure, for the disease.

Alström Syndrome is a rare genetic disorder characterized by early blindness or visual problems –

retinal deterioration, nystagmus and photophobia, sensory neural hearing loss, childhood obesity, diabetes, heart problems and other organ system failure. There are only 175 cases of the syndrome known to exist in 23 countries. More information on the syndrome can be found at www.jax.org/alstrom.

About Cheryl...

Our daughter is now 12 years old and she just wants to be like every other kid. Alström Syndrome is difficult for her to deal with. I compare it to most kids who live with monsters under their beds; our daughter must live with this Alström monster inside of her and it scares

her. She is apprehensive of what her future will bring and we have explained to her that the gene discovery is indeed good news.

In addition to what the discovery could mean for Alström families, scientists are excited about the far-reaching implications the resulting genetic research could have for other conditions. Diseases such as diabetes, obesity and even some retinal problems may benefit from the gene discovery in that perhaps it will unlock secrets common to them all.

In the end, it offers us hope. We can only pray that good things will continue to come from this discovery.

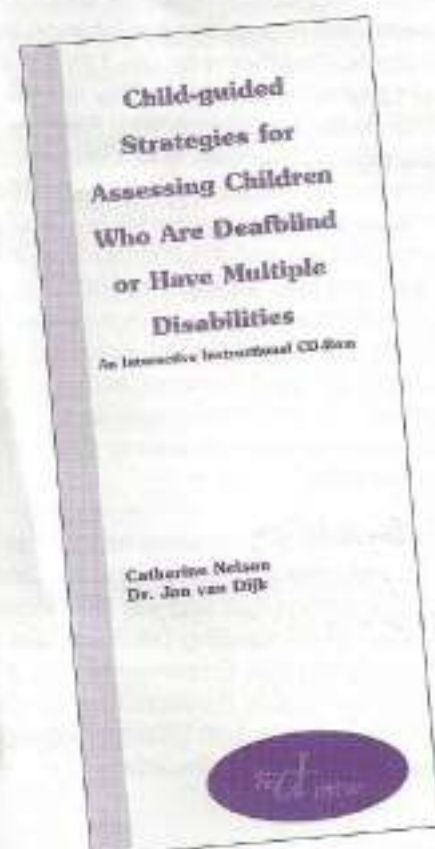
Child-guided Strategies for Assessing Children who are Deafblind or have Multiple Disabilities

In this brand new CD Rom Jan van Dijk and Cathy Nelson, two of the fields most prominent researchers, have got together to distil the skills and knowledge developed over many years in order to support others who are interested in the area of assessment.

The CD Rom contains over 40 demonstration video clips, with descriptions of the techniques being used and offers the viewer the opportunity for interactive questions and answers.

The CD Rom guides the user through the assessment process and provides information that is useful in planning assessment – emphasising the importance of letting the child lead the process! It includes definitions of specialist terms for the beginner and also demonstrates two complete assessments.

You can find out more about it and your nearest supplier by accessing the website:
www.AapNootMuis.com



13th Dbl Conference 2003



'Communication is the Key to Opening Doors Worldwide for People who are Deafblind'

**Delta Meadowvale and Conference Centre,
Mississauga, Ontario, Canada**

August 5-10

Conference theme and call for papers

Information concerning 'The Call for Papers' has been distributed and is also available on the Conference website. The theme for the 13th Dbl World Conference is 'Communication is the Key to Opening Doors Worldwide For People Who Are Deafblind'. The Scientific Committee is welcoming submissions around this theme, including any aspects of communication as it relates to individuals who are deafblind; the people around them and the communities in which they live, work and play. Presenters should consider deafblindness across all age ranges, from birth through to the ageing population, including those with congenital deafblindness, acquired deafblindness and those with additional disabilities. This conference will be committed to celebrating diversity and multiculturalism.

The Scientific Committee has further indicated that it will welcome theoretical, practical and research presentations that address the following four KEY areas: Understanding Deafblindness as a Key to Communication; Empowerment as a Key to Communication; Relationships are the Key to Communication and Sharing Knowledge / Information as a Key to Communication.

Abstracts are to be submitted by August 30, 2002 by email to stan.munroe@sympatico.ca or by regular mail to Conference Secretary, 13th Dbl World Conference, 1658 4th Avenue West, Owen Sound, Ontario, Canada, N4K 4X4. Presenters will be notified of acceptance of their proposal by January 30, 2003. Since organizers wish to publish all presentations in the conference proceedings, presenters are required to submit their complete papers to the organizers by April 30, 2003.

Conference fee schedule

The conference has established four categories of fees:

- a Regular conference participant (\$800 CAD; \$500 USD; 580E);
- b Second family member of a person who is deafblind (\$650 CAD; \$405 USD; \$475E);
- c Intervenor/Interpreter/Guide working at the conference (\$500 CAD; \$310 USD; 360E)
- d Accompanying non-conference participating persons conference (\$500 CAD; \$310 USD; 360E).

