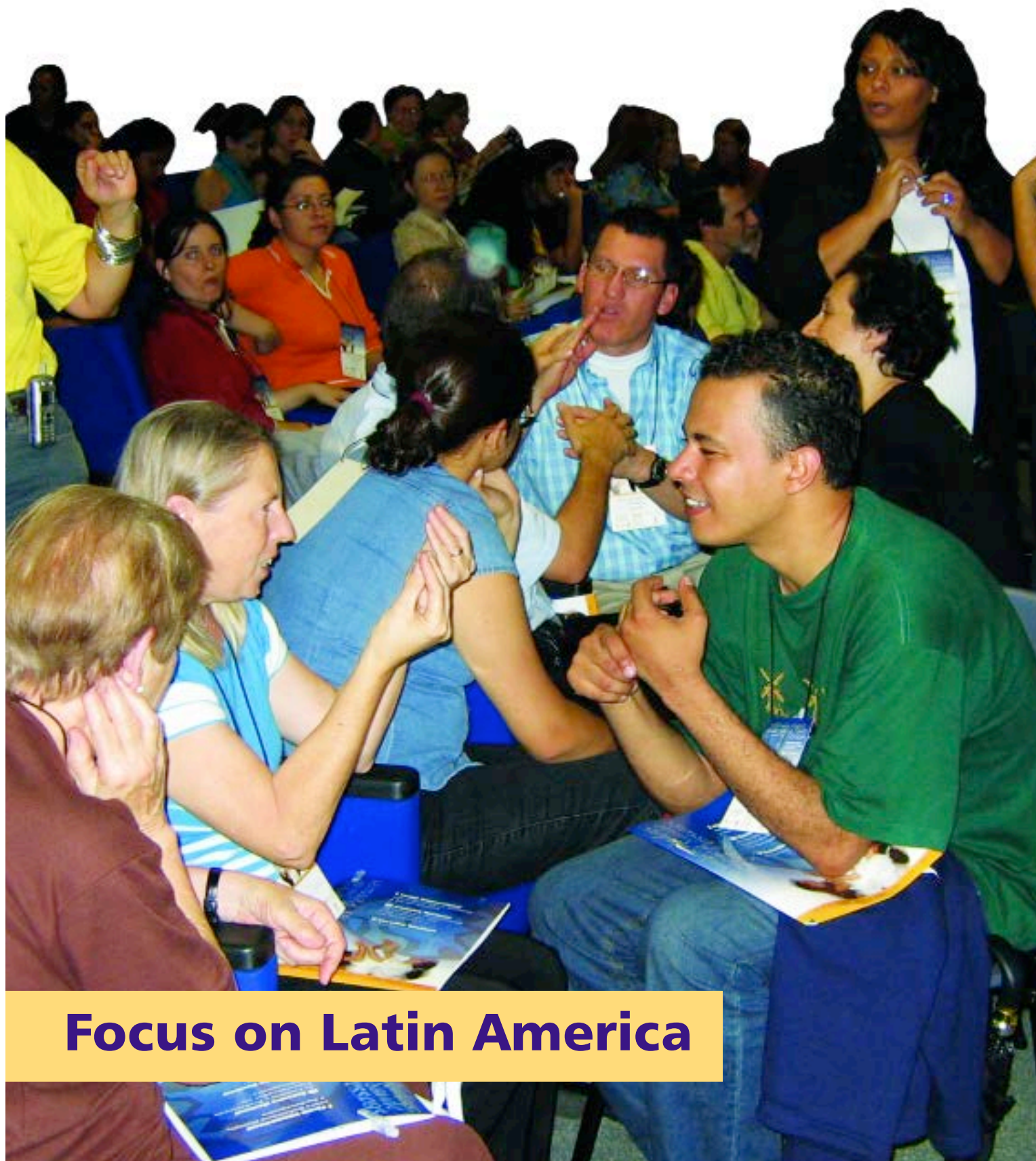


# *Review*



**Focus on Latin America**

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

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

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

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

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

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

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Cover: International Forum, São Paulo, Brazil

## A message from the president

Dear friends and colleagues!

By the time you read this it will be just a short time until we meet in Slovakia, for our European Conference.

The preparations for this conference have meant a lot of work for many people, who we should thank for their voluntary energy!

This includes the Scientific Planning Committee and the Local Planning Committee.

The stage is set. Now its up to the participants to make it a success.

Dbl collaboration is expanding. Firstly, we are in regular contact with ICEVI and are developing a Memorandum of Understanding between the two organisations. Our next Council meeting will coincide with the ICEVI world conference to be held in Malaysia in July 2006 and we are encouraging those attending, to present papers at this conference, to make sure deafblindness is on the agenda. Secondly, we continue to collaborate closely to the WFDB. In fact, at the time of writing, I am preparing to travel to the Helen Keller Conference in Finland where I will be presenting Stig Ohlson with the Dbl Distinguished Service Award, on your behalf, for his wonderful achievements!

We are still busy in the area of gaining recognition for deafblind people and the Dbl EDdB network has a formal place on the European



Disability Forum. This should ensure our voice is heard in their discussions. This participation will give us access to information and to influence decision-makers about the needs of deafblind people and their families across the European Union. We are also still working very hard on recognition issues with the United Nations, and hope for a positive outcome.

Conferences and meetings are planned in many places and your Secretary and I were warmly welcomed in Australia when we visited earlier this year. We were very impressed with the location, Perth, and the local organisation. Before that, next January, the Dbl Asia Conference will take place in Dhaka, Bangladesh and the plans for it already look very exciting.

As I am in the midterm of my Presidency, I consider it wise for your Management Committee and Council to look closely at strategic planning for the years ahead so we can plan for direction

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and future development. We will be working on this and I will keep you in touch with progress.

Finally, after reading Mike's article in our last edition, I realised that next year it is our 30-year anniversary! This seems like an opportunity to celebrate and I would love to

hear any of your ideas for this.

It remains for me to thank you all for your support and hard work – and to the Secretariat in India, which is always willing and happy to help our members.

**William**

## EDITORIAL

The magazine is full to bursting this time. As always, it reflects the work and ideas of Dbl members across the world. Klaus Vilhelmsen begins a series of articles, penned by him and other artists and colleagues, about aesthetics. He begins by introducing us to the idea of aesthetics, and illustrates its significance and value for us all with examples of his co-operation with deafblind people. Russ Palmer and Riitta Lahtinen report their work about holistic communication with people with acquired deafblindness. They are a unique partnership and in this article, which is a summary of research Riitta has been doing, they offer valuable insights. We meet an exceptional woman, Doris Herrman, who made her passion into a successful career, so much so, she is now a world authority. And from Africa, we hear about the barriers that often face deafblind children, adults and their families as they drive forward to turn their entitlements into real services.

Something we will be hearing more about in future

is genetics. Developments in this field are moving on apace and this time we report the break through with CHARGE syndrome.

Our networks are busy but the difficulties they face in maintaining contact and professional development are highlighted in the Network report, which was commissioned and undertaken last year.

As well as the magazine we have been working hard on the redesign of the website. This should be up and running before the Autumn and we hope that as it develops it will provide a useful tool for both information and sharing ideas.

Finally, I must apologise to our many readers who would like to receive the magazine in Spanish. We have had some difficulties with its production and we are hoping to resume this publication as soon as possible.

As always, I look forward to hearing from you; about your work, your life or about someone you know! Do keep in touch.

**Eileen**

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# A Study of Deaf-Blind Demographics and Services in Canada

A report prepared for the Canadian National Society of the Deaf-Blind by Colleen Watters and Michelle Owen of the Canadian Centre on Disability Studies and Stan Munroe, Project Coordinator

## Executive Summary

**A** Study Of Deaf-Blind Demographics and Services in Canada represents a unique collaboration between the Canadian National Society of the Deaf-Blind (CNSDB) and the Canadian Deafblind and Rubella Association (CDBRA). This is the first time that CNSDB (which represents the needs of those with acquired Deaf-Blindness) and CDBRA (which primarily but not exclusively meets the needs of persons with congenital Deaf-Blindness) have had the opportunity to work together to collect information about persons in Canada with this dual disability.

The project was intended to produce a report containing (1) demographic information

about persons in Canada with acquired Deaf-Blindness and those who are congenitally Deaf-Blind; (2) a discussion of the service needs of persons who are Deaf-Blind and their parents/advocates; (3) an overview of the personal stories of the barriers and successes experienced by individuals who are Deaf-Blind and their parents/advocates; (4) an outline of existing services to meet the needs of persons who are Deaf-Blind and their parents/advocates and (5) directions for future research. This complements the National Registry Project that obtained information on 777 persons with this dual disability.

This research located some of the balance of Canadians who were not registered as

Deaf-Blind during the National Registry Project conducted by the Canadian Deafblind and Rubella Association from 1999-2001. This study determined there was an estimated total of 3306 Deaf-Blind Canadians. This included persons with acquired Deaf-Blindness and those who are congenitally Deaf-Blind. It is believed this number underestimates the total Deaf-Blind population due to the difficulty in reaching individuals with this dual disability. Further research is required to locate additional members of this population and to document the needs for Intervention and other services that are currently not being met. The information gathered adds to the current registry database, identifies and evaluates existing services that are available and accessible to persons who are Deaf-Blind and provides important quality of life data about the personal stories of the barriers and successes experienced by this population, their service needs and recommendations for additional services. It enhances significantly already published data on Deaf-

“The information gathered adds to the current registry database, identifies and evaluates existing services that are available and accessible to persons who are Deaf-Blind and provides important quality of life data about the personal stories of the barriers and successes experienced by this population”

**“Consumers and parents/advocates pointed to the need for the implementation of public awareness programs to highlight the needs and capabilities of persons who are Deafblind”**

Blindness in Canada. This project provides up-to-date and relevant information that will be maintained and continually updated by the Canadian Deaf-Blind Council (a joint body composed of the Canadian National Society of the Deaf-Blind and the Canadian Deafblind and Rubella Association.)

To complement the demographic information gathered during the course of the research, ten focus groups were convened across the country to collect quality of life data from persons who are Deaf-Blind and parents/advocates. During these sessions, consumers and parents/advocates overwhelmingly recommended that federal and provincial governments provide increased funding for comprehensive Intervention services for persons who are Deaf-Blind to facilitate their access to community services and daily living. Those communities, that do not currently have Intervention programs, should put these initiatives into place. In addition, there is a need to decrease waiting times for

services and to provide emergency pools of Intervenor for evening and weekend times (this applies to children, families and adults who regularly receive Intervention services during the day), medical and other emergencies and vacations. Federal and provincial governments should increase funding for Intervention training programs to enhance the numbers of trained professionals working with those who are Deaf-Blind.

Consumers and parents/advocates pointed to the need for the implementation of public awareness programs to highlight the needs and capabilities of persons who are Deaf-Blind and to reduce the misconceptions among governments, the service sector and the general public about the uniqueness of this dual disability. In addition, respondents who are Deaf-Blind and parents/advocates identified the need for federal and provincial governments to implement assistive devices programs for those not currently involved in education or work, to increase the quality of life for

persons who are Deaf-Blind. This would provide increased access to information, offer opportunities for enhanced communication through email and assist consumers to improve writing skills. Parents and consumers alike also expressed the need for increased information about assistive devices and the availability of training in the use of this type of technology.

It is the responsibility of professionals, service organizations and the provincial and federal governments to implement the recommendations outlined in this report and to provide the additional services which are desperately needed by Canadians who are Deaf-Blind.

**The full report can be viewed on line in English and French, in both font 12 and 16, on the website of the Canadian National Society for the Deaf-Blind at [www.cnsdb.ca](http://www.cnsdb.ca).**

# Social-Haptic Communication for Acquired Deafblind People and Family: incorporating touch and environmental information through holistic communication

by Russ Palmer and Riitta Lahtinen

Last Autumn 2004 at the Nordic Staff Training Centre (NUD) in Denmark and at the NUD Icelandic Conference there was an opportunity for Riitta Lahtinen (Communication Researcher Consultant) from Finland to present her Licentiate thesis research titled, "Development of the Holistic Social-Haptic Confirmation System"

**T**his will form the basis of Riitta's final PhD work on Holistic and Interactive Communication with Acquired Deafblind People. This is a longitudinal case study of the "Yes" and "No" feedback signals and how they can become more commonly and frequently used within the family with an acquired deafblind person.

## Russ writes...

I believe Riitta's work will influence our understanding of how we can improve the quality of our communication between Deafblind, Usher's, Acquired Deafblind people, Interpreters and professionals working in the respective areas. The methods and techniques described here could be further expanded into other disability groups creating a more holistic and interactive environmental view of the world around them.

One major problem of having a dual-sensory impairment is the difficulty in

perceiving and interpreting people's body language at a specific time or event. All too often deafblind people miss out on this information increasing their reliance on friends, family or interpreting services if these are available.

The theories, methods and techniques that Riitta has identified are not necessarily new and have in fact been around for many years and are probably being used within deafblind communities around Europe. Until recently these communication methods have not been systematically recorded, identified or studied in detail. Through her own associations with various acquired deafblind people around the world over the past 20 years, Riitta has spent nearly 15 years analysing and recording her observations through her diaries. When we met in Sweden at a DBI conference in 1991 and became a couple, we both started to analyse our own methods of communication making

improvements and trying to bridge the gap between spoken and Sign Language.

As an Usher type 3 person I use spoken language as my main form of communication and up to my recent cochlear implant operation in March 2004 I was having to rely heavily on tactile or, correctly defined by Riitta, (2003) as Social-Haptic methods of communication.

This enabled me to pick up environmental, social and body language from people whether individually or in groups.

## Riitta explains...

"Through analysing how we are moving and responding, I realised, that we use our body movements "unconsciously" to respond to others. I use here the word "Social-Haptic-system" when I illustrate the combinations of our tactile environmental information, kinesthetic movements and how we use our personal space when communicating."

## Russ continues...

One specific application is the ability to assist interpreters by giving them "shortcut" techniques while at the same time providing communication that feels spontaneous or what Riitta defines as in real-time. This allows me to be part of a social group conversation without the feeling of becoming isolated because of the deafblindness. Furthermore, family, relatives, friends and professionals can also use and learn these techniques relatively quickly i.e. coffee, espresso or cappuccino coffee, all have their own symbolic notation which are clearly defined. Another example is when in a social situation where people are laughing, teasing, crying etc. these can also be applied using the Social-Haptic methods.

Riitta's licentiate work focuses predominantly on the application of the "Yes" and "No" signals, identifying the theories, methods and techniques and the various stages of the developmental processes. It took us 8 years as a couple to identify each of these stages and when we teach them in our international courses, they are automatically picked up by deafblind people and family members quickly. Very often deafblind people realise that they have already been using similar methods but have not perhaps discussed this openly.

