

## **DbI Review**

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Deafblind 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 Dbl World Conference in Perth.  
(Courtesy of Senses Foundation)

## **A message from the president**

Dear Friends and Colleagues

Its hard to believe but it's two months since many of us were together for the world conference in Australia. What a great conference it was; well organised and a wonderful programme with all the magic of such a special location. A sincere thanks to Senses Foundation and all the people involved in making this event a reality.

During the conference, the Management committee and Council looked at our new strategic plan and I would like to thank everyone who has offered, so far, to get involved in supporting and maintaining the quality of our organisation. I will asking more members to offer their support in the coming months.

Other events are already in the planning stages. I would like to mention in particular, our network activities which you can read more about in this edition. The Communication Network, the Acquired Deafblindness Network are planning international events in 2008. As well as this a Family event, in the "Listen to Me" series will take place.

All these activities take a lot of time and energy, skill and dedication and I would like to use this opportunity to thank the networks and the Dbl members who were on our various planning groups for the amount of work they have done and are continuing to do on our behalf.

On a personal level I am deeply honoured and proud to continue my Presidency for a further four years. I can promise I will continue to the best of my abilities to keep deafblindness on the top of the agenda across the world, supporting families and supporters as well as deafblind people themselves.

On a final note, our organisation is growing and we want to increase its reach and influence to an even greater degree. We are dependent upon your participation at many different levels so do not hesitate to contact us with your ideas or suggestions.

Once again, as always, I thank each and every one of you for your dedication and contribution.

Seasonal greetings to you all.

William Green

## Editorial

We have another lively magazine with contributions from across the world. The series about our “less well known” senses, from David Brown continues; this time he is concentrating on the olfactory sense or “smell” to you and me! I guarantee you will enjoy reading it!

With so much more being reported worldwide about elderly people who are dual sensory impaired, we have a timely survey article from colleagues from the Information Centre for Deafblindness in Denmark. The material it presents will be both thought provoking and challenging to service-providers and campaigners alike.

In Perth, I was fortunate to talk to a professional dancer who works with deafblind people and hear about her work. Mea Nordenfelt, who works at Mo Gard in Sweden, shares her philosophy and practical ideas about the therapeutic effects of movement and dance. In Perth, I also had the pleasure to meet, for the very first time, Mike Steer, who is the magazine’s dedicated “Australia correspondent”. To meet him personally was special and I imagine many of you may have had a similar experience with someone you talk to electronically across the world.

We have lots of news from our active networks and much of this valuable work is leading to new courses, information groups and conferences being developed to share knowledge between members more effectively.

We have made a decision to change a long standing arrangement we have with Sense to send out Talking Sense with Dbl Review. With so many excellent organisational newsletters it is not possible to include them all so it seemed like a good time make this change. In future, members of Dbl who would like to hear about what is happening at Sense will be able to access the website or make a separate subscription to the magazine, which comes out 3 times a year. Full details of how to do this will be emailed to you very soon.

In the new strategic plan and the information function is one of the areas that has been highlighted as being very important. We are very keen to maximise the impact of what our members are doing through information sharing but we also seek to support you all in practical ways too. So, we will be reviewing what we do now and making plans for the future. Do read the full report from the strategy group which describes its main recommendations.

As always, I would like to thank our contributors for taking the time to get in touch and remind you all I really do look forward to hearing from you with your ideas and your news! Keep me posted!

Eileen

## **The Sense of Smell – the Olfactory Sense**

**This is the third in the very successful series of articles that David Brown, from California Deafblind Services, is writing on the senses**

The sense of smell is crucially important for the existence of almost all creatures, for finding the next meal, for avoiding many dangers, or for choosing a partner. We humans, able to distinguish thousands of different odour molecules, utilize our sense of smell for a multitude of activities from maintaining personal hygiene, to enjoying the aroma of freshly baked bread, to deciding whom not to sit next to on the bus.