These fees are valid up to April 30, 2003. All fees will be paid in Canadian dollars, with current US and Euro equivalents shown for comparison.

Registrations will be accepted up to July 15, 2003.

Please note that registration and payment of fees with credit card, can be made on-line through the website.

Registration fees will include: Conference Registration Kit (including Abstracts and Proceedings on CD-ROM), Opening Night Festivities, Platform interpretation during plenary sessions, Continental Breakfasts, Coffee Breaks and Refreshments, all lunches, Entertainment, Educational tours, Tourist program (including supper) and Closing Night Gala (including banquet).

Accommodation

Participants need to book their accommodations separate from the conference registration. Individual arrangements must be made directly with Delta Meadowvale Resort & Conference Centre. For Special Hotel Conference rates call 1-905-542-4003 or Fax: 1-905-542-6742. The toll free line for within North America calls is 1-800-422-8238.

Guest Room Rates for conference participants are: \$122 CAD (\$75 USD) per night for up to 3 persons in a room; \$142 CAD (\$88 USD) for a room with 4 persons. Taxes (12%) will be extra.

Please note that special conference rates are not available on the hotel's website at this time.



Language

The conference language will be in English, with platform interpretation in American Sign Language provided at all plenary sessions and some workshops. All conference written material will be in English. If enough need is demonstrated, simultaneous translation into French and Spanish may be provided during all plenary sessions and for some workshops. Costs for this translation are not included in the Registration fees. Please contact conference organizers to indicate if you need French and Spanish simultaneous translation.

Special needs

In addition to regular sized English print, written material will be provided in large print and Braille as well as on diskette. Participants will need to indicate upon registration if they need written material in these different formats or on diskette.

Persons will be expected to supply their personal Intervenor/Interepreter/Guide. Registrants having special needs, such as loop systems, table/desk, monitor, outlet for electrical equipment, real-time captioning, special dietary needs, etc, should advise conference organizers, upon registration.

Supported places

We hope to provide a limited number of supported places for individuals from developing countries. For those wishing support, please advise conference organizers in writing by September 1, 2002.

More information

For complete details about Call for Papers, Registration, Accommodations, Tourist Program and other general information, check out the conference website www.dbiconferencecanada.com or contact the Conference Secretary by mail or phone 1-519-372-2068. Watch for a subsequent mailing, Fall 2002, which will contain further details, including any pre-conference program information.

Hosted by:



The Canadian Deafblind
and Rubella Association

4th European Seminar of the Acquired Deafblindness Network

Problems of Acquired Deafblindness and the Services of Professionals Today

**2 - 6 October 2002
Hotel NOVOTEL, Zurich/
Switzerland**

Seminar Languages

German / French / English
(All presentations will be interpreted simultaneously.)

Payment received before
16 September CHF 680.— /
Euro 454.—

The theme of this seminar relates to the recognition of problems within the professional and methodological fields. This is the starting point for all further action. In addition, there will be discussion about the strengths and weaknesses of the latest range of services available today, leading to the possible establishment of ideas for improvement and growth.

This conference has a wide range of eminent speakers, a well balanced programme which includes time for discussion, sharing and resolution.

Please contact the organisers:
Swiss National Association of and for the Blind SNAB
Counselling Services for Deafblind People
Ausstellungsstrasse 36
CH-8005 Zurich / Switzerland
Phone +41(0)1/444 10 80
(Maggie Gsell)
Fax +41 (0)1/444 10 88
adbn-seminar@zugernet.ch
(Catherine Woodtli)
and Acquired Deafblindness Network (ADBN)

Dreams, ambitions and realities

**5th-7th September 2002
Glasgow Caledonian University**

Book early for places on Scotland's international conference and be guaranteed a place at the inaugural Tait Mitchell Lecture from William Green, Deputy President Deafblind International, get a sneak preview of the Helen Keller Award 2002 exhibition, hear about self-determination, choice and communication, from renowned experts and how at least one psychiatrist decided medication was not the answer to communication difficulties.

The weekend costs £280 all inclusive (5% discount if booked before 31 July 2002) - get in touch for more details.

Email: info@sensescotland.org.uk
Fax: 0141 564 2443
Write: Sense Scotland, 5th Floor,
45 Finnieston Street, Glasgow G3 8JU



Book and CD-ROM

Disabled Children's Rights: a practical guide.

International Save the Children Alliance
• Published by Save the Children,
Sweden • Sept 2001

Children all over the world continue to face inequality in their everyday lives. For disabled children, discrimination and abuse, as well as lack of opportunities for education are common facts of life.

Disabled girls and boys are often excluded from mainstream society and rarely given the opportunity to participate. Their situation is often forgotten, and they are frequently ignored in measures which aim to benefit children.

Nevertheless, examples of good practice in implementing disabled children's rights does exist, although often on a small scale, or as isolated projects. Information about these good examples is often difficult to find.

This book examines the major issues arising from a wealth of examples of both violations and good or improving practice, collected from over 70 different countries. It is written in an informal and jargon-free style, with the aim of helping the reader - whether

governmental or non-governmental organisations, local or international, disabled people's, children's or parents' organisations to understand more clearly the situation of disabled children, how the UN Convention on the Rights of the Child applies to them, and ideas to take action to promote their rights.