Sometimes where there is an acquired deafblind family member and a hearing and sighted spouse, the deteriorating hearing and vision loss condition can affect their long-term relationship as a couple. I am

sure that had Riitta and I not been open about our communication difficulties, our relationship could have most certainly ceased. Through analysing our problems together, discussing and applying a mixture of Social-Haptic techniques we have identified these different stages. I have to mention at this point that Riitta has been the scientist and I have been the guinea pig!!

## Riitta explains...

"One of the main issues is how we use our language. Our culture is based on a distance communication and picking up visual clues. We understand our language is part of the holistic action and that is why we call it *"functional communication"*. We communicate through using various methods such as speech and lip-reading, using hearing aids, radio microphone, Cochlea Implant depending on the different environmental conditions i.e. contrasting lighting conditions and background noises. The methods employed may be individually used or combined together i.e. Hands-on-Fingerspelling, Hands-on-Signing, Body Signs and Signals, Information through Touch and Body Movements".

## Russ continues...

Observing everyday language behaviours with couples can give us an insight into functional solutions through analysing the processes of the different methods and techniques used in a spontaneous manner. Environmental orientation is one aspect of the social interactive process of being

able to participate as a member of a group.

Every time we leave our home environment the communication changes. The quality of conversation from both parties' point of view when walking, travelling or doing every day activities is very important. The same techniques can assist professionals and interpreters who are working with deafblind people.

The process of communication involves the situation, context, space and orientation. It is not just sharing language information, but also producing non-verbal information such as real-time feedback of emotions and behaviours. It is a question of understanding the whole phenomenon as part of the language behaviour in everyday life.

Holistic interactive communication is a philosophy where both parties identify the whole communication situation and the elements involved through the whole process. Both parties react to the

**Russ Palmer  
and Riitta  
Lahtinen**





elements of their internal and external stimulus, environment, place, objects, activities and people around them. Interactive means that both parties are sending and receiving messages all the time. This means couples need to have determination, encouragement and a lot of energy to find the right method(s). For example, Riitta and I appear to use more our sense of touch and body movements when sharing information and situations together. Social-Haptics can be summarised into the following areas:

Hands-on methods (signing, signs, fingerspelling, block letters)

- The application of social quick messages giving social information (body signs, feedback, behaviour)
- Expressing and receiving emotions
- Guiding through body movements and signals
- Sharing environmental orientation (body drawing)
- Sharing art experiences through movements i.e. kinesthetic information

### Conclusions: What the Social-Haptic methods has given us?

#### Russ continues...

"The more we use our body and touch, the more sensitive I have become in receiving and interpreting touch messages. Touch will give a greater quality to our discussions and an interaction, without it, the information does not have the true value. It also saves our energy and misunderstandings. Touch

will give me information on how other people are behaving, their feedback, non-verbal clues and emotions very quickly. It is very important to have feedback to my responses. This means that I am able to be more on equal terms with other people. For me, touch gives a feeling of security and without contact I feel isolated. Being open towards each other is the key."

#### Riitta explains...

"The interpretation of the meaning of touch can be changed and controlled by using different neutral places on the body, by applying the size of movements and pressure. Physical realisation of the hand and skin information can give different nuances and interpretations of touch. The areas of the body have been enlarged during the years. To be a participant is based on having to learn different possibilities and creating the skills or readiness of having and using different methods both at home and outside the home with a range of people. For us, repetition, being unsure, disturbing or interrupting situations made communication more stressful and we wasted a lot of our energies. But using the body when describing situations, places and different events or activities provides the possibility to be an active participant."

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# Kathmandu, Nepal... the next steps

You will have read about Lone's visit to Nepal, on behalf of the Danish Parents Association, in a previous issue of *Dbi Review*. This time Inger Rødbroe and Bente Ramsing joined Lone to follow up on the work being undertaken...

**T**here were a lot of reasons for this visit. We wanted to continue the collaboration between the Danish Parents Organisation of Congenitally Deafblind (DDBF) and the newly formed parent organisation of Nepal "Society for Deafblind Parents". We were planning to hold two workshops for the deafblind children and their parents and another two seminars for the professionals. We were also going to look into the possibility of developing a longer project which would involve training teachers and parents and supporting and opening the first school class and a residential home for six deafblind children in Kathmandu.

## Working with the families

Parents with 12 disabled children between 7 and 30

years attended the workshop and at the end of the day, we had six children identified as deafblind, or possibly deafblind. Every one participated in joint activities, with songs and movements to enable all the children to participate. By using video recording the families could see how their children were responding and it was easier for the group to explain why they believed some of the children might be deafblind.

Inger Rødbroe worked alongside the parents to explain how to begin to develop communication and daily life skills in a natural way. Lone Poggioni had a meeting with the parents about what had happened with the parent's organisation since March 2004 to share wishes for the future. The parents had a desperate wish to start to a school unit for their children.

Bente Ramsing worked with each parent and child in an individual way on support for individual development.

## The Professionals

With the professionals we covered a lot of valuable and basic information about both congenital and acquired deafblindness, how to identify, assess and intervene and use different communication methods.

During these sessions we illustrated it with video of the Nepalese children.

The professionals at the seminar were very active, interested and participated well. They already have skills and knowledge from the disciplines bordering deafblindness and this made things much easier.



**Working with individual children**

Meeting the families and children



### Proposals

After listening to these requests at this workshop we made a commitment:

- To support the parents organisation "The Society of Deafblind Parents"
- To create the first school class and a residential home for 6 deafblind children in Kathmandu and to start consultant services – as soon as possible.
- To give help in selecting and training staff.
- To provide information to medical teams, hospitals etc. with a small brochure about the specific disability, deafblindness.
- To spread knowledge and awareness on deafblindness outside the Capital area.

### Conclusion

During our visit to Kathmandu we had the pleasure of meeting a lot of people with a longing to do something concrete for deafblind people. So we really feel that our involvement in Kathmandu/Nepal has a mission and the project has a good chance of success.

## Man is man's joy... An aesthetic approach to co-operation with congenitally deafblind persons.

In this first article of a series, Klaus Vilhelmsen, uses this old Viking expression "Man is man's joy" to introduce the exciting, but often not fully understood, concept of aesthetics. Over the years he has worked with colleagues at the Centre for Deafblind people in Denmark, in an interdisciplinary way, and involved practising artists with deafblind residents to develop an aesthetic approach. He also supports and values the cooperation of the Nordic Culture Network.

### Introduction

Some years ago we went on a study trip. For a week we sailed a beautiful, old wooden ship. The deafblind students had many sensory experiences on that trip – the heat of the sun, the smell of the sea and the wooden ship, the wind and so on. Sonja, one of the students, kept us

awake until two o'clock in the morning by using her voice in a very varied and beautiful way. We thought she expressed her mood based on the experiences she had had. Previously, we thought that she used her voice mostly in a self-stimulatory way, but on this trip we realised that she used her voice as a personal

and creative way of expressing herself. We understood Sonja and the way she used her voice. We understood this from an aesthetic angle.

### Aesthetics

But how can we describe aesthetics?

The concept goes back to

Baumgarten in the 18th century. He wrote about aesthetics from a philosophical point of view. For him aesthetics was "knowledge about the beautiful and learning about this ...the learning about the substance of arts". Therefore, art and aesthetics were closely connected.

A Danish researcher, within the special pedagogical field, Søren Langager, says: "Aesthetics is about taste, experience and acknowledgement through the senses, with the expression of taste (the emotion) as its communicative form.

Originally aesthetics was described as "realising" through sensory experiences. However, I think it is in the wider understanding, and in Søren Langager's comments too, that we find most inspiration in our partnerships with deafblind people.

It is still common to connect aesthetics and art, but it has also become more common to regard aesthetics as beauty both in nature and as a part of our daily life. As aesthetics take on a broader definition, as a part of existence itself, it does not depend on a concept connected solely to art, or indeed, the individual's ability to produce or understand art.

You can have an aesthetic experience in the natural world. For instance, let's look at the experience of taking a walk on the beach. You can feel the wind against your body, you can enjoy the sun and the light, you can hear the wind, and you can feel that it is pleasurable to use your body. An experience like

this can create a feeling of beauty and meaningfulness. For a walk on the beach to be an aesthetic experience we have to be open and able to recognising it as such! In applying this wider understanding of aesthetic experience it becomes more important in our lives. It will include our feelings, soul, spirit and our unconscious mind.

The core of our new understanding is that an aesthetic recognition is all about sensory perception, sensation and emotion in our relationships with other people and in our relationship to the physically world.

To describe sensory perception, sensations and emotions as important factors in our aesthetic recognition can perhaps help us to understand why we sometimes experience success and, other times, experience the opposite. To acknowledge this as a vital part of everyday experiences can lead us to an aesthetic view about being together with deafblind people.

Dorthe Jørgensen, a Danish researcher in this field, said that the kind of aesthetics which is about "life art" (i.e. how you create your life in an aesthetic way) is the most popular kind of aesthetics these days.

## Pedagogical consequences

When we use the aesthetic perspective as part of the basis for co-operation with deafblind persons there will be at least two pedagogical consequences.

One consequence is that working together with

deafblind persons is not just about compensating for functional disabilities. We have to look at the human being behind the handicap, and give this person the opportunity to grow and express herself.

Another consequence of choosing the aesthetic perspective, is that we have to give the deafblind person the opportunity to experience sensation, refine this sensing process and refine this sensory expression. In this way other people can relate to the ideas of deafblind persons. In other words, communication can be established.

In giving the deafblind persons an opportunity to express their experiences in a non-linguistic way, the deafblind person can communicate to hearing-seeing people with their own expressions about their attitudes, feelings and existential experiences. In this way we can learn from them.

## Cooperation with artists

Based upon this way of thinking we established cooperation between Sonja, the young lady from the boat, and a multi-artist, Cathrine Lervig. She is an educated singer. During the past 10 years she has worked with an alternative way of using her voice. For instance she sings without words.

Cathrine describes her first meeting and co-operation with Sonja in an article in the Danish magazine "Deafblind-News". She describes it like this:

"When Sonja arrived we touched each other as hello.



**Riccardo  
Morrison and  
Marianne  
Rusbjerg**



I waited. Sonja used her voice. We touched each other again. In the beginning it was just like improvising with another musician. In the beginning we got to know each other and suddenly we had established contact. Sonja turned her face directly to me in a big smile from deep inside of her. She felt it too – the contact, the joy and the surprise of this kind of contact.

Now that the contact was established, we were equal. For one hour we concentrated and spoke to each other. Sonja has a very expressive voice, voluminous and dynamic. We changed between talking and singing. Or to be more precise we were between singing and talking. The feeling was exactly like improvising with another musician”.

After her meeting with Sonja, Cathrine said “I ask myself many questions. For instance – where is the

boundary between music and linguistic communication? What kind of exchange takes place between musicians when they play? What is music? What would happen if Sonja got a musical reply to her splendid communication skills? What can Sonja teach us?”

### **So how should we respond?**

We need to support deafblind persons' creativity. We can benefit from working with artists in many ways. I think they can,

- inspire new possibilities and nuances in the meeting between deafblind people and others,
- open up our senses for new expressions, both from deafblind people, and others,
- work by clarifying these expressions,
- help in creating solidarity,

- communicate on a non linguistic level.

### **Dancing!**

During the last 20 years Riccardo Morrison has practiced contact improvisation dance. It is dance with and for people, who like to dance in a common forum and use the dance as a common language. People who move differently have inspired Riccardo. He says “We all have some strange, remarkable movements, which has become a habit for us. We must accept these movements, because they are a part of our nature and our body. In connection to our bodily expressions Riccardo Morrison reminds us that we are all unique.

Riccardo has for several years worked together with disabled people. He wants to teach these people so they can encounter and feel their body, and to undo and dissolve their tensions. The purpose is to obtain self knowledge and personal development.

The technical basis for Riccardo's work is contact improvisation dance. This form of dance is based upon improvisation, dialogue through movement, weight and vigour. The form of dance

“As human beings we only have two – and nothing but two – ways of organising our access to the world. The one is through understanding, and the other is through sensation.”

K.E. Løgstrup



“The aesthetic dimension contains many of the same qualities as “the time of our life” – the sensuous, the unique, the ambiguous”

talks about the living, intelligent and sensing body. In contact improvisation dance, there is in the principle that nothing is right or wrong. The dance form is based on techniques, which can be used by anybody – whatever their disability may be.

In November last year we arranged a workshop with Riccardo Morrison. We worked on the basis I have just described, and we worked with differences rather than homogeneous movements. All movements were understood as dance and we tried to catch all the smallest movements. There were no wrong movements. Riccardo says that everyone in a room contributes something – they inspire each other!

## Society and the digital world

But why this interest in aesthetics?

It has always been that support from society to disabled people has been based on the values, norms and ethical rules which characterise it in that period of history. Today old patterns have broken down, authorities are not what they used to be. The individual has to find his own way and values. Therefore the ongoing development of the society is

more likely to pose a question about how the individual expresses him or herself, to make up his or her mind and take action. The development of digital technologies also pushes us in that direction. With all the possibilities the digital world creates, it will be essential for the individual to be able to find his or her way in this world. It will be essential to reveal themselves and make themselves “attractive” to other people so that they can take part in the developing dialogue. For the weakest citizens it will be hard to face this challenge.

Ole Thyssen, The Danish philosopher, says that we need aesthetic competence now in this society, because “renewal requires people who are not afraid to trust their senses and feelings and give shape to experiences which may, or may not, become shared experiences”. One can say “that the aesthetic dimension contains many of the same qualities as “the time of our life” – the sensuous, the unique, the ambiguous”.

Today, the concept of aesthetics, as a philosophical and pedagogical concept, underlines the meaning of sensory perception and emotions. This occurs in the meeting between oneself and another and in our approach

to the world. Therefore, in our understanding, an aesthetic paradigm points out that it is through confidence and respect we foster individuality. Our own power over the way we live our lives can enrich not only the existential meeting but cultural solidarity too.

## Equality

We would like deafblind people to have the opportunity to be truly equal members of society and have the possibility and expectation to contribute to that society as well. I think we have to help them to contribute in a way that other people find exciting and worth while. The process and the joy of working with aesthetic expression is very important even if artefacts are not created. But, if the deafblind person wants his work to be a contribution to society and the common culture, then the product is important too, so other people find it exciting and worthwhile. In this way deafblind people can be visible and equal in the society.