We think that we smell with our noses, but this is no more true than if we say that we hear with our external ears or that we see with our corneas. The part of the nose that we can see merely collects the relevant information, so that every time we inhale, air swirls up through the nostrils to the millions of smell receptor cells that are all contained deep within the nasal cavity in an area known as the olfactory epithelium, which is about the size of a postage stamp. These cells are sensitive to chemicals produced when odours dissolve in the mucous inside the nose, and they are much more sensitive than the taste receptors, being capable of collecting and transmitting information that helps us to discriminate many thousands of different smells. Researchers have claimed that smell is 10,000 times more sensitive than taste, and the system is so complex that, unlike the five taste groups, no research has yet been able to discover basic categories of smell. In fact, we tend to pay little attention to the sense of smell, except for obvious attention paid to bad smells, and the publicity of the perfume and cosmetics industry, so that we don't even have a proper range of words to describe it. Just consider how many words we have to describe different shades of blue for example (pale, light, dark, deep, eggshell, teal, navy, royal, Prussian, sky, aquamarine, and so on), and how few words we have to describe the various different smells of roses or dogs. So it is very hard to use words to explain exactly how something smells to somebody who hasn't smelled it. The sense of smell is unique in that, unlike all other sensory systems, it sends information directly to higher centers of the brain and completely bypasses the thalamus, which is the area of the brain where all other incoming sensory information is sorted into the two basic categories of what needs our attention and what does not need our attention. Because it doesn't have to pass through this preliminary sorting and analyzing process, smell is the sense that puts our brains into direct contact with the environment in a way that none of the other senses can. So the sense of smell has quick, direct, and powerful connections to the limbic system, the part of the brain concerned with primitive instincts and

drives, the part that processes emotions and memories. In 'Understanding Deafblindness' Geegee Larrington refers to smell information traveling '...on short, large, fast fibers to deep within the brain'. This is why particular smells can evoke such very strong emotions and memories, all based upon associations made through previous experiences, and do it so quickly and so vividly.

The sense of smell depends on the functioning of not only the first cranial nerve (the olfactory nerve) but also parts of the fifth cranial nerve (the trigeminal nerve). Qualitative smell sensations (for example the distinctive and unique identifying smell of a lily, or an orange, or freshly cut grass) are transmitted by the first cranial nerve, whereas other aspects of smells (for example the heat, coldness, sharpness, spiciness, and irritating qualities of a particular smell) are transmitted by parts of the fifth cranial nerve. It is helpful to know that more than the 'smell nerve' is involved in our perception of smell. In the population of children with CHARGE Syndrome, for example, which is one of the leading causes of congenital deafblindness in children, we know that about 42% have damage to the first cranial nerve and 43% have damage to the fifth cranial nerve, so that there is a high incidence of missing or reduced sense of smell.

Like the taste receptors, the smell receptors develop very early in a foetus, stimulated by chemicals in the amniotic fluid that they inhale and exhale while still in the womb, so that babies are born with an already well developed sense of smell. Babies also appear to be born with an innate ability to detect bad, aversive smells, since it is reported that one-day old babies give facial expressions that indicate rejection when they are exposed to fish or rotten egg smells. But the fact that we experience so much smell sensation before birth complicates this whole area, just as it does with early taste preferences and aversions. Since babies are exposed to a selection of 'smells' over a long period in the womb this seems likely to exert a powerful influence on their smell preferences immediately after birth. There is clearly experience-dependent learning in the smell sense, but whether the response to certain smells (in particular what we consider to be bad smells) is innate or not has still not been settled.

As with taste, so our sense of smell declines as we get older, so there is a double impact on the loss of flavour from food and drink, as well as on more generalized aspects of environmental awareness. By 80 years of age 80% of people are reported to have some major smell dysfunction, and 50% are functionally anosmic (the word used to describe someone who has lost some or all of their sense of smell). Not only is there a loss of the sense of smell, but also a loss of the ability to discriminate between smells. Disturbance of the sense of smell has many possible causes. In most instances, loss of smell is caused by nasal and sinus disease, upper respiratory tract infection, or head trauma. Patients with neurodegenerative diseases, such as Alzheimer's disease, experience significant loss of smell perception. In fact, one of the common very early stages of Alzheimer's is a loss of smell sensitivity. Medications, especially those that

increase dehydration and limit mucous production, are also an important and frequently overlooked cause of smell impairment.

