



**DbI**  
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THE MAGAZINE  
OF DEAFBLIND  
INTERNATIONAL

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# *Review*



**Sharing ideas**

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

DbI 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 DbI.

DbI Review is also available on disk. If you are interested in receiving your copy on disk, please contact:

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Cover: Delegates at the ADbN meeting in Groningen.

## A message from the president

### Dear friends and colleagues!

Once again we have been very busy as an organisation. We held our Council meeting in Kuala Lumpur this summer which was very well attended and gave us the opportunity to put deafblindness on the agenda of the ICEVI world conference.

Our Canadian colleagues hosted a fantastic conference in September which brought many parents and professional together from all over the country.

The European Deafblind Network in October brought families together in Salou, Spain to discuss issues of great importance to both professionals and parents. This meeting was extremely well organised, thanks to Ricard Lopez, and his team of volunteers, who made this event happen. Plans are underway for the next conference to take place in Scotland in two years time.

In November another of our very active networks, the Acquired Deafblindness Network, organised a really good conference in the north of Holland. And in December a small group of people will meet in Italy to discuss the ageing process of congenitally deafblind people and people with acquired deafblindness.

What is so satisfying is that we have "happenings" practically every month



somewhere in the world concerning deafblindness. I warmly congratulate you all!

Your Mancom met last month where many current issues were discussed. High on the agenda was the work being done by the Strategic Planning Committee and the Nominations Committee. This work will affect the future direction of DbI. We cannot be effective unless they have your comments so please take the time to put your views forward, as both these groups are very keen to hear from you.

Collaboration is the key word for DbI and after our successful link with ICEVI we are now making an effort to finalise the structure of working with the World Federation of the Deaf Blind.

On a final note, but of great importance, is the DbI World Conference coming up next year in Perth, Australia. Those involved are working very hard to make this an unforgettable experience. I hope you will be taking

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advantage of the extended deadlines for submitting a paper and registering your interest! I hope to see many of you there.

I finish, as always, with thanks to all of you who

strive to ensure a good quality life for all deafblind children and adults and their families.

**William.**

## EDITORIAL

We have a very full magazine this time – so thank you for keeping me up to date with all your news and views! We have our usual mix of articles, network reports, regional and country news and plenty of photographs to illustrate our activities.

We lead on a very stimulating article in which Kathleen Deasy and Fiona Lyddy from Ireland discuss the embodied cognition approach to the acquisition of language and communication skills in relation to people with congenital deafblindness.

We also have the first of a series of articles on the theme of the “forgotten” senses. David Brown begins by talking about proprioception, which rarely seems to be mentioned when children are assessed but has such an important part to play in the way we understand them. The concept of multi-sensory impairment is brought more clearly into focus through this article.

A fine survey article addressing the numbers of elderly people who are deafblind is presented by Ole Mortensen. For those member organisations that are moving towards

campaigning and providing services for elderly people the material in this article will be most rewarding.

Another area which is very current is access to cochlear implantation. Milon Potmesil describes some of the issues faced in Czech Republic by children with multi-disability.

William has already mentioned the many successful meetings Dbl networks have organised in the past three months and you will find them all reported here, as well as many others too.

Next time we will be running the full story from the UN – a major landmark or us all!

Siblings are featured across the magazine with a highly informative article from Sheri Moore and an account of the Siblings Network meeting in Spain. As part of the article there is a comprehensive list of resources, mentioned briefly here, but lodged in full on the website. Do look and download it.

Do let me know if you would like to publish an article or tell us about your work – I look forward to hearing from you.

**Eileen**

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# Embodied Cognition and the Development of Language for Individuals who are Congenitally Deafblind

Kathleen Deasy & Fiona Lyddy

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Individuals who are congenitally deafblind are presented with significant challenges when attempting to acquire language and communication skills. Since most of the information perceived is gained through direct bodily contact,

“The embodied cognition approach... may offer some insights into the way individuals who are congenitally deafblind develop language.”

cognitive processes necessary for language development remain closely connected to the body's interaction with the environment. The embodied cognition approach, with its focus on specific body-environment interactions, may offer some insights into the way individuals who are congenitally deafblind develop language.

The embodied cognition approach within cognitive psychology highlights the association between an individual and the particular way that individual's body acts upon an environment as

the driving force for cognitive development. Thereby, “cognition depends on the kinds of experience that come from having a body with particular perceptual and motor capacities that are inseparably linked and that together form the matrix within which memory, emotion, language, and all other aspects of life are meshed” (Thelen et al, 2001, pg.1). According to such views, higher order cognition has its basis in sensorimotor processing and “the very structure of reason itself comes from the details of our embodiment” (Lakoff & Johnson, 1999, p.4). The suggestion is not that concepts depend on specific physical capabilities; individuals who are differently-abled would not be predicted to possess markedly divergent concepts, nor is conceptual development limited to direct experience or activity. Rather, the approach argues that to understand the human mind we must consider its place in a body that interacts with a world. Sensorimotor experience and the recruitment of bodily resources for cognitive processing are key.

It is this consideration of the manner in which the body interacts with the environment and the resultant cognitive adaptations that develop that may contribute to our understanding of language development for individuals who are deafblind. The perceptual and motor capacities that develop for those who are deafblind will reflect the restrictions of vision and hearing impairment from birth. (Here, reference will be made to those individuals who are congenitally deafblind as opposed to those who have acquired deafblindness. Although there are difficulties inherent in developing communication skills for both populations, the particular challenges that face those who are born both visually and hearing impaired are arguably more complex.)

Embodied cognition as an approach to the study of the mind is associated with the following six claims, according to Wilson (2002). This first claim is that cognition is situated. Cognition occurs in a real world environment, with perception and action intrinsic components of



this processing. The second claim is that cognition is time-pressured. Cognition as real-time interaction with the environment is emphasised. The third claim is that we off-load cognitive work onto the environment. Because humans are limited capacity information processors, we use aspects of our environment in order to reduce cognitive workload, and maximize processing capacity. The fourth claim is that the environment is part of the cognitive system. This is perhaps the most contentious claim, effectively suggesting a mind-world continuum in terms of information processing, and limiting the usefulness of considering mind as a separate entity. The fifth claim is that cognition is for action. Thus perception and memory are considered in terms of their role in determining and guiding situation-appropriate behaviour. The sixth claim is that off-line cognition is body-based; even remote from particular activities in the environment, cognition is shaped by environmental interactions. Wilson (2002) provides a critical evaluation of these claims as they apply to normal cognition, and within cognitive science debate continues as regards the precise assumptions and merits of the embodied cognition approach. However, for our purposes the above assertions may provide a useful framework within which to consider the nature of interaction with the environment and conceptual development for individuals who are deafblind.

Combined vision and hearing impairments severely constrain interactions with the environment. While loss of one or other of these senses need not preclude alternative access to environmental information, the combined loss or deficit in both substantially reduces the sensory input available from the environment and limits motor function within it. Cognitive development for those who are deafblind will reflect these limitations and will benefit from the use of particular cognitive tools that assist in making sense of the world.

### “Combined vision and hearing impairments severely constrain interactions with the environment.”

According to the first assertion above, real-time cognition has its basis in situated activity, though much of human cognition occurs ‘off-line’. A combined loss of visual and auditory input would seem to limit the level of abstraction that can occur in off-line processing; thus cognition would involve situated action and the memory thereof. This emphasis on situated action- an action that is situated in a cultural setting, and in the mutually interacting intentional states of the participants (Bruner, 1990) - seems most relevant to the deafblind

situation. David Goode’s (1994, pg.119) sociological research of two congenitally deafblind children describes the phenomenon of a type of ‘language’ called conversation with our bodies, which is “produced by particular bodies, with specific biographies, at some specific time, in particular relationships, and interpreted as such by interactional participants”. The specific shared code for communication described develops from this link of the body within a certain environment and is understood through a process of mutual interpretation and collaboration. Communication theories addressing deafblindness have been developed which, in essence, accentuate a negotiation process whereby cognitive development is assisted through opportunities for communicative interaction (Souriau, 2002). Nafstad and Rodbroe (2000, pg. 27) contend that individuals who are deafblind refer to events by “whatever impression the deafblind individual received from the event through and directly on his body”. Conceptual processing becomes predominately and directly mapped through these impressions. How one encounters the world while performing an action in a particular environmental context determines the way one forms concepts and how they are represented and stored in memory. Conceptual categories assist cognitive processes by representing information in

an economical way (Roth & Bruce, 1995). Aspects of the world that are experienced by individuals who are deafblind will become categorized and referred to based on a specific bodily interaction or given occurrence.

The second claim regarding cognition being time pressured seems to follow closely with the third claim regarding off-loading cognitive work on to the environment. Cognition has evolved with the pressures of real-time interaction. With vision and hearing compromised the load that the cognitive system can normally bear, through use of mental images and stored representations for example, may be reduced. With vision and hearing loss, the off-loading of cognitive work to the environment may be critical in how the body helps the mind to perform more economically. Tactile objects of reference used in calendar systems or in communication books can be seen to support individuals who are deafblind at maintaining discourse while minimising the load for internal processing. Prevalent to this population are stereotypic and ritualised behaviours, like rocking or hand flapping, which have been examined with regard to their possible functional and developmental benefits (Murdoch, 2000). These behaviours may also play a role in supporting cognition. In Goldin-Meadow's (2003) extensive research, gesture has been found to be more than just communicative when it accompanies speech, for it plays an important role in assisting

cognitive processes and reducing cognitive effort. In the absence of speech, which is true for a majority of individuals who are congenitally deafblind, attempts at such adaptations may emerge in apparently stereotypic behaviours. Signed echolalia, similar to the echolalia in speech and often regarded as a stereotypic behaviour could be considered as a method of extending or externalising a thought for some individuals who are deafblind. When used in a conversational setting, signed echolalia may provide cognitive assistance to sustain discourse.

The fourth claim of embodied cognition states that the environment is part of the cognitive system. The information that flows between mind and world is continuous such that the body-world system may be considered as the basis for cognition rather than the traditional conceptualisation of mind as a separate entity. For Wilson (2002) this distributed approach to cognition is the most problematic of all the claims; however in the absence of distance senses the impact of environment on the individual's thinking is immediate such that separation of thought from the surrounding environment becomes less palpable. Perhaps Anderson's (2005) example of the "blind man and his cane" (from Merleau-Ponty, 1962) can explain how in some cases cognition is best understood by considering bridges to the environment, that outer world, and the body as a

single system of analysis. The man feels not with the hand holding the cane but with the cane, and the world is experienced through the cane almost as part of the body, the tool serving as an extension to the existing senses. With both distance senses compromised, the world exists as it makes contact with the body and the role of other people in extending knowledge of it becomes critical. Activities which involve mutual attention to particular aspects of the environment will enrich the capacity to represent that world for such individuals.

The last two claims of embodied cognition are that cognition is for action and that off-line cognition is body based. Cognition, by this view, is best understood in terms of the production of situation-appropriate behaviour. Without the distance senses to shape behaviour, developmentally, for those who are congenitally deafblind the world has been presented in a fragmented and unpredictable way. Consequences to behaviour cannot be readily anticipated, as for example when someone might see or hear a touched object fall over. Without these senses, cognitive mapping develops from individualised environmental experiences that one who is congenitally deafblind may have and 'thinking' would seem to involve physical impressions directly related to such interactions. The claim that normal off-line cognition is body based is attracting



support in empirical research in recent years. Off-line cognition refers to processes such as mental imagery, recalling memories or daydreaming, which involve the simulation of physical events internally. Visual imagery, for example, would seem to be share processing resources and have much in common with visual perception. In the absence of visual and auditory input, direct impressions on the body are internalised. Off-line cognition grounded in bodily contact is evident in natural gesture and in the

Bodily Emotional Traces (BETs) described by the Dbl Communication Network (Daelman et al., 2004).

Therefore reference to an event will rely on specific previous interactions, and the emotional significance thereof, with understanding of that event and the ability to refer to it constrained accordingly.

Individuals who are congenitally deafblind face an arduous task in attempting to acquire language and communication skills. This population is deprived from both normal

sensory input and social experience from birth, thus minimal opportunities for acquiring communication skills arise. The cognitive processes necessary for language development become associated with the specific way one who is deafblind interacts with the environment. The embodied cognition approach, by focusing on the manner in which a mind, body and world mutually interact together, may prove informative with respect to facilitating communication in this group.

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# Creating a federation of deafblind people in Africa

Lex Grandia, President of the World Federation of the Deafblind reports on the outcomes of an important meeting for deafblind people across the continent

In October 2006, a one week seminar was organised for African deafblind leaders in Mombasa, Kenya. Eight deafblind leaders from eight African countries participated very actively in this event. They were: David Shaba – Tanzania, Joash Imbwana – Kenya, Roman Mesfin – Ethiopia, Andre van Deventer – South Africa, Ezekiel Kumwenda – Malawi, Agnes Abukito – Uganda, Roman Mesfin – Ethiopia, Noukany Bagayoko – Mali, Sansan Dah – Ivory Coast

The event was organised jointly by the Secretariat of the “African Decade of Persons with Disabilities”, UN initiative which runs from 1999 to 2009, and by Penny May Kamau, leader of the East African Deafblind project, supported by FSDB and of Sweden. The “African Decade” Secretariat received financial support from the Danish development agency,

Danida.

As President of the World Federation of the Deafblind I participated and contributed to the seminar, and so did major stakeholders in the area like AFUB, the African Union of the Blind, Sense International, Uganda and CBM.

The aim of the seminar was to explore the need to create an African Federation of the DeafBlind.

## Change is on its way?

This was the 4th meeting of the African deafblind leaders in 2 years, and the seminar used the Logical Framework Approach (LFA) to explore the questions: why an African Federation of the DeafBlind? What problems do we face in Africa? In answer we identified many factors:

- deafblind people in Africa are very isolated

- very few have been educated in any communication system for deafblind people
- deafblind people are the poorest of the poor
- many never went to school or had any education
- healthcare is often inaccessible to deafblind people
- there are almost no assistive devices available, like hearing aids, eye glasses, white canes, Braille machines, magnifying systems or computers
- there are no job possibilities and very few income generating activities
- deafblind people are often victims of abuse and have a higher risk of getting HIV/AIDS
- there is hardly any awareness of deafblindness and very little knowledge about education, rehabilitation, communication methods and technical aids for deafblind people







- It is difficult to form national organisations due to lack of resources, long distances and poor infrastructure

### A Way Forward

Clearly, it was easy to formulate the problems, but most of these are best solved on a national level. What benefit would national organisations have of a continental African representative organisation? The group spent two days formulating a mission statement for an African Federation of the DeafBlind, and considering its activities for the first five years after its foundation. It was a very productive discussion.

The mission was formulated as follows:

**"The mission of the African Federation of the DeafBlind (AFDB) is to empower national deafblind organisations and to act as the unifying voice of deafblind persons in Africa, which will ensure that deafblindness is recognised and deafblind persons are recognised as persons with dignity, equal rights and opportunities.**

**This will be achieved through networking, partnership, capacity building, awareness raising, information sharing, lobbying, advocacy and technical support."**

After this inspiring work, we continued to work to develop a constitution.

### WFDB view

The World Federation of the DeafBlind, as an international representative organisation of deafblind people, strongly wants to support this development in Africa as much as we can, but our resources are limited. Our experience is that partnership between an African national deafblind organisation and an organisation or institution in a country, which has many years of experience in the deafblind area, can be very productive. Deafblind South Africa, DBSA has a partnership with the Swedish deafblind organisation FSDB and the new deafblind organisation in Uganda, NADBU, has a partnership with the Danish deafblind organisation, FDDB.



We are searching for French speaking partners for deafblind organisations in Mali and Ivory Coast and we also need partners for Kenya, Malawi, Ethiopia, Zambia and Tanzania.

I hope all members of Dbl will consider a possible partnership.

**Lex Grandia**



# 20 times more elderly people with a vision and hearing loss?

Ole E. Mortensen, Director of Information Center for Acquired Deafblindness, Denmark reports on his work studying prevalence of deafblindness in the elderly population and brings forward some important findings.

Up till now we have estimated a prevalence of 0.33 percent - approx. 750 people – in Denmark over the age of 80 with such severe dual sensory impairment that they can be defined as deafblind (see facts box). This prevalence was based on a Danish demographic survey from 1995. However, two newer and more thorough scientific studies from the other Scandinavian countries reveal prevalence of dual sensory impairment that are several times – maybe up towards 20 times – larger! A further four studies support these results in different ways, and in this article we take a closer look at them all.

Not very much scientific interest and attention have been invested in the prevalence of concurrent vision and hearing impairment. At the Information Center for Acquired Deafblindness in Denmark we have searched the scientific literature and found six studies, which we have analysed to get a clearer view of the extent of age-related dual sensory impairment in Denmark. There are no registers of people with dual sensory impairment in Denmark, but by using this approach we

have been able to pinpoint the magnitude of this issue and use this knowledge for a concentrated information and awareness raising effort aimed at politicians and the public through the media.

Our initial survey in 1995 – indicating a prevalence of 0.33 percent – created quite a stir and based on this, the Centre introduced a series of initiatives targeting the elderly deafblind and their professional carers. About 750 elderly people over 80 years old with severe dual sensory impairment was considered to be a very high figure in those days – both nationally and internationally. But now, based on surveys more thorough and valid than ours was, it seems that we must accept a prevalence that is many times higher!