Klaus Vilhelmsen

# 'Kangaroos are my life' – the life and work of Doris Herrmann

Doris Herrmann's biography is above all the story of a woman who refused to be discouraged by the difficult circumstances of her life. Iris Schelker tells us more

**D**oris was born deaf in 1933 in Riehen (near Basle). When she became a young adult the doctors noticed that in addition to her deafness she was also suffering from retinitis pigmentosa (a degeneration of the retina).



**Doris with one of her kangaroos**

Later on, her sight deteriorated to such an extent that she was no longer able to read at all. Since then, Doris has depended fully on her reading device. Over the next years other aids were to become her loyal, indispensable companions.

Today, Doris uses 'Lormen' to communicate, since she can no longer lip-read. On the other hand, she is able to answer using speech.

After finishing school, her enormous willingness to learn led her to study graphics and textiles at the college of applied art in Basle. During this period she discovered her creative talents and abilities.

Eventually, she became an active member of the 'Swiss society of fine artists'. Later on her work was exhibited in various galleries and was awarded a citation for her artistic and scientific contributions.

She has seen her autobiography and a second book published; a third book is also in the pipeline.

As a young girl she came into contact with kangaroos on a visit to Basle Zoo. The director there allowed her to enter the kangaroo enclosure and study the distinctive behaviour of these animals. It was to mark the start of her intensive research into this field. She later travelled to Australia on a number of occasions, where she met a number of international scientists. After living for weeks and months at a time among families of kangaroos, her observations led her to discover and fall in love with the many natural beauties of the continent so that this part of the world became her second home.

Her own research, particularly into the field of pouch cleaning, rumination, group behaviour and feeding earned her international recognition and despite her growing disabilities of sight and hearing, she was able to take part in scientific conferences with the aid of

sign language interpreters. Many established zoologists followed the example of Professor Grzimek in referring to the Basle researcher and her work entered into scientific literature. But for Doris, the kangaroos were far more than just being an object of scientific interest. Today she says: 'They're such wonderfully soft and gentle creatures to touch'.

Eventually, Doris was reluctantly forced to abandon her field observations due to increasing problems with her sight. But she has continued to work tirelessly and is in regular e-mail contact with correspondents from all over the world – she also writes in English.

In her extremely impressive life, her work has had a huge impact on others, Doris' story goes to show that human fate does not merely have to be passively accepted as such, but that people can make a difference to their own lives.

**Iris Schelker**  
**Social worker**  
**SZB Counselling Services**  
**for Deafblind People, Basle**

With contributions by Doris Herrmann: [doris.herrmann@dplanet.ch](mailto:doris.herrmann@dplanet.ch)



# Per Aspera Ad Astra!... for Deafblind Persons in Croatia

The Croatian Association of Deafblind Persons, Dodir, has celebrated its 10th birthday...

**T**he story of Dodir began in distant Sweden, at the heart of Dalarna valley, where dreams were born. It hasn't been easy or simple for Dodir, as a national voice of deafblind people in Croatia, to begin to pave the way to a brighter future for deafblind persons. Still, dreams turned into reality! Over the past ten years we have moved from complete exclusion to the inclusion of deafblind persons into community.

Let's remind ourselves of some significant accomplishments

- deafblindness was recognized as a special category of people with disabilities and some rights

of deafblind persons were ensured.

- Dodir's support service was established for all deafblind persons in Croatia
- A Declaration on Equal Opportunities for Deafblind Persons was passed,
- Dodir had the premiere of our play Cinderella in the city theatre Gavella, in which deafblind persons were the actors
- We held the 3rd International Scientific Seminar and the 5th European Summer Holiday for Deafblind Persons.

Today the Croatian Association of Deafblind Persons, Dodir, is a symbol for

“Over the past ten years we have moved from complete exclusion to the inclusion of deafblind persons into the community”

coming out of darkness and silence. Many people who attended the birthday celebration in Zagreb, and the ceremonial dinner and birthday ball witnessed the recognition Dodir has gained over the past ten years. Around three hundred people contributed to the majestic event, and celebrated together with stylish red and white balloons, table cloths and ribbons, because red is the symbol of Dodir.

The ceremonial opening was marked by the anthem of deafblind persons in Croatia, Dodir Ljubavi (Touch of Love), whose lyrics were written by Aeljko Bosilj, a deafblind person. The anthem was performed in three different ways – in tactile sign language, in sign language and vocally, by deafblind Dodir support service members from Zagreb and Osijek. Mrs. Sanja Tarczay, the President of Dodir, made the opening speech and both the Deputy Prime Minister of Croatia and the Mayor of

**Sonja Tarczay, President of Dodir**



“It was a night of glamour, a special night for all deafblind persons in Croatia, the night that witnessed that dreams can be realized”

Zagreb made speeches of welcome to the group. William Green, the president of Deafblind International, and Lex Grandia, Secretary General of World Federation of The Deafblind, both friends of Dodir, made special and warm speeches. Members of the theatre studio of

deafblind persons performed one act of the play, Cinderella.

There were several marvellous surprises as well! We received a great present from the Ministry of Health and Social Welfare. It was a cheque for half a million kunas for the adaptation of Dodir office space. We also received the certificate for “extraordinary achievements in advancing the rights of deafblind people in Croatia” from Sense International. We sang our thanks and after another inspirational closing speech the dancing began. As the red and white balloons

were falling around, Mrs. Sanja Tarczay and Mr. Zvonimir Costar, the Head of the City Health, Labour and Welfare Department led the dancing to the sounds of waltz.

We danced and sang together, with all our supporters from all parts of society, until it was time to blow out the first ten candles on our very special birthday cake!

It was a night of glamour, a special night for all deafblind persons in Croatia, the night that witnessed that dreams can be realized. And we are only ten years old...



**Lex Grandia  
of WFDGb**



**The team  
from Dodir**

# CESSA – Special Education Centre for deafblind children and teenagers



**Director of  
CESSA,  
Christine Tap**

We continue our series of articles about work with deafblind children and young people in France. This time Christine Tap describes the work of CESSA

**C**ESSA is located on the outskirts of Poitiers, and is currently attended by 29 children, 4 to 20 years old, coming from all over France. This is because of the low incidence of this handicap.

All the children attending CESSA have a dual sensory loss, seriously affecting their hearing and sight, so they can be:

- profoundly deaf and blind
- profoundly deaf and partially sighted
- hearing-impaired and blind
- hearing-impaired (hard-of-hearing to severely deaf) and
- partially sighted

In addition, they could have one or several other associated impairments (motor, intellectual impairment, or personality or behaviour disorders, but also other sensory impairments). Most of them need considerable medical supervision and daily care.

As to the origin of their disability, the children are currently distributed in the following manner:

Aetiology	Number of children
Congenital rubella	3
CHARGE syndrome	8
Infantile REFSUM syndrome	2
WOLFRAM syndrome	1
KID syndrome	1
USHER syndrome	4
Aftereffects of encephalopathy and prematurity	5
Unknown aetiology	5

Two thirds of the current applications for admission are from youngsters in a situation of emergency, who have either been deprived of any support – sometimes for several years – or are getting to the end of the standard integration school system and, in order to progress, need a very individualized support using very special tools, and/or multiple techniques. (Sign Language/ Braille) So, those who are arriving now are youngsters who are losing their sight, or coming out of psychiatric care, or for whom the original school “gave in” because of the complexity of their handicap and the support needed.

For several years already we have tried to be “there” for these youngsters and their families. However, this year, we will have to reject many applications, because CESSA already has 4 pupils more than the number authorized by the social security approval.

## Characteristics of Child Care

Our educational, teaching and therapy project is based on having the child in the centre of the system, not in order to “repair” his handicap, but in order to help him/her to live with it in the best possible way. Our aim is to guide him/her towards adult autonomy and, where



**Gymnasium  
and play space**



possible, towards inclusion or at least a partial integration within the ordinary environment. Therefore, this care is based on the search for consistency in the actions taken for the child in order to guarantee the achievement of the Individual Project. For this reason, services are developed according to the following teaching and educational principles:

- care must be very individualized
- regular assessment of the child needs and of the parents expectations
- partnership working with the family on the individualized programme
- inclusion in ordinary environments every time it is possible and in conditions accessible to children

This implies a close co-operation with the families in the construction of the individual programme, therefore a need to appoint somebody to be responsible for this management : the Referent. However, we have to adapt every tool to the sensory profile of each child, and to regularly check the objectives, the means used and the teaching methods implemented.

Our working lines are as follows:

• **at education level**

- **Discovering the surrounding world:** making the world more accessible, therefore less frightening for the children (after installing an emotional security to arouse the sense of curiosity)

- **Autonomy in everyday life:** we have to get the child to take initiatives, to be able to manage by himself...
- **Socialisation:** in meeting other people, the child constructs his identity, he learns from others thanks to imitation, he measures the rules of life, he confronts the limits, but he also learns how to cope with his conditions, to project himself and cope with the risk. Therefore one of our tools is integration into the ordinary environment: outdoor activity centres, schools, restaurants, shops, swimming-pools, libraries, toy and game libraries, leisure clubs, contacts with other children having different disabilities too.

• **at teaching level:**

- **Developing the child's knowledge,** always giving priority to knowledge useful for his autonomy, which can be reinforced in everyday life
- **Developing communication tools:**
  - LSF (French sign language) for most of the children, spoken French for those with sufficient hearing and abilities
  - Pictures, photographs

**Having fun!**



- Symbol objects
- Visual or tactile pictograms
- Words with pictograms
- Written French and Braille

• **at therapy level:**

- Evaluation of knowledge and of disorders by assessments and/or observations
- Evaluation of a cognitive level and of an emotional potential
- Whenever necessary and possible, a therapeutic support (with the consent of the youngster and of his family)
- Medical specialist assessments and supervision

These various services could be represented as follows:



**Stimulation resources**

Therefore the child's timetable is defined by half days and consists of activities corresponding to the child needs.

The services offered to the child are defined in close co-operation with his family. In fact, thousands of times, we observed that the results obtained with the child were much better when his family

is a participant in the action! For this reason, parents are included in numerous stages of their child's individual programme.

In order to do this, and in spite of the geographical distance between many families and us, 3 times a year we organise a Meeting Weekend, during which this construction work is elaborated between the family and the professional educational team. This is also a means of developing activities amongst parents, teachers, and children, with the aim of showing them

what we are doing with their child. Those weekends also give families an opportunity to meet and share. It allows the child to put this partnership in a concrete form and to see that dad, mum and his referent are all working together for him to succeed.

**Current research**

Finally, at CESSA we are now initiating research into CHARGE syndrome, aiming at finding the links between the multi-sensory impairments and the psycho-emotional development of these children. Currently, it involves 10 youngsters and, later, it will involve others in order to check the relevance of the first findings. We shall keep you informed of our findings, but we are going to present the first items at the next DbI International Conference, in August in Slovakia.

A part of our team is also trying to develop a pictogram dictionary, from drawings to words with pictograms. Of course, it is available to any interested educational team!

# So CHARGE really is a syndrome!

David Brown, California Deaf-Blind Services

**A**s I wrote in the CHARGE Network column in the last issue of Dbl Review, this has been an exciting and eventful time for anybody with an interest in CHARGE Syndrome. The 2004 discovery of a gene that causes CHARGE has ended the long debate about whether this is a syndrome or merely an association of features, and has given us the answers to some of the questions that are often asked about CHARGE. The publication of the CHARGE issue of the American Journal of Medical Genetics in March of this year represents another step forward, this time in our ongoing efforts to define whether or not there are behaviours that are unique and specific to CHARGE, what they might mean, and how best to deal with them. I will try to give a summary of both these developments in the clearest way that I can.

## 'The CHARGE gene'

Last summer rumours began to circulate that a CHARGE gene had been found, and these were confirmed on August 8th with the publication of an article on the website of nature Genetics<sup>1</sup>. The discovery was made by a team at the University Medical Center Nijmegen in the Netherlands, who had tested blood from 17 children with the CHARGE

Association and found that 10 of the children had a mutation on the seventh gene of the chromodomain, named CHD7. Subsequent more detailed study of this group in a diagnostic lab is reported to have identified the CHD7 mutation in all but one of the children<sup>2</sup>. Since that time larger numbers of people have been tested in several countries, either as part of research studies or on a private basis, with similarly convincing results. Geneticists are advising that CHD7 is not 'the CHARGE gene', rather it is a major CHARGE gene, the first to be discovered but probably only one of what may be several CHARGE genes yet to be identified. As a result the old diagnostic criteria (based upon identifying the presence or absence of certain characteristic CHARGE anomalies in the individual) still apply, and they can be used to determine that a person has CHARGE even though that person's blood might not have been tested yet, or even if it has been tested and the mutation of CHD7 is not present.<sup>3</sup> This latter case would suggest that some different gene mutation, a 'CHARGE gene' that we cannot yet identify, has caused the CHARGE anomalies in this person.

One of the Dutch team, Dr. Conny van Ravenswaaij, has explained that 'Some embryonic genes help orchestrate proper



development of very sophisticated organs like the heart, eye and semicircular canals. The CHD family of genes play very important roles in regulating which genes need to be used at which time, especially in early embryonic development.'<sup>4</sup> This organising and regulating function of the chromodomain genes explains why CHARGE is such a multi-organ syndrome, why so much can go wrong so early in the pregnancy, and also why the same genetic mistake can produce such widely differing patterns and degrees of malformation from person to person. While there is still much that we do not know, some firm statements have been made following the discovery of the gene:

- if the CHD7 mutation is present in the child with CHARGE but not in either parent (in other words if it is a new, or 'de novo', mutation, as most cases are thought to be) then unaffected siblings cannot be carriers and will have no increased risk of having a



child with CHARGE Syndrome

- any couple with a child with CHARGE has a 1-2% recurrence risk of having another child with CHARGE because, in a very small number of cases, the gene mutation can be in the cells that make eggs and sperm rather than in a single egg or sperm produced by a parent (this is called gonadal mosaicism). If a specific mutation is identified in a parent then pre-natal diagnosis can now be made to see if the CHD7 mutation is present in any new foetus. There is no gene therapy that can prevent CHARGE anomalies developing if the gene mutation is identified in a foetus, and no medical procedure that can be used to cure the condition after birth either.
- any person with CHARGE who has the CHD7 mutation has a 50% chance of passing on the mutation to every child that they produce
- we do not yet have any idea how to predict the severity of CHARGE in any foetus shown to have the CHD7 mutation by pre-natal testing
- we cannot yet make any predictions about the developmental pattern and educational needs of any individual with CHARGE on the basis of whether or not they have the CHD7 mutation

Some parents and professionals have already expressed to me their disappointment that the gene discovery does not enable us

to 'cure' CHARGE, but I think it is unrealistic to have such very high expectations at this early stage in our exploration of the genetic basis of the condition. I am sure that we will look back on the discovery by the Dutch team as a major event in our growing understanding of this most complex of syndromes. Meanwhile we need to keep seeking the right questions to be asking.