Smell and taste are the two chemical senses, so called because they detect chemicals, and smells and tastes are, of course, chemicals. With both of these senses we sample our environment for information. Unlike taste, of course, smell can signal over long distances and so form part of our early warning alarm system. With our sense of smell we are continuously testing the quality of the air we breathe, which will alert us to potential dangers like smoke or leaking gas, as well as informing us of other relevant information, such as the presence of food, or cooking, or of another person. The sense of smell also serves a recognition function, in that we all have our own unique smell and we can recognise and be recognised by our smell. Some children with deafblindness very clearly sniff other people because this is a help to them in identifying familiar individuals. Research has shown that children can distinguish between the smell of their siblings and other children of the same age, and also that babies recognise their own mothers' smell and mothers recognise their own babies' smell. Emotion can be communicated by smell, as when dogs are said to pick up and respond to the smell of fear in humans. Research in the 1990s showed that people can discriminate between the smell of people watching "happy" and "sad" films, which suggests that the emotions of others, for example fear, contentment, and excitement, may therefore be transmitted and recognized by smell. How we smell, why we smell, and the impact of smell on our everyday life are poorly understood, and we certainly underestimate the importance of smell to our functioning and to our general well-being. Research suggests a close correlation between missing sense of smell and depression, for example. Physiologically, the two chemical senses of taste and smell aid in normal digestion by triggering gastrointestinal secretions. There are also suggestions that smell can influence arousal levels, mood, emotions, the immune system, and the endocrine system that produces and controls hormones. So a great deal can be communicated and controlled by smell without us even knowing it.

The sense of smell is intimately linked with memory, smell evokes memories. Damage to the temporal cortical region of the brain, the site of memory, doesn't affect the ability to detect smell, but, rather, prevents the identification of the smell, because we must first remember a smell before we can identify it. Smell memory falls off less rapidly than other sensory memory, in fact smell memory normally lasts a long time. Like the stimuli we receive through other senses, a smell can become associated with a particular experience and the same smell can recall whole complex memories, complete with all associated emotions; smell is better at this memory cue effect than other senses, and it does it very quickly and powerfully. French novelist Marcel Proust claims that:

'When nothing else subsists from the past, after the people are dead, after the things are broken and scattered...the smell and taste of things remain poised a

long time, like souls...bearing resiliently, on tiny and almost impalpable drops of their essence, the immense edifice of memory.'

This is entirely unconscious, although countless studies have shown that recall of specific factual information can be enhanced if the original learning was done in the presence of a smell and that same smell is presented at the time of recall. But research has also shown that smell memory is context dependent and can be modified in the light of new experience, which implies that our smell sense is continuously dynamic, updating as we live and experience new things.

### **Smell and children with deafblindness**

Most of us have heard stories about the surprising effects of smell sensations on some children with deafblindness. A young child with significant visual and hearing impairments who always became very upset when being taken into the hospital building even though he could not possibly have seen and recognized the building nor understood from spoken conversations that he was being taken to a hospital. Another child would become excited and begin to salivate as lunch was being cooked in the room next door, even though he had not seen or heard the food being prepared. An older child would routinely search for the hand of every new person who entered her classroom and lift it to her nose very deliberately and sniff it; then she would either drop the hand and walk away, or she would smile and embrace the other person. When a girl with profound disabilities was allowed time to smell the dish of lavender-scented oil that was always used in her weekly massage session her eyes would open wider, she would become gradually more animated, and she would break her customary silence with quiet vocalizations. All of these are examples of ways in which the sense of smell can offer vital and meaningful information to children with deafblindness and enable them to connect with their environment and to recognize and anticipate what is coming correctly.

Some children with deafblindness are anosmic, they have no sense of smell (we think that this is the case with many children with CHARGE Syndrome, for example, because of the cranial nerve damage already mentioned and because of blocked nasal passages), and others don't appear to show any awareness of the sense even though it may be intact and working. In other cases children give very clear evidence that smell is an important sensory input for them, as in the examples mentioned above, and many children show levels of environmental and social awareness that are surprising and perplexing to us (like the boy upset by hospital visits), until we realize that their sense of smell must have given them the essential information they needed for this awareness and recognition. Indeed, if we think of the sensory deprivation inherent in the term 'deafblindness' it seems obvious that the relative importance of other intact sensory channels like

smell and taste might be enhanced as long as the inputs coming through those sensory channels are meaningful for the child.