## Lillehammer, Norway

Senior Researcher, Kolbein Lyng, from Norwegian Social Research (NOVA), and the deafblind consultant Else-Marie Svingen, Skådalen Resource Centre, Oslo have conducted several studies of elderly people with acquired deafblindness in Norway. In one of the studies, they mapped the prevalence of severe dual sensory impairment in elderly people in Lillehammer Municipality (Lyng and Svingen 2001).

The study focussed on the elderly who were in contact with local social services, either because they received home help or home nursing, or because they lived in a nursing home. Around 75% were over the age of 80, and the average age in this group

## FACTS BOX:

### Nordic definition of deafblindness

The first lines of the Nordic definition from 1980 read:

“A person is deafblind when he or she has a severe degree of combined visual and auditory impairment. Some deafblind people are totally deaf and blind, while others have residual hearing and residual vision.”

*(Please note: The Nordic definition is being revised, and a new definition is expected to be introduced late 2006)*

was around 87 (from 69 to 100-year-olds).

There were 719 participants in the study. The starting point was a checklist which the municipal staff were asked to fill in for each of their clients. Using this checklist, Else-Marie Svingen conducted interviews with those elderly people who had problems with their vision or hearing, and who wished to be assessed to see if they met the Nordic definition of deafblindness.

The study demonstrated that four percent of the elderly in Lillehammer, who received municipal home help and/or home nursing or who lived in a nursing home, had such severe dual sensory impairment that they came under the definition of deafblindness. Among the people living at the nursing home, the prevalence of age-related deafblindness was as high as 10%.

According to this study, almost 7,500 Danes are presumed to have such severe dual sensory impairment that they can be diagnosed as deafblind.

### Longitudinal study in Gothenburg

In 2000, ophthalmologist Birgitta Bergman and audiologist Ulf Rosenhall concluded a major study of the relationship between hearing and visual problems in old age (Bergman and Rosenhall 2001). 973 people in Gothenburg had their hearing and vision tested three times: as 70-year-olds, as 81-82-year-olds and as 88-year-olds.

Hearing was tested in one of two ways, either by

#### FACTS BOX:

##### Age-related hearing impairment

Typical age-related hearing impairment is most severe in the higher frequencies. Impairment can be relatively light at 500 Hz, slightly worse at 1000 Hz, somewhat worse at 2000 Hz and very much worse at 4000 Hz. When specifying a hearing impairment of e.g. 40 dB, it is the average of four different frequency ranges, 500, 1000, 2000 and 4000 Hz. So when the average hearing impairment in these frequencies is 40 dB, the impairment is often very much higher than 40 dB in the high frequencies than in the low. It is the high frequencies, particularly those from around 1800 to 2500 Hz that are important for the understanding of speech

pure tone audiometry or by a whispered and spoken voice test (WSV). Pure tone audiometry is a "traditional" hearing test in which the subject is presented with tones in different frequency ranges and with different volume and indicates when they have heard something. The WSV is a simple test in which the examiner stands behind the subject and tests how close they have to be before the subject can hear the whisper.

In Rosenhall and Bergman's delimitation of the group with dual sensory impairment, they used a moderate hearing impairment as the upper limit for hearing. In WSV, "moderate hearing impairment" is defined as the inability to hear a whisper further than one metre away, while in pure tone audiometry it is defined as a 40 dB hearing loss or more (as an average at 500, 1000, 2000 and 4000 Hz).

In this study, however, it turned out that what was interpreted as a moderate hearing impairment using the

WSV, in fact corresponded to an average hearing impairment of 50 dB measured using pure tone audiometry. Thus, the results of the hearing test – and the number of people found – vary depending on which method is used. However, in this study, "moderate hearing impairment" corresponds to at least an average hearing impairment of 40 dB.

**“According to this study, almost 7,500 Danes are presumed to have such severe dual sensory impairment that they can be diagnosed as deafblind”**

Visual impairment in this study was defined as a visual status of 0.3 (also known as 6/18), i.e. equivalent to the limit for partially sighted people in Denmark (see facts box). How many people had even poorer vision was not apparent from the study.



### FACTS BOX:

#### Visual status

Visual status is calculated as a ratio between normal vision and the vision of the subject. A visual status of 0.3 (or 6/18) means that the subject can see at six metres distance what somebody with normal vision can see at 18 metres. With this vision you are entitled to visual aids and training at eyesight centres. The legal limit for driving a car in Denmark is a visual acuity of 0.5 (6/12).

### Results

The study presented the following results:

- At 70 years of age: Dual sensory impairment was not pronounced and 70% had normal vision and hearing.
- At 81-82 years of age (vision and hearing tested on a total 207 subjects): three to six percent (WSV and pure tone audiometry, respectively) had at least a moderate hearing impairment together with a visual impairment of 0.3 or more.
- At 88 years of age (vision and hearing tested on a total of 167 subjects): Eight to 13 percent (WSV and pure tone audiometry, respectively) had at least a moderate hearing impairment together with a visual impairment of 0.3 or more.

“But does this mean that they are deafblind?” the sceptical reader may well ask knowing that we in the Nordic countries – as well as other countries – use a functional definition for deafblindness. Here the answer must be, “Not all – but probably most of them.”

In Lyng and Svingen’s

Norwegian study above, they gathered objective vision and hearing information from the elderly. The participants also received a visit from an experienced deafblind consultant who assessed their sensory functionality in relation to the Nordic definition of deafblindness. Of 25 elderly people who had a visual acuity of 0.3 or worse and an average hearing impairment of at least 40 dB measured using pure tone audiometry (i.e. which is the same as the limits set in the Swedish study), all except two were assessed by the deafblind consultant to be deafblind in accordance with the definition.

One can thus with a certain degree of confidence presume that most of the people in the Swedish study are also deafblind according to the Nordic definition.

### 3.8 to 6.9 percent prevalence

It is however extremely important to point out that this does not mean that this can be used as a quantitative criterion for deafblindness. There are deafblind people who hear better than 40 dB and/or see better than 0.3, but who are still defined as deafblind according to the Nordic functional definition.

And as the Norwegian study shows, there may be individuals with poorer visual acuity and hearing, who are not considered deafblind according to the functional definition.

In the Gothenburg study, the prevalence of severe dual sensory impairment was calculated among 70-year-olds, 81-82-year-olds and 88-year-olds, but not in the +80 group as a whole. To find an overall prevalence, we therefore have to pull out the calculator.

We know that the prevalence of acquired deafblindness increases with age. Three to six percent of the subjects in the 81-82-year-old group had a severe dual sensory impairment, and so we can assume that this figure is a minimum for the entire group up to 88 years of age. This means that there should be between 4,000 and 8,100 elderly people between 81 and 87 years of age with a severe dual sensory impairment in Denmark.

In the group of 88-year-olds, the prevalence increases to between eight and 13 percent and so we can assume that this at least also applies to those who are even older. This gives figures of between 4,500 and 7,300 with severe dual sensory impairment in this age group.

In total, the Swedish study reveals that there should be between 8,500 and 15,400 elderly people in Denmark above the age of 80 with a dual sensory impairment (defined as a visual acuity of 0.3 or poorer and a hearing loss of 40 dB or greater) – an overall prevalence of between 3.8 and 6.9 percent in the



## Prevalence of deafblindness in old age

+80 age group based on a population of 220,000 in this age group in Denmark.

And as seen from the experiences of the Norwegian study, most of these will probably also fall under the definition of deafblindness.

### Macular degeneration and age-related hearing impairment

The paramount cause of acquired deafblindness is a combination of age-related hearing loss (presbycusis) and age-related maculopathy such as macular degeneration. If the number of elderly people with severe dual sensory impairment really is as high as the Norwegian and Swedish studies indicate, then these two sensory problems must quite often occur together to a lesser degree. And this has been demonstrated by other studies.

At the end of the 1990s, Ronald Klein and a group of audiologists and ophthalmologists studied the relationship between age-related maculopathy and age-related hearing impairment in the inhabitants of the small American town Beaver Dam in Wisconsin (Klein et al. 1998). The aim was to find those cases where an average hearing impairment of at least 25 dB occurred in conjunction with age-related macular degeneration or pre-stages of this.

In 39.5% of the subjects above the age of 75 this was found to be the case. However, it is worth noting that Klein and his colleagues recorded the condition of the retina and hearing in the weakest eye and ear, in

contrast to the Norwegian and Swedish studies above, which measured the vision and hearing in the best eye and ear. Naturally, this produces a much greater prevalence of hearing and visual problems in this study.

In Beaver Dam, they carried out eye examinations to see if there were signs of maculopathy, but not visual acuity tests and that is important to keep in mind. In addition, a hearing impairment of 25 dB is not a particularly severe impairment and since they measured the weakest eye and ear, we cannot say how many of the 39.5% actually had a severe dual sensory impairment. But, as both age-related hearing impairment and age-related maculopathy such as macular degeneration often develop with age, the study clearly demonstrates that at least the conditions for a high frequency of severe dual sensory impairment are present.

Of particular additional interest was the fact that people with late age-related maculopathy – i.e. where the disease had developed over a longer period of time – were three times more likely also to have hearing impairment than people without the late age-related changes – indicating a connection between these two sensory problems.

### Australian, American and Danish studies

The high occurrence of age-related dual sensory impairment has been demonstrated in a further three studies. In 2005, Jeanette Jee and her

colleagues from Sydney University in Australia examined hearing and vision in 49 elderly people between 65 and 99 years of age (average age around 82), who were applying for municipal care/nursing (Jee et al. 2005). 12.2% of the subjects had a combination of at least a moderate hearing impairment (40 dB on average) and a visual impairment equivalent to a visual acuity of 0.5 and below. A visual acuity of 0.5 is not a particularly severe impairment, but still it is the lower limit for obtaining a driver's license in Denmark. The number of people with even poorer vision was not apparent from the study.

That the occurrence of dual sensory impairment rises strongly with age is also demonstrated in a study from Denmark. In 1990, Agnete Parving and Bent Philip at Bispebjerg Hospital drew up a questionnaire for 185 hearing aid users aged from 90 to 107, of whom as many as 44% stated that they were also "blind" or "had very limited vision" (Parving and Philip 1991). That they were using hearing aids most probably meant that these very elderly people had at least a moderate hearing impairment. For most of these, this therefore meant such severe dual sensory impairment that it came under the definition of deafblind.

The National Health Interview Survey has been carried out in the United States over many years and has studied Americans' health in many areas, including hearing and vision. Among the participants aged 80

years and older who were asked about their own perception of visual and hearing problems (from 1997 to 2002), 16.6 % of them stated that they had a dual sensory impairment to some extent or other (Caban et al. 2005). However, the study revealed large ethnic differences; for example, the occurrence of dual sensory impairment in Americans of Indian or Inuit descent was three times as high as that in Americans of Asiatic descent.

### Different studies – the same picture

The studies discussed here have used different methods and focussed on different groups of elderly people. Even if the results are not therefore immediately mutually comparable, seen together they draw a clear picture of the need to reassess our views on the number of elderly people with severe dual sensory impairment in Denmark – and probably in other countries as well.

As mentioned, we have no registers of people with dual sensory impairment or deafblindness in Denmark. However, we do have valid figures for the prevalence of both hearing and visual impairment, and these strongly support the results from the studies above.

In Denmark it is widely accepted that approx. half of all elderly over the age of 75 have some degree of hearing impairment. A Nordic study from 2005 with 339 elderly subjects from Denmark revealed that 25% of 75-year-olds in Denmark have

at least a moderate hearing impairment measured on the best ear (Hietanen 2005).

Dr Carsten Edmund, ophthalmologist and chairman of Øjenforeningen Værn om Synet ("the Eye Association Protect the Sight"), has in a recent article estimated that there are around 39,000 blind and partially sighted elderly people above the age of 80 in Denmark, primarily due to macular degeneration (Edmund 2005). This estimate is based on registration of the visually impaired in six of Denmark's 17 counties, and Carsten Edmund even believes it to be even lower due to inadequate reporting.

If we correlate the number of blind/partially sighted elderly people (i.e. with a visual status of or poorer than 0.3) with a 25 % occurrence of moderate hearing impairment among elderly in Denmark as demonstrated in the Nordic study mentioned above, there should be around 10,000 people above the age of 80, who are both partially sighted or blind and who have at least a moderate hearing impairment. This figure is in fact very close to the ones from the Gothenburg study, which used the same limits for vision and hearing.

So there is a highly convincing correlation both between the international studies themselves and also when compared with the Danish figures for visual and hearing impairment respectively. It therefore seems that there is no way around the fact that we need to acknowledge that severe

dual sensory impairment must occur in numbers many times greater than we - in Denmark, at least – have estimated so far.

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# Elderly people in the Netherlands

Frederike Galle



These pictures tell a successful story. This project in the Netherlands is a collaboration of key organisations: Bartiméus Sonneheerdt, Kalorama and Viataal. They offer day programmes for elderly deafblind people, at different locations. The participants have access to different types of training and rehabilitation and they participate in social activities.



# Welcome to school

**"No child or teenager should be without the opportunity to study"...  
how one exceptional school responded to the needs of deafblind children.**

**Patti V. Jones, Principal of Filadelfia School for Deaf Children in Bogota, Colombia describes the exciting partnership that led her to achieve her wish to include deafblind children and young people in school programmes. Along the way we meet a group of inspiring school students who have made it happen for one young person and hear about the plans for the future!**

**S**everal years ago, there was a deaf teenage student in our school who began to lose his sight due to Usher Syndrome. Although we all tried, and he tried, the school did not have a program that could meet his needs and so he dropped out of school. This was sad for all of us as he had studied with us since he was a young boy. When the school was founded, we had wanted to have a program for Deafblind children, but with no resources and no one to orient us, we said goodbye to José Richard.

In September of 2003, we were contacted by SURCOE, the Colombian National Federation of the Deafblind about the possibility of receiving three Deafblind students with the understanding that they would give us technical

support and accompany the process. To our delight and surprise, one of those three students was José Richard!

**“During their first days at school, the three students were made welcome and have had a good integration into the school community.”**

It has been an interesting and enjoyable experience for the Filadelfia School for the Deaf, Bogota, Colombia. We have 20 years of experience with the Deaf, have graduated 90 high school pupils who are now in university, technical schools, or working, and

have a very dedicated staff of 14 teachers, both deaf and hearing. The School uses bilingual education for the Deaf, with Colombian Sign Language as the language of instruction, and written Spanish as a second language. There is a positive and strong relationship between the 118 students and their teachers.

As Liliana Montoya from SURCOE and I discussed how to begin this new step, we decided that preparing the teachers and students was important. The teachers were given a workshop that had both information on deafblindness as well as practical experiences to give the teachers a greater understanding of what the new students would need and how they related to their environment. Secondly, the deaf high school students







## Bogota school



It's not just  
about the  
classroom!

had a similar workshop. This was a huge success, and the fact that some of Jose Richard's former classmates were still in school and remembered him helped a great deal. The students were anxious to make him feel at home and to be involved in any way possible.

During their first days at school, the three students were made welcome and have had a good integration into the school community.

As well as being the school principal, I am an interpreter and had the marvelous opportunity to interpret for the Latin Americans (spoken English to Spanish) at the Helen Keller Conference and the meetings of the World Federation of the Deafblind in Finland in 2005. This

opened my understanding to the possibilities open to our students and I must say I had a wonderful time meeting so many new people. It was a great help to get first hand knowledge of what is going on at a global level, and particularly to see the advances made in Latin America. All of this was shared with the School, and the vision related to the Deafblind students grew. I hope to see some of them participating on behalf of Colombia in the future! The president of SURCOE, Beatriz Vallejo, has shown constant support and encouragement as our deaf student body and school community has learned about the uniqueness of deafblindness.

What were some of the

challenges and difficulties?

It is one thing to be willing, but another to face the challenges related to day-to-day struggles of the students in the classroom. In the beginning, SURCOE was able to provide volunteers who came to interpret for Jose Richard while the other two students were able to use the vision they had and participate in class without a hands-on interpreter. Unfortunately, the volunteers had other commitments such as university studies and were unable to continue. At that point an unusual thing happened, classmates began to take turns interpreting for Jose Richard. Obviously, this is not the best situation, as they are also studying, but the human values expressed





## Bogota school

The playground  
is fun too



and the attitude of solidarity has enhanced their lives. With no complaints, they have faithfully interpreted during class, during break times, on field trips, and in social gatherings. Two students expressed to me their desire to go to university to prepare themselves to work with the Deafblind in the future. One of these students lives close to Jose Richard and has accompanied him each day both to and from school on the public transportation, buses. Their willingness and his motivation to learn have allowed him to reach 10th grade. In Colombia, students graduate from high school at the end of 11th grade, so we are looking forward to seeing him graduate in December, 2007. He has had the unwavering support of his mother, in spite of their difficult financial situation.

One of the most encouraging elements of the program has been the renewed vision of the parents of the Deafblind students. Knowing that the school is working with them, seeking to improve their educational opportunities and concerned for the wellbeing of the entire family has given them

strength. This has increased their ability to support and encourage their children.