### **The American Journal of Medical Genetics CHARGE issue**

As a direct response to the increasing concerns expressed by families and teachers about the behavior patterns of older children and young adults with CHARGE, the 2003 International CHARGE Syndrome Conference in Cleveland, Ohio featured a full day Symposium that looked at neurobehavioural issues associated with the condition. The presenters (American, Australian, British, Canadian, Dutch, French and Norwegian) included parents and professionals from the fields of genetics, paediatrics, audiology, education, psychology, and neuropsychology. The variety of styles, and viewpoints and methodologies was wide, and a great many challenges and questions were posed by these presentations. Almost two years later, in March 2005, the American Journal of Medical Genetics published papers based on these presentations, plus several others, making a collection of twenty articles in total, enough to account for the entire edition of the journal (Vol 133A Issue 3 March 15th

2005). The American Journal is to be congratulated for taking the unusual step of devoting an entire issue to a single syndrome, and featuring so many authors from outside the field of genetics, focussing upon broad behavioral issues rather than any narrower medical concerns. Thanks are also due to the CHARGE Syndrome Foundation which not only made the original 2003 Symposium possible, but has also made the entire CHARGE issue of the American Journal of Medical Genetics freely available on its website at [www.chargesyndrome.org](http://www.chargesyndrome.org). Anybody with an interest in this topic (not only those with a direct interest in CHARGE Syndrome) should visit the website and prepare for many hours of absorbing reading!

### **References**

- 1 Vissers L et al (2004) *Mutations in a new member of the chromodomain gene family cause CHARGE syndrome* <http://www.nature.com/naturegenetics>
- 2 Presentation by Dr. Conny van Ravenswaaij, German CHARGE Conference, Köln, May 6th 2005
- 3 Davenport SLH, Hefner M (2004) *We've found a gene for CHARGE – So Now What??* CHARGE Accounts Vol 14 No 3, Fall 2004 p8
- 4 van Ravenswaaij C (2004) *A Major CHARGE Gene Has Been Found* CHARGE Accounts Vol 14 No 3, Fall 2004 p6

# A journey of a thousand miles starts with a single step ...

Penny May Kamau reports on the barriers to education for deafblind children in East Africa, in spite of improvements in government policy. Societal perceptions of disability and lack of targeted funding for deafblind children is placing undue pressure on families who have difficult choices to make about the life chances of their children.

**G**overnments in Kenya, Uganda and Tanzania are working hard towards “Education for all” and great strides have been made in increased school enrollment in the last few years. In all three countries education is now “free” and many children who had never seen the inside of a classroom are now enrolled, but what is the situation for children with a disability and more specifically those who are deafblind?

The Ministries of Education in the three countries have recognised that deafblind children need their own school programmes and have illustrated this by helping to train and post teachers to the various deafblind programmes. In spite of this however, there are still many deafblind children who, even though they have been assessed and placement

made, are not in school. Why is this?

When parents first understand that their child is deafblind, acceptance can take a long time. Some parents will never accept that reality and there are many examples where it results in separation or divorce when one parent decides to leave the family. In such cases the remaining parent is left to cope alone.



In a society where witchcraft is still a potent force, the community may also be hostile and

accusations are flung at the family so that they believe and blame themselves as the cause of the child’s disability. In such cases it is unlikely that the child will ever move out of the home. The shame and fear can cause the child to be hidden away from view but fortunately many parents choose to accept the child and start to look for information and advice on how to cope with the situation.

The first step is often medical intervention, which can be traumatising and also costly. Parents are often told that the child will “never be able to do anything for himself” or “don’t waste time on this one”. Others pay out large sums of money for corrective eye or heart surgery and even much more to buy adaptive devices.

All this is a financial strain on the family. Many parents give up at this stage but others, at least in Kenya and Uganda where it is available, do persevere and find their way to the education assessment services where thorough assessment of the educational needs of the child are carried out. In Tanzania assessment of children with a disability is only available at

“The Ministries of Education in the three countries have recognised that deafblind children need their own school programmes and have illustrated this by helping to train and post teachers to the various deafblind programmes”



some medical centres or in a few special schools.

Again costs are involved. The assessment may take place a long distance from home, where they are sometimes told to come back another time, meaning more transport costs; many never go back! At the end of the assessment there should be a referral letter for education placement, which in the case of deafblind children in Kenya can be at one of four places or in Tanzania at only one place in the country. For many deafblind children their chance of any education ends here.

Unlike children with no disability, deafblind children cannot go to the local school. Deafblind services may be 50 km, 250 km or even further away, and if financial support is not available, either due to total lack of money or negative attitudes within the family, then the child will never go to school.

Take the case of Rose. Rose is 9 years old and lives with her father in Embakasi, a Nairobi suburb in Kenya. Her mother lives back in the rural area. Rose is deafblind and has additional disabilities which means she needs help with many things including

feeding, dressing and toileting, but in spite of this she still has the capacity to learn if given the chance.

Rose has been assessed and recommendations made that she attend a programme for deafblind children. The options available are Kilimani Unit, a day programme in Nairobi, or Kabarnet School for the Deafblind, which is a boarding school, based in the Rift Valley province. To access Kilimani Rose needs someone to take her to school and fetch her each day plus money for the transport which amounts to at least ksh 100 per day. Much of the time this money is not available. To access Kabarnet, Rose would need a list of requirements including personal effects such as soap, oil, clothes, and also money for transport.

The family are not able to manage this so Rose is kept at home without any programme that can help her to get skills to make her more independent. Rose is just one of many children with a disability who, because of poverty, cannot access school. Other parents choose not to send their disabled children to school due to lack of awareness and culturally

based negative attitudes towards disability.

If more information to increase awareness on disability was available to everyone, as well as extensive counseling services for some parents with disabled children, parents could then see their children in a more positive light and appreciate the value of medical assessment and educational placement

### **A single step....**

In Tanzania the government has set aside funds to cover transport costs for disabled children who attend schools outside their locality. This is a great step in the right direction and we would like to see this duplicated in Kenya and Uganda. Parents shouldn't have to incur extra costs just because they happen to have a child with a disability.

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# Film maker wins Helen Keller International Award!

Graeme Thomson reports on another fine event...



**Winner of 6th Helen Keller International Award: The Lost Reels by Matthew Humphreys, Wales**

**T**he sixth Helen Keller International Award had a spirit of reaching out and communication at its heart, best represented in the quality and diversity of the work displayed at the Collins Gallery in January and February. For the first time in its 16-year history with Sense Scotland, a short film was chosen as the winning piece. 'The Lost Reels', a Super 8 Film by Welsh artist Matthew Humphreys is about his father, who is deaf and recently became blind.

From the judging process at the start of the exhibition's 5 week run, to the award ceremony on the 31st January, the Helen Keller International Award attracted a great deal of interest from the public and press. The judges were Monica Callaghan from the Hunterian Museum, artist Kenny Hunter, Pauline McLean from the BBC, Alex Robertson from the Museum of Transport and Kirsty White from Glasgow City Council. From a total of over 220 entries it was decided to increase the shortlist number to 9, a reflection of the quality of the work.

Most of the shortlisted artists were able to attend the award ceremony. One of the high points was the presentation each made about their work, before the winner was announced. They were preceded by Pro Vice-

Principal of Strathclyde University, who own the Collins Gallery; Professor James Love BA MSc PhD, pointed out that they were, "so impressed by the quality of the works on display that the university has actually bought one."

Speaking about her work 'Just a small part of the bigger picture', Diana Fox-Flyn, whose son Aidan is a Sense Scotland artist, explained:

"I'm not sure that what I did was art but I like to think of it as my Tracey Emin moment...it is a statement. My aim with this work is to show that even with the best will in the world and massive efforts to overcome disabilities, the attitude of others will stymie and defeat success."

Grace Newman, whose installation of mannequin parts at the end of red and white sticks, was one of many works which referred to hands and touch, talked about how she developed the idea:

"I was intrigued by the subject of deafblindness. I didn't know anything about it and I wanted to find out more. I develop my sculptures by playing about with materials and most of my materials are medical or clinical in some way. I wanted to give a positive image of deafblindness and I imagined a group of people happily chatting away."



“It’s a true story. It’s a film about my father. It took about three years to initially make because my father was deaf and then he went blind. Making this film brought us closer together.”

Sense Scotland artist Lewis Scott presented, through one of his support workers Heather, a short film about the sculpture workshop in Sweden where he created his entry the ‘Wee Man’:

“It was the positive attitudes and commitment of all involved that made this a fantastic and enjoyable experience. Lewis had a great time in Sweden. His ability to work with a variety of media never ceases to amaze and his artistic talents have yet again shone through.”

Gavin Wilson, another sense Scotland artist, had travelled from the east coast of Scotland with support worker Ruth Hay, who discussed how she worked with him to produce his piece ‘Touching hands’:

“Gavin gets a lot out of the arts sessions. It’s good communication, he’s the boss, he’s calling the shots. The more sessions we do the more he’s in charge, the more he tells me what to do. Most of all we’re developing communication between us and I think that’s a really big thing about the Helen Keller award.”

It was only when Matthew Humphreys was announced as the winner that many people realised what a journey this had been for the Welsh artist. Not only had he travelled from Newport in Wales to Glasgow for the ceremony but his short film



**Grace Newman “The Conversation”**

‘The Lost Reels’, also depicted the particular journey that his father is still going through:

“It’s a true story. It’s a film about my father. It took about three years to initially make because my father was deaf and then he went blind. Making this film brought us closer together.”

On winning and being presented with the award trophy by Mary, Dowager Countess of Strathmore LLD

DL, patron of Sense Scotland, Matthew was clearly moved by the experience: “It’s a shame my father can’t be here but I know he will love this. I can’t wait to show this to my father.”

Work is already underway to prepare for the next Helen Keller International Award. The 7th award will be launched at the end of the year and it is planned to hold the next exhibition of entries in the Collins Gallery in January 2007.

**For more information or a copy of the catalogue, contact Lindsay Mitchell arts manager:**

**Tel: 0141 429 0294**

**email: [arts@sensescotland.org.uk](mailto:arts@sensescotland.org.uk)**

#### **Winner of 6th Helen Keller International Award:**

*The Lost Reels* by Matthew Humphreys, Wales

#### **Two runners up**

(receiving a certificate and cheque for £200)

*Jigsaw of the Mind* by Alex Cameron, Scotland and

*Limited Perception* by Gill Horn, England

#### **Three highly commended** (receiving a certificate)

*Just a small part of the bigger picture* by Diana

Fox-Flynn, Scotland,

*Touching Stillness* by Orly Orbach, England and

*Touching Hands*, Gavin Wilson, Scotland

#### **Three commended entries** (receiving a certificate)

*My Hand* by Safiya F, India,

*The Conversation* by Grace Newman, England and

*Wee Man* by Lewis Scott, Scotland

## NETWORKS

### Acquired Deafblindness Network

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### European Usher Syndrome NETWORK (EUSN)

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### Multiply Disabled Visually Impaired European Network

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Fax: +46 - 19 - 6762 210  
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### Nordic Culture Network

C/o Lone Poggioni  
Via G. Deledda, 19  
06074 Ellera (PG)  
Italy  
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### Tactile Communication Working Group

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tillaart@tiscailmail.nl

### Siblings Network

Sabine Kersten  
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B-3980 Tessenderlo  
Belgium  
Phone/fax: +32 13 67 67 50  
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## Network News

# A Review of Dbl Networks



Anny Koppen reports the summary findings of a survey of the Dbl Networks

## Network Committee

At the Dbl

Council meeting in February 2004 the decision was taken to create a Network Committee to support their work and development. Networks are an important part of Deafblind International and networking activity, both formal and informal, is encouraged.

It was agreed that I should be the Chair with Mary Guest and Sergei Sorokin as my co-workers. The first job the Committee has been asked to do is to review network procedures and ways of supporting networks and report back to the Management Committee and the Council. As a result, we decided to carry out a survey to find out how the formal networks were doing. The answers showed some variations in activity, but the main impression is that the networks are active and functioning well.

## Our findings

The networks consist of persons from different countries (at least 3) who share a common interest in one specific area connected to deafblindness. They all reported that their aims and goals were to raise awareness on deafblindness and to develop more knowledge on their chosen area.

The networks have chosen different ways of reaching their goals. They reported on several different activities from arranging conferences to distributing newsletters and running web sites.

When asked about any difficulties, the answers can be summarized in these words: "time

and money". The networks consist of persons who do this work in addition to a professional occupation. Many of them feel that they cannot find the time to do all the work they intended to, or wanted to.

It is also a general problem funding the activity. Most of the networks solve some of the financial problems by meeting at conferences or working together mainly electronically. Nevertheless, the answers reveal that some of the networks feel their activities are restricted by lack of funding. They have plans and intentions that cannot be realized because the funding isn't there.

Generally it seems to be easier to keep going if the network has connections to an institution or an organization. The network is also less vulnerable if it has more than one person with administrative responsibility. In case of illness or change of work, there is always one to take over.

You will find a list of the networks and contact persons on the back cover of this magazine. In addition to the ones mentioned, we also have a "sleeping" network, the employment network. I have contact with a couple of people who want to continue this network. We are hoping that some decisions can be made about the network at the European Conference in Slovakia.

If you are interested in becoming actively involved in this Network or leading it you can contact me, the address below.

Anny.koppen@statped.no

## EdbN

**Ursula Heinemann reports:**

**M**any activities are going on in our network. You can read in an article from Lucy Drescher in the Campaigns section about one of our activities – The survey about the situation of deafblind people in Europe. We are also working to get a Hearing in the European Parliament, where we want to present the results of this survey and do some awareness raising.

Furthermore we are also contributing to the work of EDF (the European Disability Forum), where our chairman, Wolfgang Angermann is representing us.

We feel we are on our way to try to get more recognition and support for deafblind people and we want to invite Dbl members within Europe to join us! Let's take this path together!

**Ursula Heinemann**



## The Nordic Cultural Network

**Lone Poggioni reports:**

**I** hereby have the pleasure to inform you about activities of The Nordic Cultural Network.

In the summer and autumn of 2004 the Nordic Cultural Network offered 4 courses. Across the region, in total, 27 congenitally deafblind adults and 60 companions had the opportunity to work with, and develop, creative talents to experience and express themselves in order to communicate with the outside world in a new and different way.