Sometimes people involved with a child with deafblindness think of using smells in a deliberate way to help the child know what is going on, and in these cases the following guidelines might be helpful.

1. First it is helpful to observe for, and discuss, the ways the child already responds to smells. How do they show that they have perceived a smell, and which smell? Can they locate its source in the room? Do they seek out smells? Do they recognize smells, and how do they show that they do? These are all important questions to be asking and discussing before any work is done on enhancing smells or adding new smells to the child's environment.
2. Helping the child to become more aware of smells that are already present in their existing environments and in their regular routines might be a useful thing to do, and there are usually many more of these routine smells around than we realize. This idea might involve strengthening these existing smells if this is possible, or it might mean investigating ways to draw the child's attention to the smells in a way that helps them connect the smell with the upcoming activity. These activities might also help the child to learn to seek out smells more consciously and deliberately. Time spent exploring and thinking about this, and discussing your ideas with others, should be helpful.
3. Any ideas about introducing new smells artificially should be treated with caution. If the new smell is not already an integral part of the activity or of the environment it might, in fact, be a distraction and create confusion for the child. Since the smell is being introduced artificially it might also be difficult for everybody involved with the child to remember always to introduce it consistently and appropriately, and to remember exactly which smell is to be used with which activity or in which location.
4. Many smells released into the atmosphere remain perceptible for a very considerable period of time, and they can't be 'put away' like we would switch off a light or a radio, or remove a toy from a child and put it away in a drawer. If too many different and strong smells are deliberately introduced in one place they will blend together, which could cause confusion and distraction, and might even be a potential health hazard (depending upon the type of chemicals being used). Everybody in the room will be exposed to these smells, not just the child for whom they are intended. It is reported that the sense of smell 'tires' and the nose begins to lose its sensitivity after exposure to three or four different smells in succession.



5. All of us have hypersensitivities to certain smells and to certain intensities of smell, and, while some children with deafblindness may demonstrate these hypersensitivities with obvious aversive responses, others might not be able to let us know that they are suffering. Because of that unique nerve pathway from the inside of the nose directly into the brain it is particularly important to use caution, discretion, and close observation when exposing a child to a range of enhanced smell experiences. (For more information on these kinds of hypersensitivities see [www.handle.org/miscinfo/environ.html](http://www.handle.org/miscinfo/environ.html)).

6. Hypersensitivity might be reduced if essential oils are used to provide certain smells rather than an impure source like an aerosol spray or some other type of air freshener. Essential oils are powerful chemical substances, however, so should only ever be used after consultation with an aromatherapist. Essential oils can be used in massage sessions, and this is one activity where it seems like a very good idea to introduce a consistent smell in the massage lotion to help to 'label' the activity for the child with deaf-blindness. If used in a massage lotion these oils will be absorbed both through the nose and through the skin so it is particularly important to consult an aromatherapist and to follow all safety guidelines. For massage purposes any essential oil should always be greatly diluted in a bland carrier oil, and the dilution needs to be greater for young children than for adults. Many specialists recommend that no essential oil be used in massage lotion for the very youngest infants, and then only essential oil of lavender or chamomile be used with older children (both of these oils are said to have calming, soothing properties).

With thanks to CDBS

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## **Listen 2 Me 4**

**A conference for deafblind and disabled people and their families:**

22 - 27 August 2008, Glasgow, Scotland

Sense Scotland is proud to be hosting the fourth Listen 2 Me conference in 2008 for deafblind and disabled people and their families. This is a fantastic chance for families across Europe to meet and find out about groups like the European Deafblind Network, Hilton Perkins, Lega del Filo d'Oro and of course Sense Scotland.