“One of the most encouraging elements of the program has been the renewed vision of the parents of the deafblind students”

During the last few months, with the organizational ability of Sense International Latin America, an alliance has been formed between Sense, SURCOE, a parents' organization and an institution for those with multiple disabilities, our school and the capital city's Secretary of Education. The government is now paying for the Deafblind students who are minors, and we are seeking funds from other government sectors to subsidize the students who are older than 18. A project has been developed that will improve the services and hopefully provide for full-time interpreters for

two of the students. The program now has 7 deafblind students, from 10 years of age to over 20 years old. Working together, we have been able to include two other Deafblind students in the program. One of these students uses Braille, so we have gone to class and the teachers and students will soon be learning both Braille and the use of the abacus. Our School feels that every experience is good for the Deaf, no doors should be closed, and the more opportunities given, the more they will show their ability to become responsible, contributing adults who will strengthen their community.

We expect to expand the program and use this experience to provide guidelines for other programs within the country. No child or teenager should be without the opportunity to study, and those studies should be within a quality program that meets the Deafblind student's needs. We hope to see Jose Richard graduate from high school next year and he is already making plans for his future!

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# The Forgotten Sense – Proprioception

This is first in a series of articles by David Brown, Education Specialist with California Deaf-Blind Services, exploring the part that the less well-known senses play in our development and the lives we lead

## Introduction

There is still much that we don't understand about early brain development, about the development of sensory processing abilities, about the way we develop the ability to use all our senses simultaneously without confusion, and about the complex interaction of these abilities with personality type, and with early life experiences. When we consider these issues for children with deafblindness our knowledge is even more limited; the population is extremely diverse in terms of ability and disability, and increasingly we see children who demonstrate difficulties with all sensory systems, not just with vision and hearing but also with the 'other' senses – the touch, taste, smell, proprioceptive, and vestibular senses. Apart from some work on touch there has been very little research to look at any of these 'other' senses in this diverse group of children, but we do know from experience that difficulties with vestibular and proprioceptive functioning, in particular, always need to be addressed first if the children are to make the best possible progress in using touch and residual vision and hearing effectively. Knowing

about these 'other' (I would say 'forgotten') senses will give you a different way of looking at yourselves and at other people, and should also help to make children with deafblindness less puzzling in their behaviors.

In the field of deafblind education we have traditionally, and for obvious reasons, focused on the senses of vision and hearing and on strategies for improving the use of any residual function that may be present in both of these distance senses. At the same time we have also, as I have said, paid some attention to the sense of touch as an important information channel that can help to compensate for loss of visual and auditory information. The other sensory systems, the taste, smell, proprioceptive, and vestibular senses, have received very little attention from us, even though together they provide the essential foundation upon which all of our higher vision, hearing, and touch skills are based. These other sensory systems also offer valuable channels to the children for learning and to us for teaching. In the field of occupational therapy, physical therapy, and speech therapy the situation is quite the reverse. Therapists have long been trained and skilled

in assessing and working on these other sensory systems, yet they traditionally receive no training at all in deafblindness, so we would all benefit from a two-way exchange between educationalists and therapists to share our knowledge bases that are complementary yet rarely meet. Consideration of all the sensory systems, and the ways that they work together, can help us to be more effective in our educational assessments and in our teaching, and can clarify that complex situation whereby:

**"The brain, the organ that is responsible for your conscious experience, is an eternal prisoner in the solitary confinement of the skull...and must rely on information smuggled into it from the senses...the world is what your brain tells you it is, and the limitations of your senses set the boundaries of your conscious experience."**

*Coren, Porac & Ward  
Sensation and perception  
(1984, p2)*

These topics are usually considered to be the specialist area of physical therapists and occupational therapists, but as a teacher I have been studying them for three decades in the context





In order to use her residual vision to look at fine details in a book Amy needs to be horizontal with her entire body and head fully supported: having one ankle up on the other knee sends her brain a strong message, through the proprioceptive sense, that her lower body is fixed and stable and not moving."

of working with a large and varied population of children with deafblindness, so this is definitely a teacher's perspective. These topics are also very complicated, and although I have tried to simplify the material there are certain jargon words and phrases that have to be used; knowledge of this vocabulary is important because the specialized words and phrases are likely to come up in medical and therapy reports on the children with whom you live and/or work.

### The sense of Proprioception

The way we can 'feel' where all our body parts are in relation to each other (and

also 'see' them in our mind's eye), without actually having to touch them with a hand or look at them with our eyes, is an ability that we get from our proprioceptive sense. This sense helps us to plan, to position, and to grade our movements without always having to use vision to check what we are doing. You can feel this sense working if you close your eyes and place your right index finger on your nose, and then touch the same finger on to the tip of your left thumb; the proprioceptive sense is not infallible so you may miss your targets a little, but with repeated practice your aim will improve significantly (which reminds us that proprioceptive abilities can be

learned through experience and improved through practice). Proprioception is a strange word, actually a combination of two Latin words that means 'an awareness, or a feeling, of one's own self'. Most people have never heard of this sense, and when they use the single word 'touch' they are usually thinking about several different sensory systems, including proprioception as well as perception of touch, pain, temperature, and vibration. In fact touch is a system that provides us with so many different forms of information, with so many complex and contradictory elements, that some writers have said it may actually be misleading

## The Forgotten Senses

Nick is seeking strong proprioceptive information to help him know where his body is - strong pressure from the swing on his stomach, upper and lower body stretching undergravity, and both arms inside his tee shirt for extra pressure.



to speak of a distinct 'sense of touch'. Other writers have claimed that proprioception is actually a specialized variation of the sense of touch that encompasses the sensations of joint motion (known as kinesthesia) and the sensations of joint position (known as joint position sense). As I talk about proprioception you will notice how often I mention the sense of touch as well, since they operate together so closely.

### The proprioceptors

The receptors of the proprioceptive sense (which are known as the proprioceptors) are located in the muscles and joints throughout the body, and they are sensitive to stretching and to compression. When this sense is working effectively the brain, at all times, has an awareness of where the various body parts are in space, if they are moving or not, and how fast and in what direction they are moving. This constant 'running' awareness is conveyed to the brain depending upon which proprioceptors are being stretched or compressed, and

the force applied, and the direction of the stretching or compression, and also depending upon the angle of every joint. We talk about this sense enabling us to 'feel' where our body parts are, but this does not mean 'feeling' like 'touching' one body part with another – it is an entirely internal sensation.

### Why does it go wrong, and what happens when it does?

A normal range of muscle tone is needed for this sensory system to work efficiently and effectively, so anything that causes abnormal muscle tone will interfere with the effective working of the proprioceptors. Injury, surgery, arthritis, cerebral palsy and other kinds of brain damage, poor circulation, and poorly modulated muscle tone (that is, muscles which are too stiff or too floppy, or which can only alternate between these two extremes) can all result in diminished proprioceptive perception and awareness. Problems with the proprioceptive sense can be made worse when there are also difficulties with the vestibular sense, and with the tactile and

visual senses, all challenges that are very common in the population of children with deaf-blindness. We have all experienced temporary loss of proprioceptive perception when a leg 'goes to sleep' after we have been sitting for a while with it folded beneath us, with the result that the blood circulation to the leg has been cut off; for a brief period we can't 'feel' the leg or the foot at all and it is very difficult to stand and bear weight on it because the ankle and the knee refuse to lock and remain stable for us. We use a variety of behaviors like shaking the leg, rubbing it firmly with our hands, patting it hard with the hands, or trying to stamp the foot on the floor – and all of these are strong proprioceptive stimuli – in order to restore normal sensation and function as quickly as possible.

When a child has a proprioceptive sense that is not working properly some common outcomes may be:

- An inability or a reluctance to push up on the hands and arms when laying face down due to low muscle tone and an inability to 'feel' and control the joints in the fingers, the wrists, the elbows, and the shoulders.
- An inability or reluctance to stand and bear weight due to low muscle tone and an inability to 'feel' and control the joints in the toes, the ankles, the knees, and the hips, while also maintaining vertical stability in the spine.
- Frequent use of the arms and hands to prop the head or the upper body,



or frequently needing to lean against furniture, walls, posts, trees, or other people.

- Heavy foot stamping, sometimes several times with each step, when learning to walk – literally ‘feeling the feet’ through a combination of tactile sensation and, especially, this strong proprioceptive input.
- Paradoxically, after months or years of forceful flat foot slapping on the floor while independent walking is developing, some children, once walking is mastered, develop and prefer a tip-toe barefoot style, the bare feet maximizing tactile sensation, and being on tip-toe maximizing the proprioceptive (pressure) input through the feet, the ankles, the calves, the knees, the thighs, and the buttocks – a different way of ‘feeling’ the muscles in the legs and the feet by tightening them up so that the brain knows exactly where they are and what they are doing.
- Clumsy, poorly coordinated movements, so that sometimes the child must make several attempts to achieve the desired outcome. Children may use specific self-taught strategies to minimize errors, such as close visual scrutiny, or sliding the hand or arm along a wall or a table in order to reach for an object, which provides tactile information about their movements and helps to stabilize the arm, as they reach.
- Use of too little force, or of excessive force (poorly

graded movements), when touching, patting, grasping, pushing and pulling, and lifting or placing things. The child may adopt abnormally high muscle tone, use strong movements, an over-firm grip, and excessive force in making contact with people or objects, all of which may be mis-interpreted as aggressive, rough, clumsy, or inattentive by others.

- Seeking strong pressure or stretching inputs. Examples would include squeezing into tight spaces like a cardboard box or under a chair, crossing or twisting limbs around each other, binding body parts with cloth or string or rubber bands, pulling the teeth and lower jaw downwards, grinding the teeth, tapping things on the teeth, banging on the face or head, clapping or flapping the hands, swinging the legs through space while seated, hanging doubled over a bar or swinging from it by the arms, jumping up and down with the ankle and knee joints as locked as possible, hammering an object on the floor or on a table, kicking heavy objects like furniture or doors).

Excessively high or low muscle tone is usually associated with poorly modulated tactile and proprioceptive senses in these children, tactile defensiveness may be present, and awareness of touch, pain, and temperature may be poor, or fluctuating.

Children often adopt specific postures (for example, flat on the back with both legs bent and

“As I talk about proprioception you will notice how often I mention the sense of touch as well, since they operate together so closely”

one ankle up resting on the other knee, or the legs tightly crossed, or the legs twisted around the chair leg, or the fingers crossed or bunched together, or the hands tightly fisted, or the arms folded in front of or behind the body). These postures provide essential extra tactile and proprioceptive information to the brain about where the child’s limbs are in space, and they also confirm for the child that their body is securely ‘fixed’ and not moving or floating around.

### What can we do to help?

- Consultation with an occupational therapist (preferably trained in Sensory Integration Therapy) and a physical therapist, sharing any observations you have made of the kinds of behaviors mentioned above. As well as specific therapy suggestions the therapists may have ideas on environmental adaptations that will facilitate better control of movements, or ideas to make it easier for the child to succeed at a range of appropriate motor activities (for example, simplified equipment, simplified task, providing extra physical supports, providing a heavier spoon or baseball



## The Forgotten Senses

bat or pen as appropriate to increase proprioceptive sensation, or using clearer visual markers).

- Consult with an Adapted Physical Education teacher for older school-aged children, share any observations you have made of the kinds of behaviors mentioned above, and implement the specialist's suggestions.
- Deep pressure massage, brushing protocols, and rhythmic joint compression. These might be part of a specific Sensory Integration Therapy program, or they could be considered more as part of a conversational activity between you and the child. Rhythmic joint compression and stretching of fingers, arms, legs, or the head and neck can be extremely motivating for children with this type of sensory difficulty and might be a useful strategy to help you to build a relationship with a child who is avoiding social contact. They can also help to 'wake up' the proprioceptive system for a period of time, which may facilitate better perception and performance in specific activities.
- Use weighted clothing, a weighted cloth across the lap when sitting, heavier shoes, heavier bed covers when sleeping, as appropriate. The young man you saw hanging over the swing in the photograph has learned the helpfulness of increased pressure sensation, and often likes to get both his arms inside his shirt so that it presses tightly around his body.
- Binding of whole body parts or specific joints, for example using a blanket, or tight gloves, Lycra sleeves or Lycra clothing. Bracing and wrapping have been used with adults with proprioceptive problems following illness, injury or surgery, and this is reported to serve a sensory function in addition to a mechanical function. For example, an elastic bandage has been known to enhance joint position sense in patients with osteoarthritic knees as well as in patients after significant knee surgery.
- Sports coaching programs and sports injury clinics use proprioceptive training ideas a lot, and it is also a major component of the Alexander Technique and other related disciplines, and learning a little about these might trigger some relevant ideas.
- Chewing gum or 'chewy' items that stimulate strong proprioceptive input through the jaw can be rewarding for these children, and can result in better regulation of arousal levels for calming and attending, and in improved attention span, so better functioning of other sensory systems too.
- Other ideas would include hydrotherapy or water-play (immersion in water increases pressure all over the submerged parts of the body and reduces the challenging impact of gravity), horse riding, a crash mat, a whole range of acceptable 'rough & tumble' play, a climbing frame to swing from, and a trampoline. Because

diminished proprioceptive feedback enhances the risk of injury it is always a good idea to seek professional help and guidance with any of these large movement/strong input activities, and to ensure that there is always an appropriate level of adult monitoring and supervision.

As with any sensory deficit, poor proprioceptive functioning can be difficult to identify and assess, particularly when it is only a part of a wider pattern of sensory and other impairments. However, like the other 'forgotten sense', the vestibular, it is crucially important to all areas of functioning, so proprioceptive abilities and challenges need to be assessed carefully for any child with deaf-blindness. The pressure that they feel needs to be primarily through their proprioceptors, rather than from people in their lives who look at them and can only jump to quick conclusions and think in terms like 'clumsy', 'aggressive', 'mean', and 'lazy'.

This article has been developed from "Feeling the Pressure" published in CDBS newsletter reSources.

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# Working in Clay!

A Deafblind Sculpture Week held in Lake Balaton, Hungary brings new challenges and success for all. Mary Guest joined the group

In the last few years deafblind people in Hungary have come together to work in clay and develop their skills in modeling and throwing pots under the guidance of a trained potter. This summer I

was invited to join them at a lovely spot at Balatongyörök one of the resorts along this 200-mile long lake, which Hungarians call their 'sea'.

Here are some pictures, which show how adventurous members of the

sculpture group have become in their artwork. I came back even more convinced as to the role which, creative arts can play in adding joy and satisfaction to all our lives and most especially to the lives of deafblind people.





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### Acquired Deafblindness Network

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## Network News

# Tactile Communication Network

## Bernadette van den Tillaart updates us

Members of the Tactile Communication Group have been together in January 2006, at the office of Sense Scotland. The first preparations were made to develop a product on which our current knowledge on tactile interaction can be shared with the field. Sense Scotland has offered technical support, for which we are very grateful.

In return, 3 members of our group have presented a one-day seminar organized by Sense Scotland: 'Partners in Communication - an international perspective'. Professionals of

the deafblind and associated disabilities field were invited. The requests for bookings quickly overtook the limited numbers of seats! The time to share was far too short, and the seminar was a huge success. We would like to thank Gillian Morbey for her significant support, and Paul Hart for organizing and chairing the seminar.

We were planning another meeting and seminar in January 2007, but we have put it on hold for the moment. We will let everyone know when we find a new date - and check the Dbl website for details.

From left: Paul Hart, Bernadette van den Tillaart, Gunnar Vege, Barbara Miles, and host, Gill Morbey





# Congenital Deafblindness in Adults Network

Dominique Spriet tells the story of a new centre for congenital deafblind adults in the North of France ...

Once upon a time... In 1992, a small group of parents and professionals worried about the future of their teenaged deafblind children created an association to reflect and set up a project for their children when they will be adults.

By 1997, the full document presenting the project started a long journey in the different health and social departments of the French government and local authorities offices.

Promoted by a large association (AFTAM) and after many ups and downs this journey entered its last "round":

In April 2006, a new residence for 43 deafblind adults started to be built. And in the last term of 2007, we will open the setting! It is designed for

- 14 quite independent deafblind persons. They will have access to rehabilitation (language and communication, work, daily living skills, locomotion), so aiming to be able to live more community based life style.
- 14 congenitally deafblind adults, mainly from Rubella needing a protected setting where communication, work and community activity are the main objectives.

- 15 multi-disabled C.B.D.A., very dependent, for whom this home will be a comfortable, open, communicating place where they will be able to share within a deafblind community, at their rhythm and pace.

This place is quite large with 43 residents! The reasons for this,

- finances: if we wanted to propose rehabilitation in speech, vision, locomotion, daily living skills, occupational therapy, we have to be able to share competent professionals. To do this effectively we need a sufficient number of persons
- and most important, we want to propose a community where deafblind can communicate easily, can have the possibility to choose friends and relationship among a larger group.

We aim for this place to be very open to the community in both ways: outside people coming in and residents participate in local life.

It is designed to be close to the region where the deafblind people come from so that family and friends links will be able to continue.

We wish to share this few words with you to tell you that it can be a long journey (15 years since our first meeting about this project) but we have a happy end in view! It will be the start of a new journey for 43 people, families and staff, in the small town of CALONNE RICOUART close to Lille, Belgium and UK.

Writing this few words above, leads me into the Congenital Deafblindness in Adults Network. This population is at the cross-road of many of our thoughts about deafblindness: language and communication, relationship and sexual life, autonomy and mobility, staff training, relationship with the family and the community and so on. After a few years, because this field is so wide and making choices difficult, we have decided to concentrate on staff. We will focus on the people who are in contact daily, who are the one directly involved in working with this group of people with congenital deafblindness. In Slovakia we had some very interesting papers presented by different countries and we will try to get the network to continue on this work. You are all welcome to join in this work.