All courses were a great success with very good evaluations from the participants.

### **Concentrating hard! Music with sign language**

In 2005 we have decided to offer three courses as follows:

- "Bronzing course" on the island of Gotland, Sweden from 15 – 22 August.
- "Nature sculpture" in Sömdalen, Norway from 02 – 08 September.
- "Communication in music" in Slettestrand, Denmark from 20 – 26 September.

This last course puts together the two courses last year "Music as communication" and "Dance and drama".

**More information about the courses is available from  
Else Gro Segerblad  
E-mail: [else.segerblad@c2i.net](mailto:else.segerblad@c2i.net)**





## The Siblings Network

Sabine Kirsten reports:

**A**fter moving house from Hungary to Belgium, things are finally back on track. Just to make sure you have the correct mail address: I can be reached by email at [siblingsnetwork@gmx.net](mailto:siblingsnetwork@gmx.net)

With the Dbl European conference coming up, I can tell you all that several of our members will join the conference and we will also present 2 workshops.

A last message to all professionals: during this conference you have a chance to learn about issues and concerns that siblings may have! Take this chance and talk to us! See you in Slovakia!

**Sabine Kirsten**  
[siblingsnetwork@gmx.net](mailto:siblingsnetwork@gmx.net)



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## EUSN

Carol Brill reports:

**T**here has been no networking activity recently but we are planning to get things moving again very soon. Peter Palmer will be retiring from the Chairmanship and I will become Acting Chair, subject to committee approval.

The future of the EUSN will be then be discussed at length with

the membership and new plans made.

In the mean time we are ready to welcome new members to the Network. If you are interested in the area of Usher and would like to join us, or be kept in touch with our activities, please contact me at the address below.

[doranbri@indigo.ie](mailto:doranbri@indigo.ie).



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## Tactile Communication Working Group

Bernadette van den Tillaart reports:

**T**he core members of the group are continuing to keep in touch! We are developing a presentation for the conference in Slovakia and, if you are coming, we

look forward to meeting you there. We would really like to organise an opportunity to come together but we would need to seek funds and support in order to do this. As a

result, most of our contact is by email now.

**Bernadettevandentillaart@tiscailmail.nl**

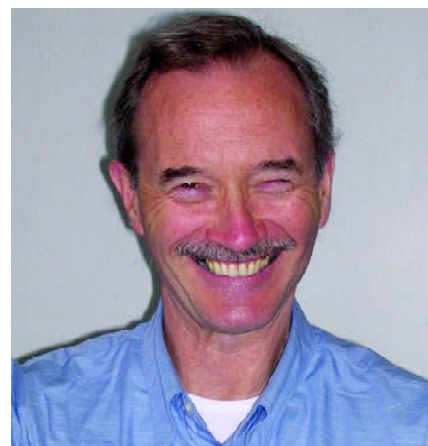


# CHARGE Network

David Brown reports

In the past nine months I have been lucky enough to attend CHARGE conferences in both France and Germany, both of which were attended by significant numbers of families and were inspiring and enjoyable. The main focus of attention at the moment is upon two forthcoming conferences. The 7th International CHARGE Syndrome Conference will take place in Miami, Florida on July 22nd-24th and will certainly be abuzz with talk about last year's discovery of a gene mutation that causes CHARGE (see article on Page ???) and what this might mean for

all of us, family members, professionals, and people with CHARGE. Then in August the DbI European Conference in Slovakia will feature a CHARGE Network Day. Unfortunately I will not be present at the European Conference due to the geographical distance between me and Slovakia and the time and expense involved in getting there, but Joff McGill at Sense in London has volunteered to organise the day in my absence, and he can be contacted at [Joff.McGill@sense.org.uk](mailto:Joff.McGill@sense.org.uk) if anyone requires further information or wishes to



offer their services either as a presenter or as a general helper.

I will be thinking about the meeting in Slovakia and sending my best wishes to all the participants.

**David Brown**  
California Deaf-Blind Services

## Usher Syndrome Study Group

Mary Guest reports

**Eleventh Meeting of the Usher Study Group  
7th-9th August 1995,  
Presov, Slovakia.**

The Usher Study Group last met in Mississauga, Canada in 2003 when it was decided to drop reference to 'European' in the title as it was felt that Usher syndrome is a condition which affects families worldwide. Although we are meeting in Slovakia which is in central Europe this does not exclude any of you from further afield joining us in Presov from August 7th- 9th.

Our theme is, 'Changing horizons for people with Usher in the 21st Century', when we shall be looking in particular at advances in genetics and how these might affect the lives of families with Usher in the next decade. The keynote speaker

from the Netherlands is Dr. Ronald Pennings from the department of Otorhinolaryngology, University of Nijmegen. He will talk on recent developments in clinical and genetic studies and what this could mean for families in the future. The talks will be accessible to people from a non-medical background.

During our two days together we shall also be looking at lifestyle, communication in families with cochlear implants both signing and oral, developments in Usher work in Warsaw and the communication needs of people going into research programmes.

We hope that the Usher Study Group in Presov will attract teachers of the deaf and other key professionals from Slovakia to join us as we have been informed that awareness of Usher syndrome is still very limited.



If you would like to attend please contact Mary Guest without delay:

**Mary Guest**  
Usher Study Group  
Sense 11-13 Clifton Terrace  
Finsbury Park  
London N4 3SR  
Tel: 00 44 (0)207 561 3372  
direct line;  
tel/text 00 44 (0)207 272 7774  
Fax: 00 44 (0)207 272 3862  
E-mail: [mary.guest@sense.org.uk](mailto:mary.guest@sense.org.uk)

# Acquired Deafblind Network

In early March the co-ordinating group of ADBN met in Poitiers, France to hold their first meeting since last years successful European conference on Acquired Deafblindness in Harrogate, UK. The meeting focussed on feedback from conference participants and an evaluation of the event. Feedback has been universally

positive, with a number of participants describing it as the best conference they had ever attended. In all, 147 people from a total of 17 countries attended for all or part of the event.

Attention now turns to the next European Conference, which will be held in the Netherlands in 2006, hopefully sometime in the autumn,

either September or late October. Please make a note in forward planners and diaries!

**Ges Roulstone**  
Chair, ADBN



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## Communication Network report

### Jacques Souriau reports

At the moment, the members of the communication network are working on various projects:

- **very short term:** DBI conference in Slovakia
- **medium term:** a conference on Meaning Making and Language Development in Oslo (April 26th-29th 2006 – run by NUD)
- **long term:** a European Masters Degree in Congenital Deafblindness and Communication.

Several meetings took place during the last months:

**January 2005:** Anne Nafstad, Inger Rodbroe and Flemming Arsk-Larsen met in NUD to write up a first draft proposal for a European Masters Degree in Congenital Deafblindness and Communication.

**February 2005:** Marlene Daelman, Marleen Janssen and Jacques Souriau met in Brugge (Spermalie) to work on this programme and investigate which Universities could eventually join in such a project. They also discussed possible sources of funding for the preparatory phases. Jacques

Souriau is taking part in a European Program called EQUAL that could be used for such a project.

**April 2005:** Inger Rodbroe, Flemming Arsk-Larsen and Jacques Souriau met in NUD. They worked on the program for the Oslo Conference and the Communication Network contribution during the Dbl Conference in Slovakia.

**May 2005:** Inger Rodbroe, Flemming Arsk-Larsen, Marlene Daelman, Marleen Janssen and Ton Visser met in NUD to work at finalising the Conference stream in Slovakia and the Oslo Conference. They will also discuss the European Masters project.

The Communication Network is working on two important topics: developing a better knowledge and expertise on meaning-making. It seems that now, the question of how to create the conditions for congenitally Deafblind people to take an active part in dynamic and sustained communicative activities is somehow answered. What has to be developed is how utterances can be understood at the right level of complexity and how to support the

potential of linguality emerging from these utterances. This means both relating them to a gestural grammar grounded in the context and using them as a opportunity for the acquisition of linguistic competencies.

From a more practical point of view, it is important to spread, support, develop and strengthen practical expertise and relevant theoretical backgrounds related to communication in the field of congenital deafblindness. Opportunities like the Dbl European Conference in Slovakia and the NUD-Oslo Conference will share knowledge with colleagues. The idea of a European Masters degree would also contribute to establishing a long-standing context for staff development at a European level. Congenital Deafblindness is such a low incidence field and it is also so vulnerable that it requires international collaboration. That could be achieved at least in Europe.

**For the Communication Network**  
**Jacques Souriau**  
[jacques.souriau@cresam.org](mailto:jacques.souriau@cresam.org)

# German CHARGE Conference

Köln Bergisch-Gladbach, 5 – 7 May 2005

Since about 1990 those of us working in home based early education or in schools for deafblind children in Germany met a new subgroup of clients. They were children with CHARGE. The cause was unknown, but since Autumn 2004, we have understood more about it because the genetics are much clearer now thanks to Conny van Raavenswaj and her colleagues from the University from Nijmegen.

When we first started to meet CHARGE children there was little knowledge available about the condition, so I was very glad to meet a person, at the DBI Conference in Argentina, in 1995, who talked about the changes in the deafblind population of children: it was David Brown. At that time he was working with Sense in London, and he made the participants aware of the specific special needs of children with CHARGE. David suggested a lot of literature and this helped German professionals to develop support for children with CHARGE and their parents – especially within the deafblind field.

## CAUSE project

In 2000 an EU project "CAUSE" started, concentrating on rare conditions like CHARGE and Usher. It ended up 2003 by a big conference for



professionals and families in the UK. My colleague Gudrun Lemke-Werner, now Director of the biggest German school for deafblind children in Hannover came with us and we decided to have our own CHARGE Conference in Germany as quickly as possible! Our colleagues from other institutions for deafblind people supported us. They felt like us that parents with children with CHARGE mostly live far away from each other. Their children attend different, non-specific schools, and this meant there was a huge need for parents and professionals to meet for an intense exchange.

Jacques Souriau in France was quicker than us and the French CHARGE Conference took place in September 2004, in Poitiers. We hoped that David Brown would

come from the other side of the world to join us as without him we would have felt somewhat incomplete.

**Parents, teachers and professionals**

## Köln Conference

60 people attended altogether, with 20 family members with 8 children with CHARGE. They attended a little extra kindergarten, with 3 nice young and experienced people to look after them. The parents could follow the

“David Brown suggested a lot of literature and this helped German professionals to develop support for children with CHARGE and their parents”



**Getting together**



lectures of the conference.

David Brown gave as an insight into the "basics" of CHARGE. He described his way of looking at the behaviours of the children. Behaviours that seemed strange and bizarre to us before became quite reasonable! And we very much appreciated his way of thinking and interpreting children's actions with us. Many parents expressed their relief about this way of looking at their children's behaviour and seeing how reasonable it was! He showed us many examples of the increasing capabilities of a child, when he / she is allowed to use his / her own strategies to find a stability or when we give the right support, by satisfying basic needs, which we could not anticipate before.

We all followed with great interest the presentation of the scientific adventure of discovering the mutation of a gene: "Genetic causes of CHARGE-Syndrome and consequences" from Conny van Ravenswaaij and

Marjolijn Jongmans. There were intensive discussions about the results of this discovery. Points of special interest were of course the genetic risk of CHARGE, which is fortunately very low (1-2%), the role of age and gender in getting a CHARGE condition, and the possibility of testing for the genetic condition of children with CHARGE in Nijmegen.

We also enjoyed presentations by Eugen Brehmer, who described his work with a child and demonstrated the progress he made in riding and jogging. Mr. Brehmer showed the positive "all over" effects of both therapies. We also welcomed Juliane Weltner-Oepen, a teacher of rhythmic and also a music-therapist.

Dr. Helmut Kruke, who has a long history of working with children with CHARGE for a long time answered the very specific questions of parents. ON Saturday Heidemarie Adam from the University of Leipzig lectured about "Augmentative communication". This

emphasised all different possibilities to give the best access to communication and included video material and a short practical demonstration of developing PECS ("picture exchange system").

The last part of the conference was open to questions and exchange with the speakers. Parents were interested in experiences of Cochlear implantation. Mrs. Skusa, a special teacher from Hannover, gave a short insight, stressing the fact that most children had enjoyed a remarkable improvement in respect of their hearing capacities and their auditive orientation, but this did not mean that all these children were able to develop spoken language.

At the end of this exchange, parents, professionals, those who had lectured and we who had organised the conference all we felt how successful it had been and we are looking forward to our next meeting.

**Hanne Pittroff, Vize  
Director of the School of  
Blindeninstitutsstiftung  
Würzburg**

**Contacts:**  
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**Blindeninstitut.de**



# Developing the identity of the red and white stick in Peru

María Graciela Laynes who works for the Helen Keller Association in Peru writes:

**T**he teaching of Orientation and Mobility to people who are deafblind is one of the challenges in the rehabilitation curriculum. Many of these people do not agree that they should use a stick to help them get around better and become independent in the street. They feel they are not "blind" and so do not have to use one, and sometimes it depresses them just to think that they will have to use it for their whole lives.

A year ago when we found we had more young adults who were deafblind at the Helen Keller Association in Peru, we talked to a group of them so we could come to an agreement about teaching them about it. We had to show them why it was important to use a stick and how it could be differentiated from the white one that blind

people use.

We told them an experience we had had in England, where people with deafblindness use a red and white stick. The important thing is that people recognise them in the street and can identify them and offer them help whenever they need it. This also helps to keep them safe in situations such as getting on or off a bus, crossing the road, going up in a lift, in a shopping centre, or wherever they go.

We feel this was important to them, knowing these are important accessories, not to segregate or stigmatise them, but to give them the chance to have fewer problems in their daily lives as part of the normal society to which they want to belong.

Many of them still have a lot of useful vision and as they do not use a stick, they are ignored when they need

help to cross the road or get on or off a bus.

We currently have red and white sticks that were acquired for our project with Sense Internacional (Latinoamérica). We are organising a mass dissemination campaign with support from the Congress of the Republic Disability Commission, so that these canes can be recognised by everyone in the country and by public and private organisations.

We are confident that the young adults who are deafblind in Peru will be the best advocates of using the red and white stick everywhere!

**Website:** [helenkellerperu@hotmail.com](mailto:helenkellerperu@hotmail.com)



**Using the cane!**

# Great news about training!

Graciela Ferioli writes

In January 2005 a new group of students began a Master's degree course in Cordoba, Argentina. The twenty-four students are professionals, working in schools for multi-handicapped children and youth. Twenty-two are Argentinian, one Uruguayan and one Cuban. So, this new training cohort will represent, for those countries, a significant improvement in services. The 22 Argentinian students are from all over the country from the Northwest to Patagonia and Buenos Aires. This course consists of four training periods of two weeks in January and July. Then the students are qualified to write a thesis. It is organized and undertaken by the Metropolitan University of

Educational Sciences of Santiago, Chile and the Institute Cabred of Cordoba, Argentina.