The CD-ROM contains a database with all the data collected during the project: over 400 pieces of information from over 70 countries around the world. (many more than are given in the book). Information is from a variety of sources - letters and stories from disabled children and adults, from parents, NGO staff, publications. These illustrate both violations and good practice in the implementation of disabled children's rights. The database can be searched using keywords according to the interest and needs of the user. (For use with Windows 95 onwards, needs 6Mb hard disk space)

For more information contact:
Save the Children Sweden,
Publishing, 107 88 Stockholm,
Sweden, Fax: +46 8 698 9025 Or to
order on-line, go to: <http://www.childrightsbookshop.org>

AN INVITATION

European Family Conference, Ruvo di Puglia (BARI) - Italy

20 – 27 October 2002

A Family Event "Listen to Me"

The Lega del Filo d'Oro in collaboration with the Dbi Networks: Nordic Culture and EDbN, as well as Sense International and the Hilton/Perkins Programme are pleased to invite you to an international gathering of families.

The conference is addressed to 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 number of issues concerning family life. Members of the scientific planning committee are:

Lone Poggioni, (Dk)
Gill Morbey, (UK)
Ursula Heinemann, (A)
Patrizia Ceccarani, (I)

This group is in the process of finalising the programme which promises to create an exciting basis for discussion.

Dates

20th – 27th October 2002

Venue

Depending on the number of participants the location will be in the area of Ruvo di Puglia (BARI) in the region of Puglia – Italy.

The hotels, under evaluation, are approximately 30 kilometres from Bari on the East coast of Italy. Transport will be provided to and from the city. The closest airport and train station is at Bari.

These are comfortable hotels that will be suitable for the participants. Rooms can be single, double or triple, although the more single rooms needed will reduce the total number of people able to participate. Large gardens surround the hotels allowing for recreational and artistic activities.

Participants

A "family" in this context can be up to four members: parent(s), their sensory impaired family member and one assistant of the families choice.

Programme outline

There will be three parts to the programme:

The parents meetings and conference will take place every morning until lunch time. During this period their children and assistants will be able to participate in artistic 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.

After lunch will be time for tourist activities, artistic activities or just simply having a break and relaxing all together. Excursions can be to the beach (13 kilometres), or to culture or shopping centres. A few parties are also on the menu!

Costs

The total cost for accommodation, all meals and tourist activities has been set at 270 Euro's per person. This price is possible because the Lega del Filo d'Oro and Sense International are kindly sponsoring the event. There are grants available from the Hilton/Perkins programme for Central and Eastern European countries. More information on these grants can be received from William Green.

For more information or to register your interest please contact us as soon as possible at:

William Green
Lega del Filo d'Oro
Via Montecerno 1
60027 Osimo (AN), Italy
email: green.lfo@usa.net
Fax: +39 071 717102
Tel: +39 071 72451

Management Committee News

On the 2nd and 3rd March 2002, a meeting of the Dbl Management Committee took place at the site of next year's World Conference in Toronto, Canada. This gave the Management Committee an opportunity to meet with Stan Munroe (from the Canadian Deafblind and Rubella Association) and the Local Planning Committee and to view the facilities on offer. Stan and his team have done a great job and announcement details have already been circulated. Log on now to www.dbiconferencecanada.com for further details.

Membership Update

There are currently 538 members from 69 different countries and membership is growing daily. Dbl would like to thank all of those corporates and individual members who have renewed their membership for 2002 and beyond. If you haven't yet renewed your membership for 2002, then simply complete the relevant form opposite and fax it through today!

Strategic Planning Update

Last year's Council meeting in the Netherlands in July involved plenty of discussion on Dbl's strategic planning process. We are pleased to say that following on from those discussions, a list of recommendations has been put together by Dbl's Strategic Planning Officer, Marjaana Suosalmi. Watch this space for further updates.

The Dbl Secretariat

If you have Dbl queries, please feel free to forward them to Emma Fisher at the Secretariat.

Emma can be contacted by email at dbi@sense.org.uk or by post to:

Dbl Secretariat
11 - 13 Clifton Terrace
Finsbury Park
London N4 3SR.



William Green presenting the symbolic statue to Janka Sarisska, whose country Slovakia will host the next Dbl European Conference

Fancy hosting the World Conference in 2007?

With the World Conference taking place next year in Canada the time has come to already start thinking about who will host the World Conference in 2007? If you are interested in hosting the Conference in your country, then please forward your application to the Secretariat at dbi@sense.org.uk



Dbl 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 Dbl through either a corporate member or an international network. Non-voting members will receive a copy of Dbl Review and other relevant Dbl 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 recognized Dbl 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.

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

The following person is a member of DbI:

Name: _____

Address: _____

Signed: _____

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 Instituut voor Doven, Theerestraat 42, 5271 GD Sint-Michielsgestel, the Netherlands.