**Dominique Spriet**

**STOP  
PRESS!**

People from the Congenital Deafblind Adult Network and Staff Development network met and created the Congenital Deafblindness Network.

The first meeting of the redefined Congenital Deafblindness Network took place in Scotland on the 20th-23rd November 2006.

Dominique Spriet remains the co-ordinator and the contact. More next time!

# The Siblings Network

Sabine Kersten reports

*"People must know we exist."*

*"It is important to exchange and share experiences"*

*"Sometimes I felt forgotten by my parents and professionals"*

*"It is good to have a voice to let service providers know that we exist and that we need services and support as well"*

*"We have an important role in the development of the deafblind child"*

*"We feel the pain they are feeling and are hurt just as much as our parents"*

These are just some of the answers to the question: Why is it important to offer support to siblings of children with special needs?

I asked this question to a group of siblings participating in the family event "Listen to me" in Salou, Spain. During this week the Siblings Network organised four workshops for the brothers and sisters who came along with their

families.

It was the first time we organised workshops like these, so it was still very new to everyone.

The age group we worked with was between 15 – 19 years old, which meant we could talk about serious issues. The emphasis was on how it is to grow up having a sibling with special needs.

We discussed questions like:

- How would you describe your relationship with your sib?
- Is your outlook on life different from your friends' outlook on life? How?
- Do you think being a sib has affected your personality? How?
- What are some good parts of having a sibling with a disability?
- What are some not so good parts of having a sibling with a disability?

We managed to talk about these personal questions, even though we had some language problems to deal with.

This time we did not organise any "fun" activities for the group, but based on the feedback we received I am sure we will do so during the next event. This way



there will be more group bonding, which makes it easier to talk about these personal issues.

The answers show that there is a need for support for siblings. Organisations offering services to families have a responsibility towards the whole family, and it is time that they recognise this responsibility.

The Siblings Network is independent from any organisation, which means we have no funding. Having no money at all means it is very difficult to get together. Several people suggested we could use email, or an internet group to stay in touch and share experiences. But how many people feel comfortable discussing very personal issues over the internet?

Another big issue for us is language, of the younger siblings the majority do not speak English.

We will stay optimistic, we came home with new inspiration and ideas. We are already thinking about our next meeting! The next family event "Listen to me" will be in Scotland (probably in 2008) and we will definitely be there. It would be great to have a meeting next year, but as I have said before: it all depends on money...

If you would like more information or if you would like to help us to meet again you can contact me at: [siblingsnetwork@gmx.net](mailto:siblingsnetwork@gmx.net)

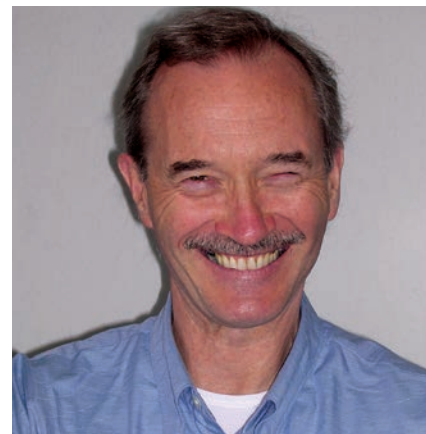


## CHARGE Syndrome Network

**T**he network continues to be a small, but international, group of individuals connected by a listserv, who also organize CHARGE events at various larger meetings and conferences around the world. This year has seen a plenty of events! We have had a three-day meeting about CHARGE, held in St Louis Missouri, that also attracted delegates from Kansas and Illinois. There has also been a first ever Nordic CHARGE Conference in Finland, the 7th Australasian CHARGE Conference, a CHARGE Focus Day included in the 7th Canadian Deafblind Conference in Winnipeg, and a CHARGE Canada conference held in Toronto. As the

population of people identified with CHARGE Syndrome continues to age we see a new emphasis at these meetings, with more of a focus on educational issues, behaviour, and possible late-onset complications. The website of the CHARGE Syndrome Foundation ([www.chargesyndrome.org](http://www.chargesyndrome.org)) has useful links to other CHARGE organizations around the world. There you will also find information about the next International CHARGE Syndrome Conference which will be held in Costa Mesa, California, in July 2007.

At next year's Dbl World Conference in Perth the CHARGE Network meeting will be organized by Tim Hartshorne and Jude



Nicholas. Anyone wishing to attend and present at that meeting should contact Tim by email at [harts1ts@cmich.edu](mailto:harts1ts@cmich.edu)

**David Brown**

## Communication Network

**Jacques Souriau**

**H**ere we are! The first European Masters degree entitled "Communication and Congenital Deafblindness" is on its way. Thanks to the University of Groningen (and with the help of the European program EQUAL),

6 students are enrolled in this programme which started at the beginning of October. They already have implemented the first part of the course and in a few days, they will have to work on their research and thesis. They all come from

the Netherlands except one from Germany. This is a first try and we do hope that in the next year they will be people from a variety of countries.

Marleen Janssen, Professor at the University of Groningen

and a collaborator of VIATAAL is the key person in this project. The communication network members organised the content and give the lectures, but without Marleen, nothing would have been possible. The students are very motivated. Some have already a good experience of deafblindness, others worked with other disabilities and one never had any practical experience. But they all are equally engaged and interested.

We are all looking forward for the new developments that will emerge from this first project.

**Jacques Souriau**

Contact Marleen Janssen on [marleen.janssen@wx.nl](mailto:marleen.janssen@wx.nl) (See page 63)







## Usher Study Group

### Mary Guest reports

One of the outcomes from the last meeting of the Usher Study Group in Presov in Slovakia in 2005 was to hold a workshop on Usher for countries in Eastern Europe but through the medium of a Slavic language rather than English. This could involve Ukraine, Poland, Slovakia and others such as Lithuania who shares a similar language base. Since then I have been in discussion with Dr. Hanna Siedlecka an audiologist from Poland about holding an Usher Workshop in Warsaw in 2007.

To get this to happen we need countries who want to develop their work to both provide funds for 'students' to attend and help implement new practice in their respective countries. Hanna has had some early discussions with the Polish Deafblind Association who have said that they would like to give some support, which

is encouraging.

A major cost to cover is translation from English and for interpretation between English and the Slavic languages used which must be done to a high standard if we are to achieve quality learning and exchange.

If anyone with connections in Eastern Europe can advise on obtaining funds for translation and interpretation please contact [mary.guest@sense.org.uk](mailto:mary.guest@sense.org.uk) and/or Hanna Siedlecka

For an update on Usher Workshop-Eastern Europe, please contact me.

### World Conference, Perth, Sept 2007

The group working with people who have Usher in Western Australia have contacted us about holding an Usher Study Group event just prior to the World DBI Conference. If it is agreed we plan to hold the USG for a day and a half from Monday 24-Tuesday 25th September in Perth.

We want to take the theme 'out of isolation' and weave that into

looking at the lives of people with Usher. People with Usher syndrome are found in most countries, Usher is a global condition. Wherever you travel people with Usher have similar stories to tell, this common experience can be used to help reduce the isolation and feelings of helplessness among people with Usher wherever they happen to be living.

During the USG we plan to look at, setting up and working with groups, maintaining e-groups, what is happening in medical and genetic research, working with parents and working in the classroom.

The Usher Study Group usually attracts a cross section of professionals and people with Usher from around the world. We try to keep the numbers attending to around 35 as we find that this encourages robust exchange and stimulates learning.

**For further information about the proposed Usher Study Group contact:** [mary.guest@sense.org.uk](mailto:mary.guest@sense.org.uk)  
Tel: +44 (0)208 272 7774.

## Rubella Network

### Join us!

In March, 2005, the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) hosted an International Symposium on Rubella at its headquarters in New York. Representatives from twelve countries participated in 2 days of presentations and discussions regarding the history of rubella, worldwide immunization

efforts, issues in education, late onset medical manifestations, areas of current research and the need for collaboration and further research. At the end of the symposium, the group developed an action plan which included an application for create a Rubella Network in DBI. This network was approved in July 2006 and the

group has established its goals, which can be viewed on the website.

**For more information about this exciting new network, please contact Nancy O'Donnell at the Helen Keller National Center, 141 Middle Neck Road, Sands Point, NY 11010 US [hkncnod@aol.com](mailto:hkncnod@aol.com)**

## EDbN

Lucy Drescher and Ursula Heinneman report

**T**he EDbN steering group took the opportunity to meet recently at the European Family Conference 2006 "Listen to me 3" in Salou / Catalonia -Spain. The conference also gave the group the opportunity to talk to deafblind people and their families about what EDbN is and what it does.

As part of the conference Lucy Drescher did a presentation about lobbying in the European Union and encouraged the families and deafblind people attending to get involved in the EDbN and the campaigning work we are doing.

EDbN is now a network of deafblind people, family members and professionals that concentrates a large amount of its effort on campaigning in addition to the sharing of information and support that has always been its role.

At the meeting of the steering

group we discussed the constitution and membership arrangements for EDbN, to make sure that they reflect the needs of the group as it is now. As a result a new constitution has been drafted and the membership arrangements have been amended. All deafblind people, family members and professionals who are interested in campaigning to bring about recognition of deafblindness in Europe are welcome to join EDbN. There is no restriction on the number of people who can join from each other country, which is a change from the previous arrangement. Members are not required to pay a membership fee but the work done by EDbN does rely on people and organisations making time and funding available.

The new constitution will be sent out to people soon with the new EDbN membership application. The

constitution and the membership application form will be also available on the EDbN website and on the Dbl website.

Another EDbN development is that Sense and Lega del Filo D'oro are planning to jointly fund a person to work for Sense, Lega del Filo D'oro and EDbN in Brussels. This person will work a few hours a week and will be helping us to monitor policy developments and possible funding opportunities. They will also be helping to raise the profile of deafblindness in the European Union, to make sure the needs of deafblind people are included in all relevant policy making.

Please do join us and get involved in making sure that deafblindness is recognised in Europe.

Steering group members Lucy Drescher, Ricard Lopez and Ursula Heinneman at the conference in Salou



## Network Seminar – Acquired Deafblindness



Participation

**A** DBN held its 5th international seminar in Groningen, Netherlands from 1ST - 5th November 2006. A total of 168 delegates from 13 countries attended all or part of the event, making it the biggest of all the seminars. This marks a growth in attendance at each successive event, something which the

organisers believe reflects the growth and understanding of Acquired Deafblindness among professionals and an acceptance of the need for greater sharing of experiences and best practice in this field.

The theme of the seminar was "The Art of Communication – Creating Solutions on the Individual, Societal and Professional Level – the World of Acquired Deafblindness". Delegates heard a range of plenary talks delivered by deafblind professionals about their personal experiences of living with deafblindness and also had advice and guidance for sighted-hearing colleagues on how best to communicate with people who are

deafblind.

Dr Claes Moller, an expert in Usher Syndrome, gave a powerful lecture on this subject, followed by 4 people with Usher who described their experiences of living with and overcoming the barriers imposed by the Syndrome in order to live active and fulfilled lives.

Other plenaries covered the emerging mobility benefits of GPS technology for people who are deafblind and a report on the 5 year Nordic Project, which tracked the experiences of people with deafblindness in Denmark, Norway, Sweden and Iceland.

The conference finished with advice on how to work with legislators and municipalities to achieve the

Lex Grandía







Interpretation...



Discussion...



Concentration...



Sensation...

services that people with deafblindness are entitled to or deserve.

In addition to the 6 plenary sessions, delegates chose from 16 workshop topics and were entertained at the start and finish of the Seminar by the Feelgood Theatre Company. They performed pieces written by a deafblind playwright that were designed to prompt debate

on the subject of the Seminar.

The Dutch organisation, Visio, kindly hosted the event. Preparation will commence next year for the 7th international seminar of ADBN, which will take place in Bergen, Norway in Autumn 2008.

**Ges Roulstone**  
**Chair, ADbN**  
**9.11.06**



**Ges Roulstone**  
**and Chris**  
**Chapman**



Ricard Lopez reports:

**T**he 6th European Conference of Families with Deafblind Children took place from 1st – 6th October 2006 in Salou, Catalunya, Spain.

Families and numerous professionals came from all over Europe and enjoyed highly quality lectures given by the best speakers in their field.

The conference was very well looked after at the Cala Font Hotel where the staff treated us like friends and the comfort of the hotel and the beauty of the location helped us all to unwind. The City Council in Salou supported the conference planning and we thank them for their practical help and advice.

During the week we discussed many themes that families had chosen: residential and occupational centres, vocational training, sexual education, cochlear implants and hereditary retinal disease, labour opportunities and projects at the European level.





EDbN

Bcn'06  Listen to me 3

Forty volunteers and mediators from APASIDE and APOSCECAT designed a fun programme for the children and young people attending and supported them in lots of activities – including participation at the conference! For the very first time the Siblings Network met together and enjoyed a programme of organised workshops for brother and sisters to take part in.

The conference called for imaginative change in Spain. Angel Sanchez, general Chairman of ONCE proposed the creation of a new “Deafblind Foundation” which would be supported by all the Spanish deafblind groups. Ricard Lopez, Chair of the conference asked for financial support for the creation of two new centres for Deafblindness – in Sevilla and Barcelona. Navidad Enjuto, confirmed that deafblindness would be recognised in the law.

The Conference achieved a perfect blend for both families and professionals. Blessed with wonderful warm weather, Catalan hospitality and an excellent programme this was an event to be remembered!

Thanks to APACIDE, APOSCECAT and EdbN





# Nordisk Kulturforbund for Døvblindfødte

## The Nordic Culture Network

Lone Poggioni



### Congratulation on the first 10 years!

**T**his very successful initiative was taken 11 years ago by a small group of people from Denmark, Sweden and Norway during the World Conference in Cordoba, Argentina.

They had an idea of offering cultural activities to congenitally deafblind adults from all the Nordic countries. The deafblind person should have the opportunity to work with, and develop, creative talents, thus giving him or her opportunity to learn, experience, express himself and to communicate with the outside world in a new and different way.

In 1995 these thoughts were very new, but the group were convinced that it was a good idea, so they decided to develop a pilot project to evaluate whether the

idea was as good as expected!

In fact, back in Denmark, the planning of the first course started at once. There were so many things to do – find the right place to hold the course with good accommodation for the deafblind people - engage good and motivated artists as teachers - find a person to take care of all practical matters! But – first of all – a lot of money should be found!

The group succeeded with all this, so in August 1996 the first 6 deafblind adults – 2 from Denmark, 2 from Sweden and 2 from Norway – went to the Swedish town Visby on the island Gothland for a week long sculpture course.

The idea offering courses to congenitally deafblind adults with a real artist in charge was really a brilliant idea, so two important things were then decided:

- a Nordic Culture Network should

be created and it should be run by a Board consisting of 2 representatives from each of the Nordic Parent Associations.

- to offer more courses to congenitally deafblind adults the following years.

Now 10 years later it gives a great pleasure to look at some statistics.

In 2006 there were three courses – one in August in Sweden, one in Norway in September and one in Denmark in October – with a total of 32 deafblind adults and 52 helpers.

During the 10 years 37 courses have been held with 232 deafblind adults and 430 helpers participating from the Nordic Countries. They have attended a sculpture course, in dance and drama, in “Music as communication” or in nature sculpture.

Behind such a success there are

lots of people, who have done a marvellous job, and I would like to take the opportunity to say thank you so very much to each of them and to dedicate this celebration to these wonderful people.



### STOP PRESS!!

The Deadline for the receipt of abstracts for the DbI World Conference has been extended to 31st January 2007! Start writing now and register at [www.dbiconference2007.asn.au](http://www.dbiconference2007.asn.au)



Welcome to

**The 6th EBU Deafblind Conference**

***“ Deafblindness: Equality and Diversity ”***

and

**The 2nd EDBU General Assembly**

5 – 10 October 2007

Four Points Panorama Hotel, Zagreb, Croatia

More information coming up!



Croatian Association of Deafblind Persons “DODIR”  
GSM: +385 91 8981313  
E-mail: edbu2007@dodir.hr

# Those Canadians can really put on a conference, eh!

A report from Stan Munroe and photographs by Amanda Newberry

**W**e did it again! On the heels of hosting the last Dbl World Conference (August 2003 in Mississauga, Ontario), the CDBRA is proud to boast another conference success. We salute the great success of "Celebrating Potential" – The 7th Canadian Conference on Deafblindness which was held in Winnipeg, Manitoba, September 21-24, 2006.

The Conference was attended by 140 people primarily from within Canada, but a few participants represented Australia, Italy, Scotland and the United States. For those

who couldn't attend...it's a pity! But watch for the conference website to obtain the Proceedings.

His eminence grise William Green was our Keynote speaker for the Opening and Closing Sessions. He performed as an Entertainer, Artist and Professional Motivational Speaker during these key times. He learned to paddle a canoe without a canoe and became an expert at beer-can chicken. In all seriousness, William made a huge contribution to the success of our conference and was very popular among the participants. No surprise, eh!

The Plenary Speakers made their marks as well. They included Paul Hart from Sense Scotland, David Brown from California, Dr. Ed Hammer from Texas and the teamwork of Tina Prochaska and Carol Robbins from Tennessee. During Focus Day, Dr. Sandra Davenport lectured on issues related to Acquired Deafblindness and Meg Hefner led discussions on CHARGE Syndrome.

The Opening Day Panel Discussion by individuals with deafblindness from across Canada was particularly enlightening. Hats off to Wayne Turnbull from Calgary,







## Winnipeg conference



Jane Sayer from Winnipeg, Karen Esmail from Toronto and Chantelle McLaren from Hamilton for their deeply personal discussions.