This main training represents an important advance for schools which are trying to enrol more deafblind and multi handicapped children and youths.

education, including how we all work together.

This conference represented a significant occasion to meet each other and exchange ideas about the future.

**Please go to the web page for more information**  
[www.adefav.org.br](http://www.adefav.org.br).

## Recent graduates

Also, Shirley Maia from São Paulo, Brazil and Beatriz Zoppi from Argentina have recently graduated. Shirley got her Masters degree at Universidad Mackenzie in São Paulo, Brazil and Beatriz at Birmingham University in the UK.

In February 2005 Alicia Picasso a consultant for Hilton Perkins Program held a consultation with the Parents Associations at Fundación Multi Impedido in Medellin, Colombia. Thirty parents from across Colombia and neighbouring countries like Ecuador, Bolivia and Peru came along. The outcome of this consultation is to foster the parents associations in the countries of Andean Region.

In April Escola Anne Sullivan and Associação para Deficientes da Audio-Visao held the first Latin America Conference on deafblindness in São Caetano do Sul, SP, Brazil. Various professionals from Latin America met together to discuss many themes about deafblind

**Beatriz Zoppi  
on graduation  
day!**





# United – Combating Exclusion from Society

Carolina Benjumea reports

## The Third International Seminar on Deafblindness

The Third International Seminar on Deafblindness was held last September at the Catarina Special Education Foundation in the city of Florianópolis, the capital of Brazil's Santa Catarina State, and was attended by professionals, parents and deafblind people from Peru, Brazil, Bolivia and Colombia. The main theme of the seminar was inclusion of Deafblind people in Latin American society.

A number of well-known personalities, with wide experience in the field of promoting the rights of the disabled, were speakers at the event. Similarly, it was a suitable occasion for joining forces and setting targets for

getting deafblindness recognised as a unique condition and a first step in defending the rights of deafblind people.

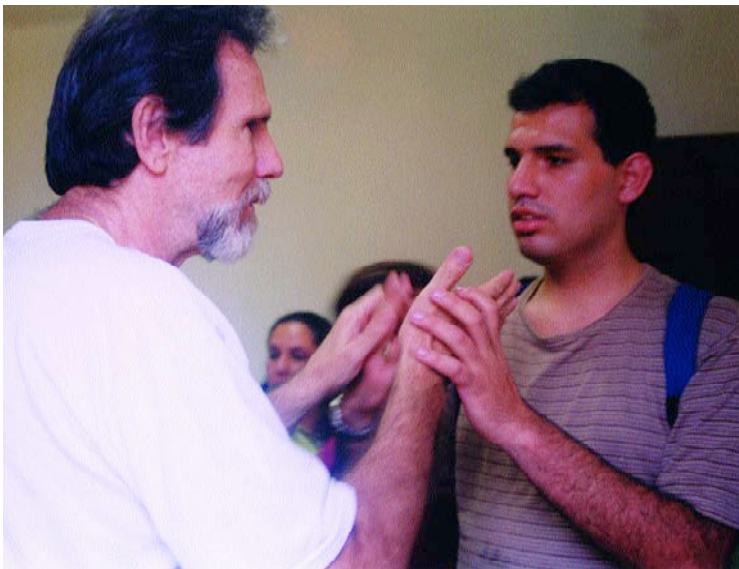
The event also allowed successful experiences to be shared by professionals from Brazil, Peru, Bolivia and Colombia. Deafblind people were panelists discussing the Deafblind Associations in the countries represented. This emphasised, yet again, that it is possible for deafblind people to be included in activities if they have a suitable guide and interpreter who can act as a communication bridge.

Finally, participants had developed an interest in the subject, and, by taking part in the seminar, committed themselves to contributing their own individual grain of sand towards always fighting the exclusion of deafblind



people from joining in wherever they are in Latin America..

**Carolina Benjumea**  
Administration and  
Resources Officer  
Sense Internacional  
(Latinoamérica)  
[cbenjumea@senseintla.org](mailto:cbenjumea@senseintla.org)





# International Forum and National Meetings in Brazil, November 2004

**T**he First International Forum on Multiple Disabilities and Deafblindness together with the Third National Meeting of Families and Specialized Professionals and the Fifth National Meeting of Deafblind People were successfully held in São Paulo Brazil, November 18-20, 2004. The Forum and Meetings were held at the facility of APAE (The Association of Parents and Friends of the Handicapped in São Paulo).



This three day event was organized by Ahimsa (School for Children with Deafblindness in São Paulo), ABRASC (Brazilian Association of Deafblind People) and ABRAPASCEM (Brazilian Association of Parents and Friends of the Deafblind and Multi-Handicapped). These organisations, together with other facilities in Brazil, comprise Grupo Brasil (Grupo Brasil de Apoio ao Surdocego e ao Múltiplo Deficiente Sensorial or Group Brazil for Support to the Deafblind and the Multi-sensory Impaired).

These successful seminars were supported by the Brazilian

Secretary of Special Education/ Ministry of Education, the National Coordination Centre for the Integration of Persons with Disabilities, Sense International, APAE and the Canadian International Development Agency (CIDA).

The general theme of the International Forum was "Hands Held: Education and Health for all the People". Speakers were in attendance from Brazil, Canada, Colombia and Portugal. Participants were there from throughout Brazil, a country not unlike Canada in its size. Participation included persons with deafblindness, family members, professionals from the field of deafblindness, physicians and representatives from Government. What was particularly interesting for me was to hear presentations from various physicians who were working collaboratively with staff from the deafblindness field in Brazil.

I had the opportunity to participate in this excellent International Forum in São Paulo and participate in subsequent seminars in Campo Grande and Rio de Janeiro as the second part of a successful Canada-Brazil Exchange Program. This Exchange was organized by Shirley Rodrigues Maia (Executive Director of Grupo Brasil) and sponsored by CIDA. The purpose of this exchange was to facilitate the exchange of information to professionals and family members in Brazil about Congenital Rubella Syndrome, late manifestations of CRS and the Canadian concept of Intervention.



The first part of the Brazil-Canada Exchange involved a group of professionals from Grupo Brasil travelling to Canada (during June 2004) to learn about Canada's Intervenor Program and to observe how persons with Congenital Rubella Syndrome receive services in Canada.

My visit to Brazil as part of this Exchange involved lecturing about the Canadian Study on Late Manifestations of Congenital Rubella Syndrome and Deafblind Service Programs in Canada.

I want to take the opportunity in this article to compliment and bring notice to Grupo Brasil and the hard work of Executive Director Shirley Rodrigues Maia and her associates for the wonderful work being accomplished in Brazil on behalf of persons with deafblindness. The exceptional International Forum that I had the opportunity to attend is one example of the under-reported achievements of Grupo Brasil and their well-trained and hard working staff and volunteers.

**Stan Munroe**  
Administration Coordinator  
Canadian Deafblind and Rubella Association

# Venezuela – more developments with SOCIEVEN

Maria Luz Troconis

**S**ocieven is a non-profit making civil association, formed in 1995 to promote actions to benefit the deafblind in Venezuela and their families. The need emerged to help the deafblind population.

At the same time, the population with multiple disabilities who benefit from the strategies and programs that are used in the education of the deafblind persons, are included.

It has the support of the International Hilton Perkins Program of the Perkins School for the Blind PIHP (USA) and the Chacao Major Government until 1993. The Christoffel Blindemission CBM (Germany) and Dividend Voluntary of the Community DVC (Venezuela) support us too.

After 10 years of existence, work and achievements, "THE NEW SOCIEVEN" is emerging, to continue defending the

rights of the population in today's Venezuela.

## Vision

The deafblind and multidisabled people, their families, professionals and institutions who work with them join SOCIEVEN in supporting them. Together, we unite to improve their quality of life, improve communication and develop independence. We strive for recognition of deafblindness and multiple disability, the value of the family and equality of opportunity in school and employment. We support training for professionals. We do this with support from public and private organizations.

## Beneficiaries

Our resources are directed at:

- Children, youngsters and adults deafblind (congenital or acquired and/or with

multi-impediments) in the whole country.

- Families (parents, mothers, brothers and others) of these persons.
- Professionals of different specializations from the country and out of the country
- National Institutions and public, private or international organizations that have a connection with deafblindness and multi-disability.

## Present projects

SOCIEVEN develops and searches for alliances and partnerships in the following programs:

- **A space for deafblind people, parents and professionals:** SOCIEVEN'S headquarters, adapted to the necessities of the population brings together human groups that are



**Maria Luz Troconis**

**Pedro**



**Gregory**







**Pedro, Pao and Tania**



**Staff training**



**Janice Alcantara, Fundraising Director with the children**

dedicated to the cause to unite efforts. Furthermore, in that space, programs are developed that benefit the population.

- **Inter-Institutional relations:** Work in harmonious manner with the Department of Education, Culture and Sports, Department of Social Development and others as to benefit the population of the deafblind and those with multi-impediments in the country.
- **Capacity building:** To be able to reach a major number of states in the country where the professionals will receive adequate information to work with this population in their institutions; strengthen them with support visits and conduct

work consultancies with their students.

- **University project:** SOCIEVEN elaborated a "Curricular Design Proposal for the Distance Master's Degree in Education of Multi-impaired and Deafblind Individuals in Venezuela" to create this V level of studies in a university in the country with the Hilton Perkins Program support and others institutions that will show their interest.
- **Knowledge about deafblindness and multi-impediments:** With "COMMUNICATION". We are trying to reach the different levels of society so they acknowledge the existence of deafblindness as a unique, special condition, with its own

character of multi-impediments. In the next 5 years there will be spectacular advances for them and their families.

- **Usher syndrome:** We have located a group of young deaf adults, with Retinitis Pigmentosa that are becoming deafblind and we want to approach them in a professional manner so as to make real changes in their lives.

**Av. Jalisco, Edif. La Colonia, Piso 3. Urb. Las Mercedes, Caracas – Venezuela**  
**Telefax (0058-212) 9911037 –9911725.**  
**Email: socievenac@cantv.net**



**Program members**



# Developing services in Romania

Romania

Andrea Hathazi, Special Education teacher in Romania, discusses the developments taking place.

**W**hen talking about deafblindness and the services provided for people with deafblindness, Romania has made huge steps in a short period of time.

Because of the involvement of the Ministry of Education and Research in Romania and the activity of Sense International, Romania, a new protocol was signed for the next 5 years. More and more deafblind units are being set up in different regions and cities. This means that more children have the opportunity to be identified and to benefit from proper intervention. After embedding these units in the Romanian educational system, a new issue has arisen. What about the training of the teachers who are working in these units? Most of them are special education teachers working already in schools for sensory impaired children. But deafblindness is about new approaches and different

methods of intervention, so training of teachers in this area of skills and knowledge was a necessary thing to do. So, an in-training course for teachers was organized in two parts with 6 months in between. The trainers were specialists from both the UK and Romania; the latter coming from the Ministry of Education and Research and Special Education Department of the "Babes-Bolyai" University, Cluj Napoca. In all, 25 teachers were trained and they received a certificate that acknowledges their acquired competencies.

At the moment, a new phase in teacher training is being developed. Another 30 teachers who are already working at the units or who will be working at the units from September, will participate on a new course that will take place this June. The important change is that, this time, the course will be delivered by Romanian specialists, Mircea Vlad and

Prof. Vasile Preda, in cooperation with John Shaw, a UK specialist. Two special education teachers, who have already had training, and who are working at the deafblind unit in Cluj, Andrea Hathazi and Oana Farcas, are involved in delivering different topics and carrying out practical activities. A manual for the course has been written and it contains all the materials that were used in the previous course and some more.

The teachers also have the opportunity to share experiences and access information on different topics at the network meetings and seminars that take place twice a year. Teachers present activities, methods of approaching and intervening with the deafblind child, followed by discussions. It helps them to think about the next steps in development and understand the complexity of dual sensory impairment.



**Andrea Hathazi**

## Physical Education and Deafblind Children – can you help?

Greece

My name is Fenia Karkaletsis, I am 25 years old and I am from Greece. I am from the post-graduate Department of Physical Education and Sport Science in Athens and my major is on Adapted Physical

Education. I'm working now on a project about deaf-blind children and I would be very pleased if you could help me by sending me a bibliography about physical education for

deaf-blind children.

Thank you in advance

**Fenia Karkaletsis**  
feniakarkaletsis@yahoo.gr

### Canada

## CDBRA Elects New President



**Patrick Peterson**

Patrick Peterson was elected President of the Canadian Deafblind and Rubella Association at its Annual General Meeting in New Westminster, British Columbia, September 2004. Patrick replaced Linda Mamer who was Dbl 2003 Conference Chair and President of CDBRA since 1995.

Patrick has been involved as a volunteer with CDBRA since 1991. He was President of the

New Brunswick Chapter and Vice President of the National Board of Directors from 1993 through 2004. Patrick was Chair of the 5th Canadian Conference on Deafblindness (1993) and a member of the Management Committee of the 13th Dbl World Conference held in Mississauga, Canada 2003.

He is a retired Senior Public Servant, having worked in an executive function with the

Province of New Brunswick's System of Provincial Parks, Historic Resources & Archaeology. Outside his volunteer career, Patrick is currently working as a Project Management Consultant. He also is the Project Coordinator for the establishment of Curtis Complex, a ten-apartment facility to house deafblind adults in Fredericton, New Brunswick.

### Australia

## Events and policy change affecting Australians who are deafblind



**Mike Steer reports:**

**Australian DeafBlind Council (ADBC) research project:** One of the most important and exciting things to have happened for people with deafblindness, their carers and support agencies in Australia for some time, reports ADBC Executive Officer John Finch, is the receipt of a \$15,000 grant from the Commonwealth Government's Office of Disability to undertake a review of the Mary Ward (1994) report Deafblindness in Australia. Some information on the new project appeared in the last issue of Dbl Review.

"While in the short term services hardly, if ever, seem to improve and ADBC members often feel they are hitting their heads against a brick wall", says Finch, "If we stand back, especially in some States over a period of 20 to 25 years, the improvement in services has been dramatic. Often these improvements

result from a report that service providers are able to use as a weapon to persuade Government Departments to improve services. I sincerely hope we are going to make the most of this latest opportunity without thinking it will provide anything like what is actually needed".