These persons mentioned above were not meant to overlook the additional presenters who led 28 other workshops presented over two-days. The topics included such titles as Transition, Siblings-Their Perspective, Intervenor Competencies, Stepping Out of the Shadows

and Into the Spotlight, CRS – What's going on?

The food was excellent, the presentations top rate, the entertainment superb and the organization by the Manitoba Chapter of CDBRA was second to none.

Nobody left the conference unhealthy, unwealthy or unwise. Watch for CDBRA again as we plan for the 8th Canadian Conference on Deafblindness. Don't miss it!



# Romania Education Programme



In 1999, when Sense International started working in Romania, there were no services for deafblind children whatsoever. There was very little knowledge or understanding of deafblindness in the country, not least amongst the authorities, who claimed there were no more than three deafblind people living in the country. Seven busy years later, we are delighted to be sharing our experiences of building up an innovative education programme for deafblind children, and in particular in developing an in-service teacher training programme in partnership with the Romanian Ministry of Education and Research (RMER).

From the start, we did not want to simply set up, fund, and run education services indefinitely, as we felt that this was not a sustainable way of ensuring that deafblind children received the education and support to which they had a right. Such

is the demand for support that Sense International (Romania) saw its role as a facilitator of change rather than a long-term service provider. So it was decided from the outset that we would work closely with the RMER to ensure that together we developed the necessary in-country expertise. This would mean that the Romanian authorities had a real sense of ownership of these new education initiatives for deafblind children and would take on responsibility for further developments in the future.

We began by entering into a formal partnership with the Ministry of Education, and ran a number of workshops for School Inspectors, Head teachers and civil servants in the RMER. This meant that senior decision-makers became fully aware of deafblindness and ways in which education can be made accessible for deafblind children. It also meant that they were fully supportive

of the teachers who went on to specialise in teaching deafblind children.

With enormous support from a number of individuals based at Sense UK and other British agencies, we developed an in-service teacher training programme made up of two week-long training sessions, incorporating practical experience and mentoring support from specialists in deafblindness between the two sessions. This programme has now run twice, training a total of 60 in-service special needs teachers in skills for teaching deafblind children. During the second round of training, two teachers who were trained in the first round were supported to deliver sessions alongside specialists from the UK, the RMER and the University of Cluj. This gradual transfer of expertise to Romanian education professionals culminated in a Training of Trainers session in March 2006, in which eleven







teachers were awarded 'National Trainer' status by the Ministry of Education and were accredited by the University of Cluj. This means that in future years, new national specialists will be in a position to deliver training to younger generations of teachers. Whilst this approach was not without its challenges, by investing in local expertise and working alongside the RMER, we are confident that education for deafblind children is now firmly embedded in the national education system.

Alongside this teacher training programme, the RMER has established fourteen deafblind education units across Romania since 1999, of which the first two units have become 'centres of excellence'. In partnership with Sense International (Romania), these first two units have also developed

a range of additional services including a Resource Centre in Cluj and an Early Intervention Support Service in Bucharest. Twelve of the fourteen units are fully funded by the government.

The teacher training programme was made possible by CfBT, who funded this unique initiative from 2002-2006. At the end of the project period, an external evaluation was commissioned. To read the full report, please do visit the Dbl website at [www.deafblindinternational.org](http://www.deafblindinternational.org). Whilst the evaluation report notes our success in working with the RMER to develop the first ever training course of its kind in Romania, developing local expertise, and embedding deafblindness within the education system, it also highlights areas for follow-up. Many new teachers work in isolated

areas of the country, and so alongside our support to a Teachers' Network, we have secured funding to develop a peer mentoring programme, whereby more experienced teachers will undertake learning exchange visits to offer practical classroom support and advice on good practice to newly-trained teachers. We will also continue to develop our training materials, and ultimately hope to adapt the programme for replication in other areas of the world.

For more information, contact Cristiana Salomie (Director, Sense International (Romania)) at [csalomie@senseint.org.ro](mailto:csalomie@senseint.org.ro) or Julia Peckett (Programme Officer, Sense International) at [julia.peckett@senseinternational.org.uk](mailto:julia.peckett@senseinternational.org.uk)

**Cristiana Salomie**



## Conditions Associated with Deafblindness

# Stickler Syndrome

### What is Stickler Syndrome?

It is a genetic progressive condition, which can affect both sexes and is normally passed on from parent to child. It affects the body's collagen (connective tissue) which is the most plentiful protein in the body - about one third of all our protein is made up of collagen. Collagen forms a major part of connective tissue, which can be described as the supportive tissue of the organs of the body. Some connective tissue acts like a glue or binding, in other areas it acts like scaffolding, and can also allow for the elastic stretching and tightening, especially in the muscles. Collagen is also an important part of the cartilage which covers the bone ends of the joints. In the eye it is found in the sclera, cornea and vitreous humour.

Several genes which control and direct collagen synthesis (the building up of complex substances by the joining and interaction of simpler materials) may cause Stickler syndrome.

- **COL2A1.** This gene is responsible for Stickler syndrome in the majority (about 75%) of people diagnosed with the condition. It causes 'full' Stickler syndrome (including joint, hearing, eye and cleft abnormalities) and has been classified as type 1 Stickler syndrome. Not all symptoms need be present from birth, some may manifest later.

Two other genes are now also known to cause some of the features of Stickler syndrome.

- **COL11A1** again causes 'full' Stickler syndrome including joint, hearing, eye and cleft abnormalities, and has been classified as type 2 Stickler syndrome.

- **COL11A2** causes a 'Stickler-like' syndrome, which affects only the joints and hearing with no eye problems. This condition has now been given the name Oto-spondylo-megaepiphyseal dysplasia (OSMED).

In a fourth group the genetic cause is yet to be determined.

### Why Stickler Syndrome?

Stickler syndrome is named after Dr Gunnar B Stickler. In 1960 a twelve year-old boy was examined at the Mayo Foundation in Minnesota, USA. The boy had bony enlargements of several joints and was extremely short sighted. His mother was totally blind. Dr Stickler discovered that there were other members of the family with similar symptoms, the first family member having been seen by Dr Charles Mayo in 1887. This prompted Dr Stickler to study the family. With colleagues he worked to define the condition, the results being published in June 1965. Dr Stickler tentatively named the condition hereditary progressive Arthro-Ophthalmopathy known world-wide as Stickler syndrome.

### Who is affected?

One in 10,000 persons may be affected by Stickler syndrome. Some medical professionals believe that as many as 3 in 10,000 persons are affected, but further research is needed to confirm this. As an inherited condition, Stickler syndrome is normally passed from parent to child. There is a 50% chance of children being affected in this way although there are some recorded cases where it has occurred for the first time in a child.

### How does it affect a sufferer?

The symptoms and severity of Stickler syndrome vary from patient to patient, even within a family, and can be difficult to diagnose. There is a range of treatments and support available. With this help it is possible to learn to live within the limitations of the condition.

### What are the symptoms?

#### Eyes

Short-sight (myopia)

High risk of retinal detachments, which may affect both eyes.

Cataracts

Glaucoma

#### Bones and Joints

Stiff joints and over-flexible joints

Early joint disease leading to osteoarthritis in later life

#### Mouth

Cleft palate, submucous or high arched palate and/or bifid uvula

Micrognathia – where the lower jaw is shorter than the other resulting in poor contact between the chewing surfaces of the upper and lower teeth.

#### Ears

Possible hearing loss

Glue ear in childhood caused by cleft palate

#### Other symptoms

These may include curvature of the spine (scoliosis) and mitral valve prolapse

### Management of the condition

Once Stickler syndrome is diagnosed, a co-ordinated multidisciplinary approach is desirable. This should include:

- Ophthalmic assessment. Due to the high risk of retinal detachment, all patients also require long-term follow up and are advised to seek ophthalmic help if they see new floaters or shadows in their vision.
- If there is evidence of midline clefting, a maxillo-facial assessment.
- Hearing tests and management of combined conductive and sensorineural deafness.
- Joint hypermobility should be assessed
- Rheumatological assessment and follow up is advised in older patients who may benefit from physiotherapy for arthropathy.
- Children should be educationally assessed. Although intelligence is normal, patients of school age may face considerable educational difficulties because of combined visual and auditory impairment and these needs should be met.

**With thanks to the Stickler Syndrome Support Group – based in the UK. The website provides links to lots of groups across the world [www.sticklersyndrome.org.uk](http://www.sticklersyndrome.org.uk)**

# International Program Models for siblings of children with disabilities

**Sheri B. Moore, Associate Professor at University of Louisville, Kentucky, USA discusses the challenges facing siblings with disabled brothers and sisters and provides an excellent section with useful material and references.**

**T**here are many challenges for parents as well as siblings of children/youth/adults with dual sensory impairments or deaf blindness. Often the needs of our children who have dual sensory impairments take much family time and energy. This frequently means that less time, attention and effort can realistically be devoted to the siblings of the disabled person. These siblings are often expected to be more independent earlier in life than their peer group. Additionally, siblings often have more autonomy and more responsibility because of the care needed for a sibling with disabilities. The siblings may have difficulty understanding the parental demands that children and youth with dual sensory impairments necessitate. Often, the needs of the siblings are downplayed because of the time, stress and physical demands of caretaking.

In my own work with sibling groups of children with dual sensory impairments, often siblings will stress that they need more one on one time or individual time with their



**Sheri B. Moore**

parent/s. They often also need additional information to better understand the disability of their sibling along with the implications for care and education. Siblings sometimes have the additional challenge of spending a great deal of time assisting in the care taking of the sibling. This may cause resentment towards the sibling as well as the parent/s. Siblings need to also understand the long term implications of the disability; this too can create stress and or resentment if a care taking role is to be assumed by the sibling. However, there is great variation, in my experience,

in how siblings deal with the above mentioned challenges. Some siblings take the situation in stride and manage to maintain a lifestyle similar to that of their peer group. Other siblings have told me that they have missed part of their youth and numerous social and related opportunities with their peer group because of the direct or indirect needs of their disabled sibling who has dual sensory impairments.

The professional literature on siblings of children/youth/adults with disabilities echoes many of these themes and challenges. For example, a journal article by Heller, Gallagher and Frederick (1999) specific to siblings of deaf blind individuals, reported on a survey of parent of some 35 children with deaf blindness. This survey reported that often the relationships of siblings consisted of unequal roles, with siblings taking too much care taking responsibility. Another article by Banta (1979) discusses the effects of a deaf blind child on the family and siblings, and identifies questions and concerns for additional research. Further, a recent





article by Australians Ross and Cuskelly (2006) specific to families of children with autism spectrum disorder (ASD), notes that siblings of children with ASD exhibit/express more problem behaviors and experiences than do children in families where all children develop typically. So, this study specific to ASD is of concern because of the increased potential of risk for siblings developing and internalizing their own adjustment problems. The article also comments on the need for further research and investigation. An interesting article in the New York Times on April 4, 2006 was entitled, *Siblings of Disabled have Their Own Troubles*, authored by Gretchen Cook. The article notes that an estimated seven million typically developing American children have siblings with disabilities and that these siblings often face similar positives and challenges as their parents. Specifically, some of the siblings felt neglected by their parents who had demanding caretaking responsibilities and also resented extra demands placed on them by the needs of their sibling. Importantly, the article quotes Donald Meyer, developer of Sibshop materials, that many of the siblings will have the longest lasting relationships of anyone – some in excess of 65 years. Concludes Mr. Meyer, the siblings should be remembered in all contexts relevant to their sibling with a disability. The New York Times article makes the interesting point that with the advent of increased

inclusion of students with disabilities in schools and society, there should be a corresponding lessening of uncomfortable issues related to disabilities. On the humorous side, the New York Times article had a response from a disabled young person with autism. Her comments were in the vein that she had typically developing siblings that weren't so easy to live with either (Kassiane Sibley, Missoula, Montana). Kassiane concludes, that disabled should have equal time in griping about their siblings – so much for sibling rivalry!

**“An estimated seven million typically developing American children have siblings with disabilities and that these siblings often face similar positives and challenges as their parents”**

There are however, familial and cultural variations to the articles presented. Generalization cannot be made relevant to individual families and their specific familial and sibling related needs. For practitioners, each family should be approached with their individual needs and situation in mind. Families and siblings should be asked how their needs can best be addressed. Although

not specifically designed for the siblings of children and youth and adults with dual sensory impairments, there is value in studying the Sibshops materials by Donald J. Meyer of the University of Washington in Seattle, Washington, USA. *Sibshops: A Handbook for Implementing Workshops for Siblings of Children with Special Needs* is a product of a project involving 8-13 year old siblings of children with disabilities. Many suggestions are given regarding programs for the siblings. Some of the challenges that siblings face are reviewed, including resentment, over identification, and embarrassment. Guidelines for implementation of activities for both siblings and interaction with their parents are included.

These Sibshop materials were used recently as a model for an inaugural program for siblings of individuals with deafblindness by Sabine Kersten in Spain in Fall 2006. Sabine reports that the Sibshop materials were used and were helpful in working with the siblings of deafblind individuals at the Spain meeting. Clearly, there is a need for the development of more programs and offerings for siblings. Much remains to be accomplished to better meet the needs of siblings and families who have a deafblind individual within their family unit. Sabine Kersten from Belgium has developed a site, Siblings Network, on the Deafblind International website. Go to: [www.deafblindinternational.org](http://www.deafblindinternational.org) and the sibling network

## Siblings

page for further information. Email: [siblingsnetwork@gmx.net](mailto:siblingsnetwork@gmx.net), as listed on the site, to register your interest in the development of more programs and opportunities for siblings. Along with an email to Sabine, please also copy [sheri.moore@gmail.com](mailto:sheri.moore@gmail.com) with your email to Sabine; I am interested in obtaining more information on groups for siblings related

to deafblindness. There has also been frequent mention of the needs of siblings at Deaf blind International conference/ events. Additionally, looking at international models, a bibliography is posted on the website of the Italian Downs Syndrome Association (AIPD) with books and references in Italian journals/books and also offerings in English. The

website is: [www.siblings.it/english/bibliografia/index.htm](http://www.siblings.it/english/bibliografia/index.htm) and contains some additional material of interest. Information on a Sibling Support Group meeting in Tokyo in 2001 ( not specific to deaf blindness) is given, along with pictures, at the website: <http://homepage2.nifty.com/togaras/sibshopintokyo/sibshopintokyo.html>.

### References:

- Banta, E., **Siblings of deaf-blind children**. Volta Review v81 n5 p363-69, September 1979.
- Cook, G., **Siblings of disabled have their own troubles** New York Times, April 4, 2006.
- Heller, K and Gallagher, P. and Fredrick, **Journal of Association for Persons with Severe Handicaps**, L v24, n1 p33-43 Spring 1999.
- Meyer, D. J., **Sibshops: a handbook for implementing workshops for siblings of children with special needs**. University of Washington, Seattle, WA.

### List of other useful materials

The author and the Perkins School for the Blind Research Library are hopeful that you will find this material helpful in learning more about siblings of deaf blind individuals. There is a very full and detailed list on the Dbl website in the Siblings section. Do look!

**The brothers Prouty/Prouty**, Bill **News from Advocates for Deaf-Blind**, v.7, n.3; pp.6-8. Winter 2003. (Journal article)

**California Deaf-Blind Services fact sheets/** California Deaf-Blind Services California Deaf-Blind Services, 2004. 50+ pp., unnumbered ([www.sfsu.edu/~cadbs](http://www.sfsu.edu/~cadbs))

**The strength of siblings**, p.9. Special Education Service Agency (SESA), Spring 2003.) Downloadable from <http://www.sesa.org/newsltr/ref/siblings/sibtoc.html> Reprinted from Disability Solutions: [www.disabilitysolutions.org](http://www.disabilitysolutions.org)

**Brothers and sisters: Strategies for supporting siblings of children who are deaf-blind/Kenley**, Jackie; Medina, Myrna. **reSources**, v.10, n.14; pp.5-6. Fall 2002 (also in Spanish)

**Meeting the unique concerns of brothers and sisters of children with special needs/Meyer**, Donald <http://www.sesa.org/newsltr/ref/siblings/sibtoc.html> Reprinted from The Sibling Support Project website: [www.thearc.org/siblingsupport](http://www.thearc.org/siblingsupport)

**Perceptions of parent-child relations by parents and siblings of deaf-blind children/** Banta, Elizabeth. Doctoral dissertation.

**The brothers Prouty/Prouty**, Bill **CHARGE Accounts**, v. 12, n.4; pp.2-4. Winter 2002.

**Planning for the future: An adult siblings' suggestions**, p.8. Special Education Service Agency (SESA), Spring 2003 from <http://www.sesa.org/newsltr/ref/siblings/sibtoc.html>

**School-based strategies/Powell**, Thomas H <http://www.sesa.org/newsltr/ref/siblings/sibtoc.html>

**The strength of siblings/Smith**, Julie. From <http://www.sesa.org/newsltr/ref/siblings/sibtoc.html>

**Tall tales – short stories** Sense Scotland, 1995. ISBN: 0 9526697 0 6. 218 (Book)

**Under the magnifying glass: Sibling support in Deafblind Focus**, v.13, n.3; pp.1-2. Winter 2003. Website: <http://olrs.ohio.gov/ASP/olrs/Siblings.asp>

**The UPLIFT Educational Series: Siblings/UPLIFT** from <http://www.sesa.org/newsltr/ref/siblings/sibtoc.html> Reprinted from UPLIFT Educational Series: [www.upliftwy.org](http://www.upliftwy.org)

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Email: [moore.sheri@gmail.com](mailto:moore.sheri@gmail.com)

# "Communication and congenital deafblindness"

## The first booklet is ready

"Congenital deafblindness and the core principles of intervention", the first booklet and DVD out of a series of four titled "Communication and congenital deafblindness" is ready. The booklet is written by Inger Rodbroe and Marleen Janssen.

The first part of the booklet contains detailed information about the disability, the recent population, and an introduction to the core principles of intervention, which will be elaborated in the following 3 booklets. In the second part of the booklet you find the DVD and a guide to the video illustrations.

The target group of these booklets is the network around each congenital deafblind child and adult. For parents a special edition of each booklet will be written. When these are due is not decided yet. The booklet is written in English.

At the moment a cd-rom is in production with all information and instruction needed to translate

the English version of the booklet and subtitles on the DVD into another language.

The titles of the following booklets and their date of availability is as follows:

### **2 Social interaction and contact**

Ready in January 2007

### **3 Communication based on non-conventional "signs"**

Ready in October 2007

### **4 Communication based on conventional "signs"**

Ready in June 2008

### **Where to order**

The booklet "Congenital deafblindness and the core principles of intervention" can be ordered at Viataal, the Netherlands. The negotiation with the organisation that is going to take the orders and send the booklets is not completely finalised



yet. Please send an email to [centrumvoorexpertise@viataal.nl](mailto:centrumvoorexpertise@viataal.nl) to show your interest and you will receive an email with the exact address where to order as soon as this is known.

The price of the booklet will be about 15 euro plus costs for administration and sending.

Do also send an email message when you are interested in the translation cd-rom.

**More information about this project can be found in the Dbl Review no 37 (January – June 2006), page 43.**

## Tactile signals for working with computers

The signals are intended to give deafblind people, guides and interpreters a tool to use when communicating via tactile signing. Using these signals, tactile communication can become more flexible and working postures can be optimised.

This CD ROM was produced by Devofilm for:

**Danish Association of the Blind.**  
Kloverprisvej 10B  
2650 Hvidovre, Denmark  
Tel: (+45) 3675 2096  
Text Tel: (+45) 3648 5096  
Web: [www.fddb.dk](http://www.fddb.dk)





# Khyran treads the Boards!

Keith Park writes original material and adapts literary classics to enable children to work together in the creative cauldron of the theatre! He is completely committed to making theatre accessible and bringing all children together with professional actors to have fun!

## The Actor

Khyran is 11 years old and moved from his primary school to a secondary school in Lewisham – a district in inner London, in September 2006. He has a significant dual sensory impairment. Over the last year Khyran has been participating in an inclusive drama project with a local mainstream school. The staff and pupils of both schools hope to show by this account that enjoyment of the creative arts is irrespective of disability and sensory impairments.

## The Theatre

Shakespeare's Globe Theatre, London – on the banks of the River Thames

A group of pupils from two schools, special and mainstream participated in a series of workshops on 'Twelfth Night' using the Globe Theatre. They were on stage for an hour a week for four weeks and performed an interactive version based on one of the characters in the play and called Malvolio's story. For those readers who don't know the play, Malvolio is an unpopular steward in the house of the Lady Olivia, who gets a cruel trick played upon him that makes him wrongly believe that Olivia is in love with him. Malvolio is publicly humiliated and vows revenge but the others finally 'entreat him to a peace.' The following extracts of original text are all performed in "call-and-response". (This means that one person calls out the line that is then repeated by everyone else.) This method quickly establishes a communicative atmosphere in which pupils (and staff) are encouraged to participate in any way they can: speaking, signing, clapping, stamping, rocking, and so on.

## The Play

**Episode 1:** Maria, the maid, explains that Malvolio thinks everyone likes him, when in fact it is quite the opposite:

Oh Malvolio!  
He is a kind of puritan  
It is his grounds of faith

That all that look on him  
Love him  
Oh yeah right!

**Episode 2:** Maria and others follow Malvolio around the garden calling him names. After the word 'sheep-biter' everyone bleats like a sheep!

Here's an overweening  
rogue  
Fie upon him, Jezebel!  
Turkey-cock!  
Fire and brimstone!  
Bolts and shackles!  
Out, scab!  
Sheep-biter!  
*Baaaaa!!!*

**Episode 3:** Malvolio finds a letter. It was written by Maria, but made as if to look as though it is from Olivia, telling Malvolio of her love for him, especially when he dressed up in yellow:

My lady loves me  
Yellow stockings!  
Cross-garter'd!  
I thank my stars  
I am happy  
I will smile  
*What a dish of poison!*





## Khyran treads the Boards!

**Episode 4:** Malvolio dresses up and goes to Olivia. He starts to flirt with her, and she – not having any idea of what is going on – screams the place down.

Be not afraid of greatness  
Some are born great  
Some achieve greatness  
Some have greatness  
Thrust upon them  
Yellow stockings!?  
Cross-garter'd!?  
*Aarrgghh!!*

**Episode 5:** finally, Feste the clown explains that it was all a cruel joke. Malvolio swears revenge but the others try to persuade him to make peace.

And thus the whirligig of  
time  
Brings in his revenges  
I'll be revenged  
On the whole pack of you  
Entreat him to a peace  
*Peace*



The episodic sequence of verse makes the script easy to learn and many of the children learned all the text, and the key signs from British Sign Language that were used with the script, very quickly. As they did so, they took over the workshop and ran it themselves, and the staff became observer-participants.

### The Theatre The Churchill Theatre

The Churchill Theatre in Bromley, Kent kindly invited groups of pupils from various local schools to take part in a pantomime project. Over the Christmas period, the professional pantomime 'Cinderella' was running at the Churchill, and so in early January 2006, Khyran and his group had 3 one hour workshops on stage doing an interactive version of Cinderella. They were surrounded by all the props and the wonderful backdrop, that showed a glittering magical castle. Like all pantomime scripts, the interactive 'Cinderella' was extremely silly and great fun was had by all. As an example, here is an extract of the text, where the ugly sisters are being horrible to Cinderella. It is performed in call-and-response in the same way as the Twelfth Night workshop, with everyone joining in the final line (in italics). Volunteer Cinderellas are invited to go the middle of the circle and are subjected to the following verbal barrage, which ends with everyone thumbing their noses at the stay-at-home Cinderella:

You can't go 'cos you can't  
dance  
You can't go, you got no  
clothes  
You can't go cos you stay  
here  
You are so not going  
*Nyah nyah!!*

And, perhaps the favourite  
episode, where Cinderella,  
now dressed in her magical  
ball-gown meets Buttons,  
who says:

Cinderella!  
Love the dress!  
Love the shoes!  
Love the hair-do!  
Love the bag!  
I'd look good in that!  
Oi! You! Buttons!  
*Zip it!!*



## Khyran treads the Boards!



### The Holocaust Memorial Event

On a Sunday at the end of January, Lewisham holds its annual Holocaust Memorial Day at the Broadway Theatre, Catford. The theme for the January 2006 event was 'reconciliation' and Malvolio's story from *Twelfth Night* was clearly a story of reconciliation triumphing over revenge, and so the group was invited to perform on stage as part of the memorial event. Khyran and the 'Globe group' went on stage and performed the five episodes of Malvolio's story from *Twelfth Night* in front of audience of about 700 people. One of the things that make this so impressive is that the group performed the story without any members of staff onstage with them. One of Khyran's peer group from school led one of the episodes, and I thought this was fairly impressive until one of the staff told me afterwards that three years ago the pupil had been non-speaking.

### The BBC's 60 Seconds of Shakespeare

Over the last year, the BBC has been running a '60-second Shakespeare' project, in which any school is invited to make a 60-second film of a Shakespeare story and send it to the BBC, who may then post it on their website. So, in February and March 2006, Khyran and the Watergate-Fairlawn schools group returned to Shakespeare's Globe for more performances of *Twelfth Night*, as well as *The Tempest*. A 60-second film was made of an extract of 'Twelfth Night' and sent to the BBC who duly posted it on their website, where it can be seen ([www.bbc.co.uk/drama/shakespeare/60secondshakespeare](http://www.bbc.co.uk/drama/shakespeare/60secondshakespeare))

It remains the only entry by an inclusive groups of pupils (from a special school and a mainstream school). The photograph 'Act IV' shows a *Twelfth Night* workshop being filmed for the BBC website, and also recorded for American radio. The workshop was subsequently broadcast in the USA on coast-to-coast radio.

### The Old Vic

On a very hot day in July this year, Khyran and his group visited the Old Vic Theatre at Waterloo and were lucky enough to have a two hour workshop on the stage, led by an Old Vic practitioner. This workshop included working with masks, and various role play activities. Khyran discovered that the auditorium sloped gently downwards from the back stalls to the stage, and found it great fun to run backwards, towards the stage, while looking over his shoulder to keep to the aisle pathway. Some of us tried this and we can all testify that it is extremely difficult!

### Epilogue

The schools hope to return to the Globe Theatre later this year for another series of workshops. This time two plays will be performed in workshop, Shakespeare's *The Taming Of The Shrew* and John Fletcher's *The Tamer Tamed*. We also hope to return to the Churchill Theatre for a series of workshops on *'Mother Goose'*.

Contact me directly at [keithpark1@onetel.com](mailto:keithpark1@onetel.com)



## What's on down under

### Australian Services: A Status Report

While few would argue that Australia is a paradise for its citizens who are deafblind, a Google search provides plenty of evidence that services are gradually improving. For example, a lengthy list of Australian deafblindness agencies is provided for the reader at: <http://www.deafblind.com/australia.html>

Several of our States provide excellent educational and support facilities for children with deafblindness. Of particular note in this regard is Sydney's Royal Institute for Deaf and Blind Children (RIDBC), which has world wide recognition. It was established in 1860 and was responsible for initiating one of the first international conferences on deafblindness in the 1970's. Information about its services can be found at: <http://smiley.ridbc.org.au/>



Adult facilities and programs across Australian states and territories vary quite significantly, with Western Australia (where Senses Foundation will be responsible for the next Dbl International Conference in 2007) and Victoria having a high level of service provision,

to Queensland where services are almost non existent. As another example, Sydney's Forsight Foundation has for many years offered high standard residential and vocational support to adults who are deafblind. Victoria's Deafblind Association, with its head office in Melbourne, was established in 1967. It employs over 100 staff and provides fully staffed accommodation in homes in the community, support for people living in the community, respite care, day services, recreation, support for community clubs, computer training and establishment of related services in people's own homes, music therapy, advice and information. Senses Foundation in Perth has a similar wide range of services for people with deafblindness

The Australian DeafBlind Council (ADBC) was established in 1993 to represent and advocate for people with deafblindness, their parents and support persons, their service providers and related professionals. In 2004 it was funded by the Federal Government to update the 1990 Ward Report on Deafblindness in Australia and review numbers of people in Australia with deafblindness and services available. This report, mentioned in the January-June issue of Dbl Review, known as the Prain Report, is currently being considered by the Federal Government. The ADBC has members from each state and Territory in Australia and

has a committee of three deafblind members, a parent and three organisational representatives, a New Zealand representative and a representative from the organisation acting as its secretariat. Its President is a person with deafblindness. It is the only organisation in Australia advocating for people with deafblindness and is a truly national organisation.

### Reports, Conferences and Special Events

Currently the Prain Report (described in the January-June issue of Dbl Review), is at the time of writing, sitting in Canberra with the Federal Government's Disability and Carers' Branch of the Department of Family and Community Services (FACS). Delay by Government in acting upon its recommendations is highly frustrating for members of the Australian Deaf Blind Council (ADBC). The report, funded by the Minister for FACS, not only covers the numbers of people with deafblindness nationally, but also examines the services available to them. Its author makes a number of recommendations for improvements in these services, plus other proposals relating to people with deafblindness. Report author Meredith Prain, the project's Steering Committee, its Reference Committee and ADBC's Management Committee have worked hard on the project and a great many other people

## Australia



**Mike Steer**  
reports

### Australia (continued)

have put much effort into assisting with it. ADBC now plans to take the issue of the report's lack of progress to a higher level and with other people and bodies that might assist it.

The Perth conference will be, for many people with deafblindness, parents, supporting people, professional staff and for anyone interested, perhaps the only opportunity they will ever have to attend a major international conference on deafblindness. The last, and only other one in Australia, was held in Sydney in the 1970's. The international conference is the Deafblind International 14th World Conference and it is being held from 25th to 30th September 2007. Registration for the International Conference is at [www.dbiconference2007.asn.au](http://www.dbiconference2007.asn.au). The Conference language will be English and Auslan platform interpreters will be provided for all plenary and key note addresses. Anyone needing an interpreter should

contact the Conference organisers, Senses Foundation, before they arrive in Western Australia.

### PPert

Deafblindness Awareness Week was held across Australia from 25th June to 2nd July. Each state was responsible for organising related events. The Victorian Deafblind Association (based in Melbourne) offered a two week program including sensory activities, afternoon drinks for the Deafblind Community, an art exhibition and dinners for the public including a lunch at its head office for people with deafblindness and friends. An education pack on Deafblindness was sent to all schools in Victoria.

### Access to Independent Voting

Contrary to the recommendation of a joint parliamentary committee, the Federal Government has decided not to trial electronic

voting for people who are blind or vision impaired at the next Federal Election.

After the Inquiry into the 2004 Federal Election, recommendations were made to the Federal Government that a trial of electronically assisted voting be undertaken at the 2007 Federal Election so people who are blind or vision impaired could cast their vote independently and in secret. Despite this recommendation, the Electoral and Referendum Amendment (Electoral Integrity and Other Measures) Bill 2005, currently before Federal Parliament, contains no provision for a trial of electronic voting at the next Federal Election.

The ACT parliamentary elections (2001 and 2004) demonstrated that electronic voting allowed people who are blind or vision impaired to vote in secret. However, all States and the Northern Territory continue to deny independent voting to people who are blind, vision impaired or Deafblind.

## Cost of Hearing and Vision Loss to Australians

'Listen Hear! Report' from Access Economics has identified that hearing loss is costing Australia \$11.75 billion a year, or 1.4% of GDP. One in six Australians is affected by hearing loss and that figure is projected to rise to one in every four Australians by 2050. Hearing loss is also age-related, affecting three in every four people aged over 70 years. For more information go to [www.vicdeaf.com.au](http://www.vicdeaf.com.au) and follow the Listen Hear! link.

'Clear Insight: The Economic Impact and Cost of Vision Loss in Australia' from Access Economics found that vision impairment is a huge and overlooked problem in Australia. Total real financial costs (direct and indirect) of vision impairment were \$5.0 billion in 2004. Almost half a million people have impaired vision and over 50,000 of these are blind. The prevalence of vision loss trebles with each decade over the age of 40, increasing dramatically

in the last decades of life. By 2024, the number of Australians with vision impairment or blindness is expected to increase to nearly 800,000. Another study by Access Economics, 'Centrally Focussed: The Impact of Age-Related Macular Degeneration', reported that AMD is the leading cause of blindness in Australia, responsible for 48% of severe vision loss. More information: [cera.unimelb.edu.au/publications/reports/access/access\\_amd.pdf](http://cera.unimelb.edu.au/publications/reports/access/access_amd.pdf).



**A**fter 20 years as Norway's first residential services for adults with congenital deafblindness we found it was time for celebrations. We divided the anniversary into three parts, allowing each group to benefit the most from the program.

People with congenital deafblindness were invited to a music workshop and various other activities and good food, while their families and staff were invited to lectures about musical aspects in

communication.

People with acquired deafblindness and their families were invited to a guided tour on our premises, various activities, good food and lectures about haptic signals and the use of guide dog.

Finally our own staff members, previous and present board members, colleagues and friends from around the Nordic countries were invited to a historic journey concerning how communication has been considered throughout the

years and the world : Where have we been and where are we heading? It all culminated with a gala dinner with lots of speeches covering memories from more than the past 20 years.

I think it was important to stop for a while and reflect upon the development we have been through during these years, with a tremendous effort put down from all involved.

I am happy to say that it turned out to be 3 successful days, and I want to express a hearty thank you to everyone who remembered us through their congratulations, e-mails, letters, presents and otherwise, including a congratulating letter from the Dbl.

**Norway**  
**Knut**  
**Johansen**  
**records**  
**very special**  
**anniversary!**

**Z**amir Dhale has been appointed to the new post of Advocacy Officer with Sense International, India. He is their first deafblind member of staff.

The key area of work for Zamir is to develop greater awareness and recognition of rights of deafblind people and their family members throughout India. He will be responsible for developing, implementing and monitoring the lobbying and advocacy plans of S I India and he will be managing this process. with the support of the SI (I) Programmes

team. Zamir's work will include interacting with a host of stakeholders, namely deafblind people, their family members, government officials, representatives of other development organisations, practitioners and general public. Zamir will have a full time interpreter/guide.

Zamir was educated at the Helen Keller Institute for Deaf and Deafblind Children. Ms Beroz Vacha was Headteacher when he joined the school and has been the one who gave the "education for life". She made sure that, in spite of all the odds,

Zamir has been given the chance to develop his skills as a 'leader' in the deafblind sector. Zamir has been the "Braille Press Assistant" in the M.A.Rangoonwala Mini Braille Press at the Helen Keller Institute for the Deaf & Deafblind, Mumbai. One of Zamir's more glamorous assignments was as sign language and mobility trainer to both Rani Mukherji and Amitabh Bachchan for their successful roles in the movie "Black".