The research grant resulted from the ADBC Committee taking the case to Government and pushing very hard to the effect that nothing positive had happened as an outcome of the National Forum held in Sydney in 2001. A report from this meeting had been sent to the National Advisory Council on Disability and after a meeting with representatives of ADBC's committee its members agreed that the deafblindness situation in Australia warranted further investigation. The grant was an outcome of this decision.

Since notification at the end

of June 2004, ADBC has prepared a Brief on the way the Council plans to undertake its research. The national Office of Disability has since approved this Brief. A Project Steering Committee has been organized, comprising a person with deafblindness, a parent, an organisational representative and a person to coordinate and act as secretary to the meeting. A Reference Group of eight people was also initiated, providing Australia-wide representation.

A project consultant has since been appointed and commenced working on the project in mid-December last. The Project Consultant is Meredith Prain, who is well known to many Australians with deafblindness, their families and professionals in the field. Terms of reference have now been formulated and since her appointment, Meredith has designed the project methodology,

reviewed literature relevant to the report and prepared a questionnaire. Her next step is to meet people. It is anticipated that her report will be completed in July, 2005.

#### **Disability Support Pension (DSP): Welfare Reform.**

Unless the recently re-elected Commonwealth Government cannot be convinced of an alternative, it is likely to proceed with a version of its 2002 Disability Reform Bill, which would tighten eligibility for DSP by changing the work capacity test. At present, in Australia, a person is eligible for DSP if, because of a disability, he or she cannot work for 30 hours per week at normal award wages. The 2002 Bill would tighten that test to 15 hours. It exempts existing DSP recipients. The DSP applies to people of working age and (except for those in the category DSP-Blind) is means-tested. The Government has indicated that one modification it might consider is to allow people who try work and fail, to have their pension restored easily.

Approximately 705,000 Australians are in receipt of DSP, equivalent to 5.2% of the working age population. The Commonwealth Government has recently stated that it will consult the disability sector before finalising its welfare reform plans, which include restricting the growth of the Disability Support Pension (DSP) population. However, there are concerns that the timeframe (which may be as short as a month at the time of writing) will be too tight to allow meaningful input from

people with disabilities. In mid February 2005, representatives of the newly-formed Disability Participation Alliance met with the relevant Ministers and representatives from Opposition parties. The group presented the politicians with a list of principles for disability reform. These state that welfare reform should focus on developing wide-ranging strategies to assist people into employment, rather than simply shifting people from one form of income support to another. A key message to the Ministers was the value of open, public consultation. Through its organising committee, the Alliance is currently working to develop specific policy alternatives on welfare reform. Further meetings with the Ministers are planned.

Following a recent strategic planning meeting of Federal Cabinet, the Government announced the appointment of Mr Noel Pearson as a consultant to it on welfare reform. It has also now established a Ministerial task force to develop detailed proposals.

A Disability Participation Alliance was formed in February this year at a meeting in Melbourne of national disability and welfare organisations (for details see [www.afdo.org.au](http://www.afdo.org.au)). It is a loose and temporary alliance of more than 20 national disability and welfare organisations. The Alliance is not opposed to reform. Indeed, it seeks comprehensive reform that would dismantle the range of barriers that prevent or discourage people with

disabilities from more fully participating in Australia's economic and social life.

Day to day work of the Alliance is led by an organising group elected at the Melbourne meeting. The Alliance has no Secretariat.

#### **Disability Discrimination Act, Education Standards.**

After failing to pass, the Disability Discrimination Amendment (Education Standards) Bill was introduced into Parliament on 17 November 2004. The Bill amends the Disability Discrimination Act in order to ensure that the provision of draft Disability Standards for Education are fully supported by the Act by:

- introducing and defining the term 'education provider'
- providing that it is unlawful for 'education providers' to discriminate on the ground of disability in the development or accreditation of curricula or training courses
- providing that education providers may be required to develop strategies and programs to prevent the harassment and victimisation of students with disabilities
- extending the defence of 'unjustifiable hardship' in education to post-enrolment situations, and
- clarifying that disability standards made under section 31 of the Act may require reasonable adjustments to be made in order to avoid unlawful discrimination on the ground of disability.

## **Australia**



### Australia (continued)

The new Education Standards will cover government and non-government providers in all sectors: pre-school, school, vocational education and training, higher education and adult and community education.

**Web Site Discrimination.** In a recent article in 'Computerworld', Australian community activist, Bruce Maguire states that the Commonwealth Government's trend towards using online PDF documents was attracting 'a growing number of Disability Discrimination Act complaints'. Adobe's portable document format (PDF) remains relatively inaccessible to people who are blind, vision impaired or deafblind. Although software exists to use these formats, the training required and the financial freedom of the \$1000 to upgrade to read documents is beyond most people with a disability. This is despite a directive from an Australian Council of Government Ministers that all government web sites be accessible to people with a disability. To read the article, go to <http://www.computerworld.com.au/index.php/id;973165449;fp;16;fpid;0>

**Airline Policy on Guide Dogs.** Australian domestic carrier Virgin Blue has reversed its policy of not providing mats to people with guide dogs after 'The (Melbourne) Age' newspaper revealed the airline refused to allow a blind woman to fly

because she did not have a mat for her dog. The airline admitted that it put Katrina Stewart 'through hell' and apologised to her and her family. The Age' article can be read at

<http://theage.com.au/articles/2004/11/16/1100574464664.html?oneclick=true>.

**Blind Citizens Australia (BCA)** has published on its web site at <http://www.bca.org.au/airlinepolicy.htm>, an airline policy for Qantas, Jetstar, Singapore Airlines, Virgin Blue and Pacific Blue. BCA advises its members and those who are deafblind, to call the relevant carrier prior to purchasing a ticket on order to clarify their policy on fares and guide dogs

**Accessible Telephones.** The Australian Communications Industry Forum (ACIF) has recently developed a Draft Industry Code on Accessibility Feature Information for Telephone Equipment. The Draft Code enhances the current regulatory arrangements by providing information about key features on handsets. This information is not currently provided and will enable consumers to make more effective choices about the products that best meet their needs. Public comment on the Draft Code has been invited. For more information, go to [http://www.acif.org.au/current\\_activities/public\\_comment](http://www.acif.org.au/current_activities/public_comment)

**Universities:** Provision of Course Materials. The Federal Magistrates Court recently considered the issue of disability discrimination in relation to higher education in its decision *Hinchliffe v. University of Sydney*. Hinchliffe had a 'vision disability' that required special assistance in the provision of course materials. Her argument was that the University of Sydney discriminated against her by failing to provide her, in a timely way, with course materials in the form of natural voice audio tapes or, alternatively, in written form in 24 point Arial font on light green paper, together with enlarged diagrams. The University of Sydney denied the claim.

The Court ultimately concluded that Hinchliffe failed to establish a case of indirect disability discrimination. The case sets a clear precedent for other institutions to follow. For a copy of the case go to <http://www.austlii.edu.au/cgi-bin/disp.pl/au/cases/cth/FMCA/2004/85.html?query=university+and+2004>

**Copyright and Print Disability.** The Human Rights and Equal Opportunity Commission has compiled a list of Frequently Asked Questions about how the copyright legislative and administrative regime affects producers and users of accessible-format material (audio, Braille, e-text and large print) in Australia. To access the list, go to [http://www.hreoc.gov.au/disability\\_rights/education/copyfaq.htm](http://www.hreoc.gov.au/disability_rights/education/copyfaq.htm)

## The Norwegian Association of the Deafblind NADB

Norway

The Norwegian Association of the deafblind (NADB) is the oldest organization of and for deafblind people in the Northern hemisphere, maybe in the whole world. Since 1957, we have worked for the good of Norwegian deafblind people. In about two years time, we will look back on 50 years of providing information, cultural and social activities to support deafblind people in this country.

In 2005, and in the following years, we will continue this work. We will also participate in the Nordic, European and international deafblind work. But all the activities in the association must, now as before, be done within our economic limits!!

### Arendal

The Summer gathering has been, and still is, the most important meeting place for the members of NADB. In 2005, the summer gathering will be held for the 50th time. This anniversary-gathering will take place in Arendal. One of the reasons for this is that at the end of this year, the present editors of NADB are celebrating their 25-year

anniversary. Thus, the board thinks there should be an opportunity for the deafblind people to get together with them.

There is a main task for NADB and that is to offer the members courses that lead to qualification and arrangements that give them the opportunity to meet others, get new information and have a good time. Moreover, by arranging gatherings for the members in the local clubs of NADB, we completed the project "A better everyday". The activities are social and provide an important meeting place, where deafblind people meet each other. In this way, we help many deafblind people to break out of daily isolation.

Among the new government actions to support deafblind people in 2004, we have to mention the print-out service. NADB fought for this for years, and we finally succeeded to get it on the government budget for 2003.

Now, the Norwegian Sound and Braille library has put the service to action and this service is an important step towards equal opportunities

regarding deafblind people's access to information.

We have been actively involved with many partner organisations in Europe to campaign for equality issues for deafblind people including EDU, EdbU and DbI. The day the European Parliament passed a declaration which states that deafblindness is a unique disability was a great day for us. As a consequence of the EØS cooperation, this declaration will also be important in Norwegian deafblind work.

We are also involved in campaigning for improved services at home and we support our members with their individual requests. We enjoy two publications, *Dovblines Ukebad* and *Punktnytt*. Also, to increase and improve the information to the members about the association, the NADB publish its own member's magazine. This magazine is published twice a year, and we know it is well received.

Fortunately, a number of government departments understand our needs and support us financially and we thank them for it!



Geir Jensen

## The School and the Super Bowl!

USA

This year, the Florida School for the Deaf and the Blind is celebrating 120 years of successfully developing children's potential. With a current enrollment of 750 students from kindergarten through 12th grade, the school provides outreach services to an additional 116

infants and pre-school children throughout Florida with sensory impairments. The Education services are provided free to eligible children in the state of Florida, USA. It's a school with an extensive campus and an enviable record for pupils' achievement: in the classroom, on the sports field

and in the community!

To celebrate this wonderful anniversary the school was recognised at one of the most prestigious sporting events held in the USA – the Super Bowl. Grammy Award winner Alicia Keys sang "America the Beautiful" to honour the school and its achievements!

# World Bank Meeting on Disability in Washington, USA

Mike Collins, our Past President and Larry Campbell, President of ICEVI were there together and want to share their joint impressions with Dbl and ICEVI.

## General Impressions

The World Bank is definitely taking the issue of including persons with disability into development programs seriously. Judy Heumann and her "disability team" have clearly had a positive impact on staff of the Bank. In his keynote address World Bank President James Wolfensohn apologized for their late entrance in addressing this issue but it was clear from his approach that this is not "window dressing" and the Bank is taking it seriously. Mr. Wolfensohn seems keenly aware that with an estimated 600 million persons with disabilities that it will be virtually impossible to reach the Millennium Development Goal of "poverty alleviation" unless the Bank more effectively addresses the needs of

persons with disabilities within ongoing development initiatives. It is interesting to note that Wolfensohn had a connection with the disability community long before assuming his post at the World Bank and he is comfortable and conversant with the issues and challenges. He is also a wonderful speaker.

## Session on Inclusive Education:

There has been a noticeable moderation in the viewpoint of many on inclusive education. The President of "Inclusion International", Diane Richtler, articulated what we felt was a very sensitive and sensible position that made particular note of the special and unique needs that deaf and blind learners

have that may require alternative program models and more assistance from trained specialist teachers. She also specifically referenced deafblind students among those sensory impaired people who have such special needs. We felt this was a very encouraging sign that people are looking beyond philosophy to the realities of implementation and doing so in a more thoughtful way. We think the position papers that ICEVI and WBU have developed along with the work that WBU and IFD have brought to the table at IDA meetings is being heard and appreciated.

## Implementation

All panelists seem to express the feeling that the most significant challenges we now

Mike Collins



Larry Campbell





face with inclusive education relate much more to good implementation rather than good policy. While all agree that the policy issues will continue to need attention, we really have to direct our attention to good implementation; particularly in those developing countries where issues such as class size, lack of trained teachers and shortages of materials pose significant challenges.

### Data collection

There was pretty much universal agreement that we face real challenges related to lack of data on both the scope of “the need” and classroom cost analysis. This will be required to make the case with policy makers who are juggling competing priorities.

### Extending the work

The representative from UNICEF made the point that while there are some good model programs of inclusive education we need to spend less time pointing to those success stories and more to successfully “scaling-up” programs to the point where we are reaching significant numbers of children. ICEVI and Dbl should keep an eye on the “child friendly schools” that UNICEF is developing. They clearly are looking for help in developing “tools for implementation” that can help children with specific disabilities succeed in these schools.

Representatives from three World Bank regions; Latin America, East Asia/Pacific and Asia gave examples of World Bank work to support

“We felt this was a very encouraging sign that people are looking beyond philosophy to the realities of implementation and doing so in a more thoughtful way”

inclusive education. Programs in Laos, Brazil were highlighted. Particularly impressive was Mr. V. Sundaraman (Asia) who is an Indian economist at the Bank involved with education and social protection programs in Asia. He talked about both demand and supply side issues and said that his analysis was showing that many disabled children in inclusive education were getting poor access to the standard curriculum and virtually no access to extracurricular activities. He is now completing a major report on the situation in India that could be very helpful to us. He did not offer comments to discourage but said that unless we objectively look at the situation as it is there isn't much chance that we are going to make any headway, particularly since the issue of “disability” in many countries is lodged within the weakest and lowest level ministry. Everyone was amused when he said the current situation related to inclusive education reminded him of a response that Gandhi gave when asked what he thought of “British civilization” and responded “that would be a good idea”.

Larry commented that he found Sundaraman brilliant; a young man with a keen mind.

### UNESCO

UNESCO introduced a new publication “Embracing Diversity: Toolkit for Creating Inclusive Learning Friendly Environments” was introduced by Olof Sandkull (UNESCO Regional Office, Bangkok). Kenneth Eklund said the “Flagship was built and ready to sail” but there was “no wind” i.e. funds. Both UNESCO speakers pointed out the need for better coordination between the various UN agencies working on this issue.

The UNESCO initiative, we both felt to be very general and “lame”, in that it really lacked substance.

### Conclusion

In a nutshell: the political landscape seems to be changing positively on the issue of inclusion. Rather than it being viewed as a handy and popular political catchphrase, serious discussion is now happening on the need to implement and not just to wave banners. And the serious acknowledgement that people with sensory impairment need something special due to their special needs is encouraging indeed.

This is all good substance for our dialogue within Dbl to discuss how we must interact with these initiatives.