**Akhil S. Paul**  
**Director**  
**Sense International (India)**  
**[www.senseintindia.or](http://www.senseintindia.or)**

**India**

**G**reat News for Bolivia and well done campaigners!

Ximena Serpa wrote to tell us that Deafblindness has been recognised by

the Ministry of Health and the Bolivian Committee of Disabled people as a UNIQUE disability! Patricia and Sandra, who work for Sense International, Latin America,

have been campaigning with colleagues and deafblind people and families to secure this success!

**Bolivia**



## Argentina

# First National Congress in Deafblindness and Multiple Needs



**President of the Congress: Mgter. Beatriz Zoppi reports:**

## "Communication, a path to quality of life".

General Pico, La Pampa, was the place where parents, professionals, government representative and the community met for this Congress. It was organized by Escuela de Ciegos y Dism Visuals n°2, Hilton/Perkins Program, Councillors and the Mayor of the city and was held in the Auditorium of Faculty of Veterinarian Science. It was considered of special interest to the national authorities: the Education and Culture Ministry, and Director of Inclusive Education. It was a good opportunity to share professional knowledge with families. We had a successful time.

### Here are the conclusions:

- a) Communication is essential to be considered at all levels and in all interactions for
  - i. the development of each person with multiple needs, giving a possibility for their self-determination.
  - ii. his/her inclusion in the community.

- iii. the relationship between professionals and parents and how they can achieve the same goals.
- iv. the interaction between different institutions and community.
- b) Communication is the foundation of an educative approach, related to quality of life. It is also related to an ecological paradigm of inclusion.
- c) It is considered necessary to change attitudes, have access to critical reflexions towards the psychological/ medical paradigm that is present in our model of Special Education.
- d) It is vital and important that each professional, family, institution, organization shares with others the knowledge about rights and possibilities for a deafblind person and with multiple needs.
- e) The families are essential to the approach, together with professionals. We must respect their way of participation and try to

support them and promote a more active role.

- f) There are no models that can be applied to persons or Institutions, but there are projects that can be a starting point for change, being adopted as a principle of individualization or contextualization – each place taking into account their own realities.
- g) The transition to adult life must have solid statements that can help to guide the process for persons, for families and communities.
- h) We must have a commitment from the State, Institutions, NGO, professionals, families, persons with disabilities, to share knowledge and try to increase the work with Institutions that work with people with deafblindness and multiple needs and their own families.
- i) We must influence the the authorities for legal recognition of deafblindness as an unique disability.

## Canada

# CDBRA Elects A New President



**Stan Munroe**

**A**t the recent Annual General Meeting of the Canadian Deafblind & Rubella Association – National, Wylie Bystedt of Quesnel, British Columbia was elected as National President. Wylie replaces Patrick Peterson as President. Patrick stepped down from the National Board of Directors after 18 years of dedicated service.

Wylie joined the National Board in 2003 as the representative of the British Columbia Chapter. She served on a number of national committees, recently completing two years as Editor of the Intervention News magazine and two years as the Vice President of Special Projects.

Wylie is the parent of two daughters, the younger

of whom is deafblind. She is currently finishing her Bachelor of Arts in Applied Communication from Royal Roads University along with being a very hard working business lady. As well as her work in the deafblind community, Wylie is also active on a number of provincial and municipal business and social development boards.

## SOCIEVEN – Working on Behalf of Deafblind People Venezuela

Dbl's newest corporate member has been spectacularly successful in raising the profile of deafblind people in Venezuela.

**S**ordociegos (Deafblind) of Venezuela (SOCIEVEN has worked for 10 years, teaching and improving the quality of life of around 100 deafblind people, and is now seeking out many more people. This is the aim of María Luz Neri, director of the non-governmental organisation.

According to her estimates, there could be as many as 4,000 dual sensory impaired people in this South American country of 26.5 million.

The situation is similar or more accentuated in other countries of Latin America, according to reports by the International Council for Education of People with Visual Impairment (ICEVI) and the Perkins School for the Blind, based in the United States.

SOCIEVEN now understands that just like it directly helps a few dozen people, it can have a

multiplying effect by training professionals. Maria Luz says that they are pushing for a master's degree programme in a local university.

Centres for "Integral Attention to the Deafblind" have been set up by the Education Ministry in all of Venezuela's 23 states, and deafblind adults have created a mutual help association which also seeks to promote their interests. The centres and the association have located some 400 people suffering varying degrees of dual sensory impairment. Some are deaf people who have developed cataracts. Others, in the Caribbean island of Margarita, involve cases of Usher Syndrome.

As dual sensory impairment is not linked to poverty, Maria Luz knows the people who are the least informed are the most vulnerable.

In Venezuela, SOCIEVEN has adopted a multi-

pronged strategy, seeking sponsors for its activities and financing for technical aids such as hearing aids, special glasses and magnifying glasses, organising educational projects, and recruiting volunteers and "ambassadors" for the cause.

These ambassadors are public figures from the arts or from show business, like Vanesa Peretti, one of the contestants for the 2005 Miss Venezuela beauty pageant, which is watched by millions of TV viewers every year.

Peretti was the first deaf woman to take part in the pageant since it began over half a century ago. She drew a great deal of attention as she communicated with her companions, the jury and the public in sign language.

"Vanesa has been a beautiful example of reciprocal support for SOCIEVEN"!



**Maria Luz Troconis**

## Deafblindness is recognised as a specific disability in Nepal!

**Nepal  
Lone  
Poggioni  
writes**

**T**his morning I got a wonderful mail from the president of National Federation of Disabled, Nepal (NFD-N) Mr. Birendra. It means that the Nepalese government has recognised deafblindness as a specific handicap.

During my four visits to Nepal I have talked a lot with Birendra to help him understand that

deafblindness is not a multi handicapped disability but a specific handicap. I have send him lots of papers about deafblindness and finally during the conference in Dhaka, where I asked him to take part he really understood that deafblindness is a specific handicap.

Now I think it will be easier for us to get support from

the government for the Deafblind cause in Nepal.

The handicaps which are now officially recognised in Nepal are:

- Physical handicaps
- Blind and low vision
- Deaf and hard of hearing
- Deaf-blind
- Speech impaired
- Mental handicapped
- Multi handicapped ”

# Multi-handicapped children – Cochlear Implant Users and their Education

Ass. prof. Milon Potmesil, Department of Special Education,  
Faculty of Education, Palacky University, Olomouc, Czech Republic

## Summary:

The author is dealing with the problem of the quality of life concerning multi-handicapped children. He suggests some changes that may be enabled by the use and accessibility of cochlear implantation. To express life quality it is possible to consider financial costs and also immaterial costs. Both types of expenses are described here. The author is convinced that sign language as a way of communication before the implantation is a very important condition for developing the spoken language afterwards. The author concludes by proposing a list of steps needed to provide conditions for further cochlear implantations for multi-handicapped children.

In the last couple of years, the numbers of people having a cochlear implant have increased because of a new group - multi-handicapped users. The first case of cochlear implantation in a multi-handicapped child generated discussions

in several specialized areas. Because of that first case, those of us working in special education were stimulated to consider the repercussions of extending the group of children, to those that are very severely disabled.

For such cases, the extent and methods of pedagogical work before and after the implantation should certainly be considered. We have in mind those children whose disability makes traditional education very hard. In terms of quality of life we believe that a cochlear implant can improve opportunities to learn and lead to a markedly higher quality of life. We are sure that the post-implantation aim to build functional speech, as the means of mutual communication, will not be applicable to all of these children. It is desirable to determine and adopt different and more appropriate criteria for choosing implantation applicants, and at the same time, to extend the admission guidelines for considering the

children wishing to become involved in the programme. It is also necessary to reflect on the fact that not all of these children have a fully functional or complete family to support them.

## New Project

Currently we are opening a project whose aim is to research the numbers and types of disabilities in children who are brought up/taken care of in a non-family environment.<sup>1</sup> The project is looking at children, up to 15 years old. In addition, we suppose that there may be a relatively large number of older people with combined handicaps and that some of these people may benefit from cochlear implants as well.

We use a model of an individual's quality of life as the area defined by a triangle whose apexes are:

- the child
- the parents
- quality of life of the society

The child, in this context,

<sup>1</sup> We have in mind children who were placed into various institutions by a court decision. We believe that there are a relatively large number of children placed in nursing homes, social welfare institutions, institutes for infants and in other similar institutions. One of the conditions, which are essential for the Health Insurance Companies when deciding on the implantation, is a complete and functioning family. Apparently, children without their own families, placed in various institutions are evidently disqualified. In our own experience we can state that these children have both the professional special pedagogical care and health care generally on a higher level than children do with a family. And this is also true for the accessibility and frequency of sessions.





has a combined handicap and has special educational needs that are extremely hard to meet. In most cases the child does not learn in traditional ways due to their multiple problems and as a result had become labelled as resistant to education or even upbringing.<sup>2</sup>

We consider it very important that the list of conditions that qualify for an assessment for "quality of life" includes all conditions, ranging from those of a wider ecological character to those with a lower incidence. Nowadays, one of many important parameters for describing quality of life is school attendance and its accessibility. In the Czech Republic school attendance is based on a legal requirement which states that "Everyone has the right to be educated." Citizens have the right to get free education in primary and secondary schools; and according to an individual's abilities can also move into higher education. However, there is a very different interpretation of this law for "really severely handicapped children". For this group there are a number of barriers that are put in the way of children with complex needs ever joining the school system. In fact these children can have school attendance postponed or are even exempted altogether

### Quality of life issues and economic challenges

While assessing life quality one cannot disregard the economic point of view. If we are to talk about the quality of life, we should include both children with various types of handicaps as well as children who suffer from a long-term disease and those with poor health. Only when the whole group is characterised in this broad way we can assess the life quality of individual case studies. Clearly, decision making is difficult when resources are limited and how we make judgements related to different children is very tough indeed. How do we value a child receiving a hearing aid against a child admitted for an emergency cause by a traumatic event? Both demand resources from the public purse and both children have needs that are real to them.

If we are to consider the group of multi-handicapped children we must admit that the benefit of having a cochlear implant will hardly be comparable to the expected benefits for children with a single handicap - a hearing handicap, generally deafness.

This means that the expected speech quality factor and the factor of successful spoken communication or the

factor of school involvement cannot serve as criteria for measuring success the most complex group of multi-disabled children. What is apparent is that the benefit of having a cochlear implant improves the life quality for a deafblind child. This is indisputable. Furthermore, if the criteria were adjusted to take account of their different requirements then access would be fairer.

**"Firstly, the quality of life is not limited either socially or by state of health, secondly, the basic prerequisite is to approach life quality as a trend, not as a state."**

Health care economics are involved in considering the costs and outputs of various alternatives. A comparison with the principles of microeconomic theories are used (O'Neill) and present three types of economic evaluation/measurement of health care effectiveness.<sup>3</sup>

The first type deals with direct costs. These are the costs that are derived from all steps/items connected with the surgery. In the case of cochlear implant, these costs include all examinations, the special-pedagogy pre-operation examination, the implantation and the

<sup>2</sup> Not all of the terms used previously have vanished without a trace in history. Some doctors still have not completely abandoned their out-of-date positions in the relationship to children with multiple handicaps. Thus, nowadays we can still meet expressions like "asylum child", "much too expensive examination", "zero future", "bed-ridden patients", "bed-warmers" and the like.

<sup>3</sup> the economic view of health cares must have priority. Only then comes the special-pedagogy view – after the surgery. However, it is one of the criteria for including the applicants in the list because of its potential, availability, intensity and expected results.

following after care including rehabilitation. However, in different countries the direct costs do not consist of the same items so it is hard to compare accurately with other countries.

The second type describes the indirect costs. These costs include items that are not directly related to the implantation and special care. They are related to external factors like the costs of parental absence from work, travel costs, costs connected with the purchase of special aids – toys, with the re-organisation of the acoustic character of the flat, etc. However high, the indirect costs influence the parent's decision-making processes. In the case of children without their own families the costs must be covered by an institution, generally a state institution, that is responsible for the child's care.

The last group of costs is "immaterial" costs.<sup>4</sup> They arise on the part of the implant receiver. They relate to hurt and pain and can be reduced with professional support.

### Early is better?

The German author Schulze-Gatterman reports the success of early cochlear implantation and we would like to speculate about a

similar result in the case of children with combined handicaps. There is, though, one basic prerequisite common to both the groups – the prompt special/ pedagogy care, even during the pre-operation stage.

### Sign Language

The important role of sign language has fortunately been recognised in the wider world. Let us hope that soon all the specialists involved in cochlear implantation in the Czech Republic decide to follow the direction and pace of psycho-linguistic progress and knowledge. Let us hope so on behalf of children being implanted, whose mental development should include the development of language and thus the development of communicative behaviour.

Furthermore, the fact that students of special pedagogy are able to explain basic mental and language development phenomena as soon as they finish the second semester of their studies may serve as guarantee that we will not have to spend time and energy to dissuade people from their out-of-date views. This progress will enable us to use methodology of work with children with combined handicaps. We would like to stress here the need for professional discussions,

discussions across the branches of study, sharing experience.

It is not only economic costs that we should consider. It is essential to consider those types of "costs" that are not economic, but personal. We know by intuition that these are hugely challenging. But, we also know they are expected by parents and children.<sup>5</sup> The child with the implant can "feel different" and not feel they belong in the deaf community or "the hearing". Being comfortable in society is vitally important. Parents are always worried about the decision they are making partly because cochlear implants are a relatively new technology and are based on less experience in comparison to the traditional approaches. Parents and educators of multi-disabled children have an even greater decision to take, but often the decision is made for them as surgery may be contraindicated.

### Work from Hanover

In the next part of the text we would like to try to reflect on some experience and opinions published by Bertram, Lenarz and Lesinski in 1997, from the Cochlear Implantation Centre lead by Wilhelm Hirt in Hanover.

The authors specify the

<sup>4</sup> The word "deposits" may illustrate the situation in a clearer way

<sup>5</sup> It is important to stress here that in the proposed cases we also deal with children who do not have their own families. Apart from the term "a parent", we automatically think about "a substitute" person. The more the institutional care and other types of non-family advance, the more often we must notice these children and consider the starting conditions of these implant applicants without a regular family

<sup>6</sup> 1. Somatic disorders: endocrinological, heart, motor, sight, neurological, nephritic

2. CNS disorders: sensory-motor integrity disorders, psycho-motor retardation, cortex deafness

3. Mental retardation: serious behaviour disorders, developmental retardation

4. Syndromes connected with a serious hearing disorder: Schwarz – Bartter, Undine, Landau – Kleffner, Peutz – Jeghers, Pendred, Jervell – Lange, Waardenburg, Schwachmann, CHARGE, Usher, Alport.



group of children with multiple handicaps that they believe are suitable to benefit from implantation and those who would not. In their paper, four groups with combined handicaps<sup>6</sup> are perceived by the authors as appropriate applicants. On the other hand, the authors introduce a list of handicaps that may contra-indicated for cochlear implantation because of their complex disabilities.<sup>7</sup> The German authors based their work on data obtained from 570 implanted children. 110 are children with combined handicaps. We do not have the courage to say that the German colleagues made a mistake, however, we have been trying to find ways to make cochlear implants more accessible to those children who may be omitted from consideration because of the above mentioned contraindications. We have in mind children whose severe

combined hearing and vision loss that has such an impact on their ability to learn that it does not allow them to successfully pass at primary school. We have in mind the children whose life quality may be increased by means of special pedagogy methods and techniques that may enable them to decide on the issues of their own lives, or at least enable them to take part in the decision-making process.

If we want to try to find a basis for determining life quality we must choose the technique of comparison that does not discriminate against children with disabilities. It is important to adopt the following statement as a basic principle: **"firstly, the quality of life is not limited either socially or by state of health, secondly, the basic prerequisite is to approach life quality as a trend, not as a state."**<sup>8</sup>

To support further progress we regard the following demands as necessary:

- to propose a life quality definition that respects people with severe combined handicaps
- to characterise the target group in the most detailed way possible, on the basis of nation-wide research not only within families but also in various institutions providing care
- to construct a questionnaire for clients with the aim to find out what they regard as a good life quality and well being
- to construct questionnaires and find out the current views on life quality in the respective interest groups (parents, educators/social workers, teachers, medical staff, health insurance companies).

## Bibliography

O'Neill, C.: *Economic evaluation in health care*. Proceedings of a Conference on Health Technology Assessment, Queen Medical Centre, Nottingham, UK, 2001

Schulze-Gattermann, H. et al.: *Cost – benefit analysis of pediatric cochlear implantation – the experience of the Medical University of Hanover*. Proceedings of a Conference on Health Technology Assessment, Queen Medical Centre, Nottingham, UK, 2001

Bertram, B; Lenarz, Th; Lesinski, A; *Cochlear Implant For Multi-handicapped Children – Pedagogic Demands and Expectations*. Cochlear Implant Centrum Wilhem Hirte Hanover, 1997

<sup>7</sup> We choose e.g. autism, serious behaviour disorders, auto-aggressive behaviour, hyperactivity, distorted social environment, serious intellectual disorder, transfer or central hearing insufficiency, sensory-motor insufficiency, limited or non-existent learning ability, states of spasms or attacks, malign diseases with a short or unfavourable prognosis

<sup>8</sup> An illustration of a common life quality may be the following situation: the child is able to decide whether he or she wants to go to the swimming pool with the school-mates and later decide that he or she does not want to go into to water.