# Does Europe recognise deafblindness?

*"In 76% of the Member States of the European Union deafblindness is not recognised as a distinct disability."*

*"In 67% of the Member States there is no specific programme for the identification of newly diagnosed deafblind children and adults."*

**T**hese are two of the findings of a report that has been produced by the European Deafblind Network (EDbN) based on a survey of organisations across the European Union, which was carried out to give a picture of the recognition of deafblindness across Europe.

## Continuing the campaign

In 2004, a Written Declaration (1/2004) on the needs of deafblind people was adopted by the European Parliament calling for the recognition of deafblindness across Europe. In response to this a survey was undertaken to find out the

actual situation of recognition of deafblindness in the Member States of the European Union, in order to highlight the change that needs to happen. The survey covered a wide range of areas relevant to the needs of deafblind people and all sections of the population. As well as asking whether deafblindness was recognised as a specific disability, the survey covered other important areas. These included the provision of specialist social care, systems for identification and support to newly diagnosed people, early intervention, the right to education for children, and a number of questions about communication support and training for interpreters. The response was good with 21 of a total of 25 countries responding, plus Romania and Norway.

## A taste of the results...

One of the questions the survey asked colleagues in each Member State was whether training is provided for interpreters and communicators supporting deafblind people. In 38% of those that were represented in the survey there is no training of this type provided. Without the support that properly trained interpreters and communicators can provide, deafblind people will remain isolated and unable to carry out even the most basic everyday activities. The survey results have also highlighted the fact that

deafblind people are not being given the support they need to work and take part in training at work in 48% of the countries who responded. In a more positive light, there was only one country where deafblind children do not have the right to receive an education.

The report, called "Does Europe recognise Deafblindness?" makes a number of recommendations, including the setting up of programmes to identify newly diagnosed deafblind people across the European Union, so that specific services can be set up, or legislation can be amended, to include deafblind people.

The report will be available in English and French, as these are the two main languages of the European Parliament, and it will be used to highlight the actual situation of deafblind people to MEPs in the Parliament. It will also be useful for individuals who want to show national decision makers how the situation of deafblind people in their own country needs to improve in comparison with those living in other Member States.

**If you would like a copy of the report please contact Lucy Drescher at**  
**Lucy.Drescher@sense.org.uk or**  
**telephone +44 207 561 3400.**



# Deafblind International

The 2nd Asian Conference, January 29-31, 2006, Dhaka, Bangladesh

## First Announcement

### “Deafblindness – Breaking Barriers in Asia”



Organized by

**National Forum of Organizations Working with the Disabled (NFOWD)**  
and  
**Deafblind International**

The first DbI Asia Conference with the theme of “Deafblindness – The Asian Awakening” was organized at Ahmedabad in India from 8-12 February, 2000. The Asian conference helped several participants from developing countries to gain from the experience shared in the conferences. Encouraged from the success of first Asia conference, DbI has decided to organize the second DbI Conference with the theme “Deafblindness – Breaking Barriers in Asia” from January 29-31, 2006 at Dhaka, Bangladesh.

Important dates to notice are:

Last date for abstract submission: 31 July 2005

Last date for final paper submission: 15 November 2005

Registration Fees will be charged as follows:

Category of Participants	If Registration is completed	
	Before August 31	September 01 onwards
In-country Participants	BDT 2,000.00	BDT 2,500.00
Participants from Asia	USD 75.00	USD 100.00
Participants from Beyond Asia	USD 200.00	USD 250.00

Deadline of Registration for Reduced Fee: August 31, 2005

and all **registration will close on Monday, November 30, 2005.**

For more details, go to the website: [www.dbiconference.org/asia/](http://www.dbiconference.org/asia/)



## La Sordoceguera

– un análisis multidisciplinar

**T**his very comprehensive book has just been published by ONCE, in Spanish, and covers a huge amount of information about deafblindness. The first part of the book contains detailed sections on both vision and hearing and there follows a section on deafblindness and its unique challenges. This leads to an extensive chapter

on communication and methods that are used. The final chapters contain, amongst other things, advice working with families and technical support and devices that can be helpful.

This book has been written by colleagues at ONCE and it also has a CD ROM  
ISBN 84-484-0142-5



## Challenging behaviours in children with multiple sensory impairment

**A**pnootmuis Educaintment from the Netherlands are launching a new CD-ROM

"It is estimated that over one third of the children with multiple disabilities display challenging behaviors such as self-injury, extreme withdrawal, non compliance, and aggression."

Together with the staff of the Children's House at Sergiev Posad, Russia, Drs. Jan van Dijk and Ton van der Meer, with the cooperation of Dr. Catherine Nelson, from the University of Utah, have developed a comprehensive intervention plan to deal with such challenging behaviours.

The CD-ROM works with the learner, in a step by step procedure, to encourage



understanding of the most important principles of behaviour support (e.g. functional and A.B.C. analysis, observation of target behaviour, use of the Motivation Assessment Scale). It supports the learner to formulate a hypothesis, about the possible reason for the challenging behaviour, and how to develop strategies to prevent or change it. In the second part of the CD-ROM children and staff in real teaching situations demonstrate how

the learned principles are put into practice. Follow-up studies of the children are shown which clearly demonstrate the effect of the intervention.

The approach is eclectic and so principles from different disciplines are applied.

This CD-ROM will be available in Russian in the beginning of March and in English during the autumn of 2005.

Website: <http://www.aapnootmuis.com>

# Deafblind International World Conference 2007

25th – 30th September 2007

Experience Spring in Perth, Western Australia.

Senses Foundation's Conference Committee is developing a scientific program for the conference which will challenge and inform you and a social and recreational program which will introduce you to the uniqueness of Western Australia.

Perth is one the most stunningly beautiful cities in Australia yet it is one of the most isolated capital cities in the world. With pristine white sand beaches, pleasant Mediterranean climate, clean environment and open relaxed lifestyle, Perth is the place to be in Spring 2007.

Perth, named the "City of Lights" by astronaut John Glenn during his 1962 orbit above the city and, as the "Friendly City" by visiting international tourists, is the capital of Western Australia and Australia's western gateway. Perth offers an easy-going lifestyle – the beautiful Swan River and inner-city parks like Kings Park add to the relaxed, natural feel.

There is much to see and do in this part of Australia, from swimming in crystal clear ocean waters to enjoying a taste of rural Australian living at relaxing country retreats and secluded chalets. So make sure you have a look at our suggestions for pre and post conference holidays to make the most of this fabulous opportunity.

Nestled on the banks of the scenic Swan River in Perth the Burswood International Resort Hotel, chosen as the conference venue, is one of the world's most spectacular resort developments, in one of the world's most beautiful cities.

Located only 10 minutes from the domestic and international airports and a short five minutes from the city of Perth, Burswood is surrounded by 100 hectares of superbly landscaped gardens and parklands.



Perth has much to offer, but the differences in the vast state of Western Australia provide a wide range of other features and attractions to visit. From the gorges of Kalbarri National Park and whales migrating past Kalbarri, Geraldton's history, dolphins of Monkey Mia, Carnarvon's outback, Exmouth's Coral Bay and the Ningaloo Reef – the list is endless. Whatever you like to see or do, Western Australia has it.

**Come to Deafblind International World Conference 2007 and see for yourself!**

## Course

# Rubella

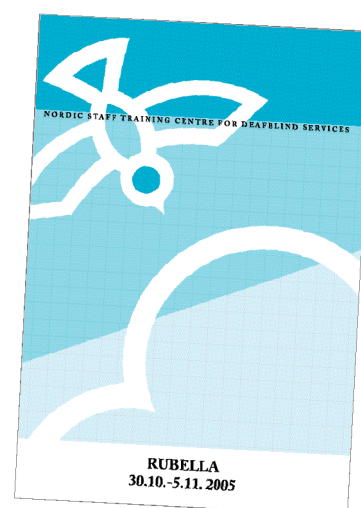
30 October – 5th November 2005-05-09

Nordic Staff Training Centre

This course will first and foremost focus on deafblind adults and young people with congenital rubella syndrome (CRS) and the challenges this group face. The course will highlight the late manifestations and examine in more detail the studies that have been undertaken. The main emphasis will be on assessing which medical and educational interventions are relevant for people with CRS.

The course tutors are drawn from all over the Nordic region and from Europe and Canada.

For information and application form: [www.nud.dk](http://www.nud.dk)



### Management Committee News



**Sumitra Mishra**

The next meeting of the Dbl Management Committee will be on Monday 1 August, 2005 and the next Dbl Council meeting

is on Tuesday 2 August, 2005. These meetings will take place in Slovakia prior to the Dbl European Conference.

### The major Dbl events coming up are:

**The 2nd Dbl Asian Conference will be held from 29 – 31 January 2006 in Dhaka, Bangladesh.** The First Announcement for this conference is out! It is being hosted by the National Forum of Organizations Working with the Disabled (NFOWD) from Bangladesh. The theme of the Conference is "Deafblindness – Breaking Barriers in Asia". For details please visit [www.dbiconference.org](http://www.dbiconference.org) or contact the Conference Secretariat at [nfowd@bdmail.net](mailto:nfowd@bdmail.net)

If you register before 31 August 2005, you can take advantage of the early bird registration fee of \$200 US. The regular registration fee is \$250 US. Registration closes on 30 November 2005. The abstracts submission deadline is 31 July 2005 and the final paper submission deadline is 15 November 2005. Please send your papers to Akhil Paul, Chair of the Scientific Committee, at [akhil@senseintindia.org](mailto:akhil@senseintindia.org) or fax at +91.79.279 11054.

**The 14th Dbl World Conference will be held from 25–30 September 2007 in Perth, Australia.** It is being organised by Senses Foundation. In February this year William Green and Richard Hawkes (President and Secretary of Dbl) visited Perth to meet colleagues from the Senses Foundation and discuss plans for the conference. A Scientific Committee has now been

agreed by the Dbl Management Committee and the first meeting will be taking place this August. We will bring you more information in the next issue of Dbl Review.

### Membership Update

All Dbl members are encouraged to renew your membership, if you have not done so already. Please quote your specially assigned membership number in all communications.

There are currently 622 members, including 50 corporate members, from over 80 different countries.

We are pleased to welcome all new corporate and individual members to the Dbl family!

If you know of any organisation that may be interested to join Dbl as a corporate member, please pass on their details to the Secretariat now!

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

If you have any queries regarding the status of your membership, please do not hesitate to contact the Secretariat at [secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org)

### The Dbl Secretariat

We hope that you received your copy of the previous issue of Dbl Review. If you have not received your copy, please contact the Secretariat. We are also keen to update the information we have about you and your organisation, so kindly make sure you send your membership renewal forms with your latest contact details to the Secretariat.

If you have any queries regarding your current membership or would like to complete the membership form via email, please contact Sumitra Mishra at: [secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org) or post your query at: **Dbl Secretariat, Post Box No: 9601, Janakpuri**



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 €30 a year or a discounted €100 for four years.

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

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

*Large Corporates:*  
Annual Fees between €3,000 and €5,000

*Small Corporates:*  
Annual Fees between €300 and €1,500

Corporate Members can be nominated to sit on the Council.



### Deafblind International Individual Membership

- ☐ I would like to join DbI as an individual member  
☐ I would like to renew my DbI individual membership

Member details		Membership No.
Title	Surname	First name
Organisation		
Job Title		
Address (Line 1)		
Address (Line 2)		
Town/City	State/County	
Zip/Post Code	Country	
Telephone no.	Fax no.	
(Please include country and area codes)		
E-mail address:		

- Are you:  
☐ a deafblind person ☐ a family member ☐ a professional  
 Does your organisation work primarily for/with:  
☐ blind people ☐ deaf people ☐ deafblind people  
☐ disabled people ☐ other (please specify)

*Your contact details will be made available to DbI members for DbI purposes but will not be made available for commercial purposes.*

#### DbI Review (please check one box in each category)

- A. I would prefer to receive *DbI Review* in:  
☐ English ☐ Spanish  
 B. I would prefer to receive *DbI Review* on: ☐ paper ☐ disk\*  
 (The disk version of *DbI Review* is supplied in text only format, on floppy disk)

#### Membership Fee please tick where appropriate

- ☐ I wish to pay an annual membership fee of €30  
☐ I wish to pay for 4 years' membership at the **discounted rate of €100**  
☐ Please waive my membership fee as I am unable to pay it at present



### Corporate Membership

There are two tiers of Corporate Membership:

#### Large corporates

Annual fees between €3,000 and €5,000

#### Small corporates

Annual fees between €300 and €1,500

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

We submit an annual fee of € \_\_\_\_\_  
 Corporate members are entitled to receive up to 25 copies of *DbI Review*. We would like \_\_\_\_\_ copies in ☐ English ☐ Spanish (delete as appropriate)

Member Details:	
Organisation	
Representative	
Address (Line 1)	
Address (Line 2)	
Town/City	State/County
Zip/Post Code	Country
Tel:	
(please include country & area codes)	
Fax:	
(please include country & area codes)	
Email:	

### How to pay?

In order to enable us to put your entire membership fee to use, we would kindly ask you to avoid sending us cheques as much as possible. By arranging your fee via bank transfer, we are able to keep banking charges to a minimum, thereby increasing the value of your membership fee. Naturally, for those of you who do not have access to this facility, we will be delighted to accept your fee by credit card, cheque or in cash. However, if it is really not possible for you to pay by bank transfer and you do have to pay by cheque or credit card, maybe you could do so for four years instead of just the one.

Payment method ☐ Bank Transfer ☐ Credit Card ☐ Cheque

#### A) Payment by Bank Transfer

If paying by bank transfer, please make payment to the following account:

Name of Bank: RABOBANK  
 Address of Bank: Sint-Michielsgestel, The Netherlands  
 Account Name: Instituut voor Doven: INZAKE DBI  
 Account Number: 11.29.09.825  
 Swift Address: RABONL2U  
 IBAN: NL31 RABO 0112 9098 25

Date of Bank Transfer:

Please quote the Swift Address and IBAN number in your instructions for Bank Transfer (If this is impossible and you have to send a cheque or international postal order then please contact us)

#### B) Payment by Credit Card

Card type: ☐ VISA ☐ American Express ☐ Mastercard

Card no:

Expiry date \_\_\_\_\_ Name on card: \_\_\_\_\_

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

#### C) Payment by cheque

If paying by cheque, please make cheques payable to 'Deafblind International' and send to the address given below. If paying by Eurocheque, please make out cheque in euros.

**Please fax this whole page to 91-11-25618430 or return to:**  
 The Secretariat, Deafblind International, Post Box No 9601, Janakpuri, New Delhi – 110058, INDIA.

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