# Opening doors to “Person Centred” communication

Seija Troyano and Tiina Latva-Aijo-Kortelainen write about a new professional qualification and role – the sign language instructor!

## Seija writes:

After more than ten years with a cochlear implant I have seen my need for interpreters change quite a lot.

I use spoken Finnish language and thanks to CI can normally copy independently with my daily communication situations. I also profit by induction. But when I get into the situations where there are many people around me all speaking and chatting at the same, it is certainly the place of interpreter!

Normally, my requirements are less demanding and then I am happy to have a modern alternative to it. In Finland we have now sign language instructors! Their strength is versatility. After 3 years of studying they can communicate in sign language when needed and they have large knowledge about the needs of deaf and deafblind people. Their job is not to interpret but they can repeat to you what someone says if you miss it.

They are just ideal for the person like me!

I have booked them for weekend trips and meetings to the places that are unfamiliar for me. I



Seija Troyano

have booked an instructor for my hobbies, such like photography in the forests, swimming, taking part in a marathon and when I go shopping. It has opened new doors for me and ...freedom!

In Town Council meetings I get valuable information from the instructor. She acts as intermediary in giving me rapid information about how people vote. I can not see the “yes” or “no” that are electrically thrown back on the wall of the room where the meetings are being held. However we have developed very effective way of our own using simple letters and symbols. When there is “block” of same letters we use English alternatives happily and fluentlyJ - B(oss)

C(igarette) M(iddle)...

The more we use it, the more surprised we are how much information it is possible to receive during the meetings. The Instructor sits behind me as my seat is the last one in the row near to the back wall. So there she is and she lets me know when the Chairman of the cabinet slips out for a cigarette in the middle of the meeting with a member of his party!! Or when other changes happen.

After three years of study these sign language instructors are very rich skilled alternatives for deafblind people who do not need an interpreter but still need support.



### Seija Troyano's instructor, Tiina, writes:

I am a Sign Language Instructor-student from Finland and my name is Tiina Latva-Äijö-Kortelainen. I was interested in this occupation for its various possibilities. Sign Language Instructors work in different communities using sign language in many different ways with a range of different people from young children to the elderly. We support deafblind people by learning the principals of communication, guiding and changing conditions. In my course I study issues related to deaf-blindness for which I receive credits towards my qualification.

This is my final and third year of study. I will start my new occupation next May 2007. Before that I have to work on with my Final Project.

### About my Project

I am also working at the Kuopio City Interpreter Centre as an instructor and a guide. This is how I ended up working with Seija. We met for the first time at the Varkaus Marathon. And as you can imagine we had a good time to talk about everything we were



Tiina Latva-Äijö-Kortelainen

interested in. We were discussing how you can get information if you have serious limitations of seeing and you see a narrow field. Seija communicates with speech, so she doesn't want to use sign language and sign language based methods to get information. We started to think how I can pass on to Seija all the important messages, that I see and hear, for example at the City Council, where she works.

We are developing a method that is based on letters and simple drawings. We used English words because they are familiar to both of us. So I write or draw on her back at the same time she concentrates at her work.

My Final Project has just started, so we've just been

taking our first steps to develop and try this method somewhere. We are both really excited about this all and we also wanted to share this with you. We were wondering if this kind of method have been used before? So please, don't hesitate to contact us if you are interested in keeping in touch or can help in any way.

**Tiina Latva-Äijö-Kortelainen**  
Vaahteratie 24 B 5  
70420 KUOPIO  
FINLAND  
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**Seija Troyano**  
[seija.troyano@dnainternet.net](mailto:seija.troyano@dnainternet.net)

Please contact Tiina or Seija for further information of the course being undertaken.

## A new organisation

### Alfred Josep Pevcin, President, introduces the Deafblind Association of Slovenia "DLAN"

The Deafblind Association of Slovenia "DLAN" is a voluntary, non-profit making, non-political, independent

group of individuals who are connected by common interests. They are deafblind persons and legal representatives, others that support the Association in its aims in respect of deafblind people. DLAN has a President who is deafblind

and the association already co-operates with various organisations in Slovenia and would like to have more contact with other countries and International associations.  
[drustvo.gss@gmail.com](mailto:drustvo.gss@gmail.com)

## DbI Strategic Review

### Have your say in planning for future developments!

**W**hat is DbI's future? You will have the opportunity to contribute your ideas in the next few weeks.

All members now have the opportunity to complete an on-line questionnaire, which is available on the DbI website. Selected members, particularly those actively involved as network chairs, will be contacted personally over the next few weeks by members of the Strategy Review Group. They will talk with them about the impact DbI should try to achieve in the next few years.

The Strategy Review Group was set up by Council and ManCom and asked to consider the organization's future. It has already met to identify the main issues over the future. We are now consulting members about their views. The Review Group will meet in January to discuss the ideas for the questionnaires and interviews and put these into a strategic plan. The final plan will be considered by DbI Council and announced at the DbI International Conference in Australia 2007.

If you want to be involved with

this consultation, be sure to fill in the online questionnaire. If you have some specific points you want to make, then you can contact any member of the Strategy Review Group. They are:

Tony Best UK –  
[tony.best@sense.org.uk](mailto:tony.best@sense.org.uk)  
Akhil Paul –  
[akhil@senseintindia.org](mailto:akhil@senseintindia.org)  
Sergei Sorokin –  
[Sergei.Sorokin@mogard.se](mailto:Sergei.Sorokin@mogard.se)  
Maria laynes Valdivia –  
[osada95@yahoo.com.ar](mailto:osada95@yahoo.com.ar)  
Isabel Amaral –  
[iamaral@sapo.pt](mailto:iamaral@sapo.pt)

**Tony Best**  
Chair, DbI Strategy Review Group

## Nominations Committee

### Who will be on the DbI Council in 2007? It's up to you.

**Y**ou may be aware that the current Council members, including the President and Vice Presidents, have the opportunity to stand for re-election in 2007. Small corporate associations and networks together can make up to 20 of a total of 35 seats on the Council. Currently there are 44 small corporate associations and 15 networks so there are more associations than there are available places on Council.

The Nominations committee are looking for a balanced Council that reflects as many geographical areas as possible. We also wish as many interests of deafblindness as possible to be represented so we will be taking account of areas of interest including siblings, acquired deafblind, congenital deafblind, development, service based, employment etc.

The President and Vice Presidents are also standing for re-election. You may want the current officers

to continue and if that is the case then please tell us. The current President and Vice Presidents need to know if you wish them to continue beyond 2007. However you can also choose to put forward new candidates.

In nominating individuals for the officer roles for Council you should make sure the person you are nominating agrees and is willing to stand. The person nominated must be able to attend DbI meetings and have the capacity to contribute to the Council.

The individual or the person's corporate body must be a paid up member of DbI. We know this has caused some concern but the Council have taken the view that the membership fee is relatively low. Further if the fee is too much it is likely that attendance at meetings would also be difficult and contributing to meetings is an essential part of being a Council member.

In nominating your network or small corporate your organisation must have paid the DbI membership fee. The representative from your small corporate or network must be able to attend Council meetings and be willing to contribute.

It's important that we hear from you. The nominations committee are likely to be faced with difficult decisions about who to recommend to take up the limited number of places. Your view counts and the nominations committee wish to be guided by the thoughts of the wider membership.

You can make your nomination by contacting the Chair of the Nominations Committee, Gill Morbey. You will then be e-mailed a nomination form for you to complete. The first step is just to contact Gill at the address below. Please make your nomination by 30th January 2007 at latest.

**Gill Morbey**  
[gmorbey@sensescotland.org.uk](mailto:gmorbey@sensescotland.org.uk)  
**Nominations Committee**  
Knut Johansen  
Bushan Punani  
Mike Collins



# University of Groningen, the Netherlands

Masters Programme, Educational Sciences Section

## MSc Communication and Congenital Deafblindness

### Description of the programme:

The Master of Science programme – Communication and Congenital Deafblindness – is a unique programme which provides students with the opportunity to acquire theoretical and methodological skills enabling them to analyse communication in complex situations.

The methods used will enable them to apply this knowledge in the context of research and intervention. This course aims to provide deafblind persons and hearing sighted persons with tools that help them in their mutual efforts to understand each other.

This innovative European Master's programme is based on and inspired by the work of the Dbl ECN.<sup>1</sup>

### Contents

We will explore the possibilities of a dialogical approach to communicative development including:

Dialogicity of mind: intersubjectivity-subjectivity;  
Conversational practice: tactile approach;  
Communicative intentionality; Joint attention;  
Spontaneous gestures: meaning potential;  
Spontaneous utterances: meaning potential;  
Referential gestures: mimetic, iconic and pointing; Narrative frames; Negotiation of shared meaning.

The students will learn how to apply this conceptual framework in the context of assessment, intervention and research.

### Structure of the Curriculum

The total programme is 1680 hours of study (60 European Credits)

This is made up of:

- specialised theoretical themes, including the study of literature (10 EC)

- a project, that is a research or clinical-based thesis (45 EC's).
- a reflective essay linking project work to overall theories and models (5 EC's).

### Structure of the programme

The programme is a year in duration. In September, in order to prepare the first module, students will study advanced literature at home.

In October, students spend 4 weeks at the University of Groningen, attending lectures, and preparing the topic of the thesis.

In November, students return home to start their project. This will be related to practice with congenital deafblind people through either direct work or video-recordings. During the implementation of their project, students will keep contact with their supervisor.

In May, students write the reflective essay. All work has to be finished by 31st August

### For more about admission requirements, fees and facilities

Dbl European Communication Network  
Curriculum coordinator: Dr. Marleen Janssen

Address:

International Master of Science in Education  
Section: Communication and Congenital Deaf blindness

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Tel: +31 50 363 6575 Fax: +31 50 363 6564

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Groningen University website:

[www.rug.nl/corporate](http://www.rug.nl/corporate)

<sup>1</sup> The Deafblind International European Communication Network started in 1988. This working group gathers knowledge about communication and congenital deaf blindness, combining recent research with examples of practical knowledge from the field. This has resulted in the production of video's, seminars and papers, which continuously provide state-of-the-art reports. Five different countries are represented in the working group. The members are: Marlene Daelman, K.M.P.I. Spermalie, Brugge, Belgium; Flemming Ask Larsen, NUD; Marleen Janssen, University of Groningen, The Netherlands; Anne Nafstad, Skådalen Resource Centre, Oslo, Norway; Inger Rødbroe, Resource Center on Congenital Deafblindness, Aalborg, Denmark; Jacques Souriau, CRESAM, Poitiers, France; Ton Visser, Viataal, Center for Expertise, Sint-Michielsgestel, The Netherlands.

# Experiences from People with Deafblindness

## Booklets published by the Information Center for Acquired Deafblindness

By Ilene D. Miner, Services to Deaf and Deafblind People, USA

The booklets on Deafblindness of the Nordic Project, published by the Information Center for Acquired Deafblindness, taken all together present a picture of the lives of 20 deafblind people in Norway, Sweden, Iceland, and Denmark. The members of the study were interviewed yearly for five years, not only giving a snapshot of their lives, but a longitudinal look at lives and changes over time. This kind of longitudinal study has never been completed before and contributes enormously to our understanding of the lives, feelings, opinions, and perceptions of people with Usher Syndrome.

What is extraordinary is that the patterns, problems, observations, needs, and conclusions that are identified are drawn from the signs, words, and lives of people with Usher themselves, not from what professionals think that people with Usher need.

The informants are articulate and willing to share their lives. The interviewers are clearly highly skilled and able to make the interviewers comfortable enough to share this material and their lives.

These booklets are important for people with

Usher Syndrome, for families and friends of people with Usher syndrome, and also for every professional involved with people with Usher.

“This kind of longitudinal study has never been completed before and contributes enormously to our understanding of the lives, feelings, opinions, and perceptions of people with Usher Syndrome”

Although some people with Usher often know others with Usher, it is not common for people to reveal themselves to others with the depth that they do here. Informants said that they wanted to know about the lives of others and these booklets provide that opportunity.

Many friends and families never share feelings on the level presented in these booklets. In my professional

work, I have often spoken of the well-known phenomenon of the ‘elephant in the living room’: a family member with Usher which is never discussed.

For professionals, reading these booklets is a humbling experience for it shows us clearly the perceptions of those we serve. These booklets highlight some of the issues that we have been missing and our own attitudes that cause difficulty for our clients. We are reminded again that the most important person and mentor for a person with Usher is others with Usher. We service providers are NOT the most important people in the lives of deafblind people.

For me, as a provider from the US, reading about the lives of people with Usher in the Nordic countries leaves me intensely envious; the baseline of services, i.e. the availability of contact persons, and interpreters, although not perfect, means that deafblind people can lead and control their lives. Some of what is a daily struggle in the US, securing services of a contact person and/or interpreter in many cities, states, and towns, is less of an issue in these four Nordic countries.

Throughout the booklets,



applicable information and research is discussed and connected to issues for people with Usher. This provides context and a framework for understanding the comments of informants in their own life cycle.

There is important information in each booklet that can inform the work of every professional in the field. Each booklet ends with a Summary section and a section called Worth Thinking About wherein there are conclusions and trends and of course questions about the implications of what has been found.

### In Summary

These booklets make an important contribution to the field of acquired deafblindness and Usher Syndrome. There is so much information about the real lives of people and their struggles and joys that is impossible for the average person to know about. We all benefit from reading these booklets.

Additionally for readers to remember is that this information comes from people with Usher

themselves, not from professionals or even from family around the person with Usher. These are the real experiences and feelings of people with Usher Syndrome, living their lives quite fully.

The arrangement of interviews by topic at yearly intervals without including retrospective changes in the one year period in some way loses the benefit of interviewing longitudinally. Knowing how informants coped with a setback or handled a difficult experience they faced during the previous year would have provided information to others facing that situation.

The recurrent themes of communication, interaction, life and work, the struggle to find meaning in a new and different life are woven throughout. We all benefit and grow from reading about Life with Usher from the viewpoint of the person with Usher. This is the heart of the



beauty and importance of this series.

The lives of people with Usher are

each complicated and unique. There are of course commonalities with others who have acquired progressive disability, such as the need to re-grieve and reintegrate losses and changes over time, to develop a new integrated and cohesive sense of self, the impact on life's meaning and relationships, there are few other situations in which communication and therefore one's lifeline can be lost.

The Project is to be commended for this extraordinary undertaking. I only wish the project could have taken place in the US as well!

**The booklets can be downloaded as pdf or Word files from the Information Center for Acquired Deafblindness' website at [www.dbcent.dk](http://www.dbcent.dk). From the front page, choose the English version, then choose "Publications" and finally choose "Printed material".**



## Secretariat News

DbI Management Committee and Council meetings were held on 16 and 18 July 2006 coinciding with the 12th ICEVI World Conference at Kuala Lumpur, Malaysia. If you want more details on these meetings contact the Secretariat at [secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org). The next ManCom meeting was held on 17 and 18 November in Boston.

Since the last issue Emanuela Brahamsha has taken over the role a DbI Secretary. She can be contacted on [Emanuela.Brahamsha@senseinternational.org.uk](mailto:Emanuela.Brahamsha@senseinternational.org.uk)

### DbI World Conference

The 14th DbI World Conference will be held from 25-30 September 2007 at Burswood Resort in Perth, Western Australia. It is being organised by Senses Foundation. The Scientific Committee held a planning meeting in July 2006 in Malaysia.

Exciting international and national speakers will form part of the Conference Programme based around the Conference theme, "Breaking the Isolation - Forming Worldwide Connections".

The Call for Papers has been extended and now closes on 31 January 2007.

For more information please visit <http://www.deafblindinternational.org/standard/conferences.html> or contact Conference Planning Committee at [conference@senses.asn.au](mailto:conference@senses.asn.au)

### Membership Update

All DbI 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 more than 650 individual members and 56 corporate members, from more than 80 different countries.

If you know of any organisation that

may be interested in joining DbI as a corporate member, please pass on their details to the Secretariat now!

DbI would like to express its appreciation for the continued support of the large and small corporate members. We strongly encourage individuals to join DbI in order to contribute to and widen 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)

### DbI Website

The DbI website is available with updated information. Please visit the website and share your feedback with us.

We welcome new submissions to the website. If you would like to contribute or advertise an event or recent success, please send details to Eileen Boothroyd, DbI Information Officer, at **Eileen.Boothroyd@sense.org.uk**.

### The DbI Secretariat

The DbI Secretariat is always aiming to improve the service that we offer. We look forward to your suggestions, advice and support for providing a timely and effective service.

We hope that you received your copy of the previous issue of DbI Review (issue 37). 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 Parag Namdeo at: [secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org) or post your query at: DbI Secretariat, Post Box No: 9601, Janakpuri, New Delhi – 110058, India.



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

**Non-Voting Members** consist of individuals, national networks and non-subscribing Corporates. Non-voting members can contribute to the decision making process of DbI through either a corporate member or an international network. Non-voting members will receive a copy of DbI Review and other relevant DbI information.

Non-voting membership costs €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 DbI networks.

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

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

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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

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Job Title	
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- 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

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  
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- ☐ 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 (delete as appropriate)

Member Details:

Organisation	
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Zip/Post Code	Country
Tel:	
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### 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

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

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 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 credit 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:**

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