Accommodation for visiting families will be found a short distance away from the conference venue at the Campanile Hotel in Glasgow. The cost per delegate is 350 euros. English will be the language used throughout presentations and workshops. The programme will be developed in consultation with families, deafblind and disabled people and other agencies. The conference will include:

- workshops, presentations and plenary sessions both by and for families, support staff and specialists
- speakers will include William Green - Lega del Filo d'Oro, Ursula Heinemann, Sabine Kersten, Paul Hart and Ricard Lopez who will be part of the international parents panel
- the chance to share ideas and experiences with families from across Europe
- opportunities to develop communication through a wide variety of creative approaches and the chance to explore the aspirations of deafblind and disabled people and their families
- a full programme of social activities including family get-togethers and excursions
- the chance to take part in arts, music and drama activities at the fantastic new TouchBase resource

To register an interest and find out about the conference, fill out the online form at [www.sensescotland.org.uk](http://www.sensescotland.org.uk) or contact:

Listen 2 Me 4

Touchbase,

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## **Being happy in our own skin**

### **Dance therapy has a lot to offer deafblind people...**

Mea Nordenfelt is a Dancer, Dance Teacher and Dance Therapist. Mea has been working as a dance teacher for more than 20 years, both with children and adults. Mea has experience of working with deafblind people, and since 2006 as a dance therapist.

## **Therapeutic dance**

Is it possible to develop communication through complementary ways? This article describes the development of mutual experiences through music, dance, movement and body action. It describes a project which aims to explore possibilities for contact, social interaction and communication.

Communication is difficult and complicated for deafblind people. This problem in communicating with others affects deafblind people very severely when it comes to their ability to make contact and interact with their surroundings. The creative arts offer a variety of routes to expression and thereby strengthen communication.

The lack of deafblind habilitation can result in aggressive behaviour, passivity, emotional and social problems. Many deafblind adults are passive, due to lack of experience of good interaction. It is important for the adult congenital deafblind person to demand more from their social surroundings and support. A response from their surroundings is a prerequisite if the deafblind person is to regain the desire to explore the world around and to be more motivated in interactions with other people (Nyling, 2003).

## **The Project**

The project was based on four sessions during one month, focussing on an individual way of working with a congenitally deaf blind person. To evaluate and to document the work, all the sessions were filmed and analysed. The documentation was based on the films and collected experiences from previous work with deafblind people. It had a psychodynamic perspective, based on dance therapeutic methods, as this is my area of interest and expertise. It describes mutual experiences and their development through music, dance, movement and body action. The aim was to explore possibilities to contact, social interaction and communication.

The project was supported by Iréne Karlsson Marki from Resource centre Mo Gård and Lena Hammarstedt from the Swedish Resource Centre for Matters regarding Deaf Blindness.

In the sessions I used my own body movements, sounds, rhythms as well as physical contact to gain the attention of my partner. I also used musical instruments and different props, like bean bags, scarves, balls, pillows etc.

## **The basis of the study**

The project was based on a number of key principles.

- Everybody can participate in their own way – right and wrong does not exist

- Success originates from an individual's own presumption
- Communication through music, dance, movement and bodily interaction is possible without using tactile language or any other language
- Work is only with the deafblind person's own movements, sounds, and body expression
- Create a confident atmosphere, both mentally and physically, the holding environment
- Have a playful, flexible and tolerant atmosphere, taking care of creative resources. This will increase the joy and give courage to be more daring to explore ourselves through dance
- Be unprejudiced, have very sensitive ears and to be open for situations here and now

This will lead to:

A strengthening of the bodily anchorage, creating more stability, and improve self esteem by giving more opportunities to arouse experience and happiness.

### **Dance and Music are communication!**

In dance you express something as you execute a movement with both your body and your feelings. Dance and music is also about rhythm, timing, sounds and song. With dance and music you can arouse your own joy and happiness, and at the same time you also can arouse other people around you, and in doing so, connect internally and with others at the same time. Dance and music give you power and energy: they give you joy and a feeling of affinity with other people.

### **Understanding our body image and its importance**

Using body contact and touch of different kinds a constant flow of sensory signals are experienced – even though the senses of hearing and sight are missing. Our skin is the greatest sensory organ. Touch is necessary for our cognitive experience and reactions and, as a result, it also affects our feelings. (Langlo Jagtøien, Hansen, Annerstedt, 2002).

Grönlund (1988) stresses that understanding our body requires both an intellectual and an emotional knowledge. Birkestad (2004) claims that touch is basic for our understanding and knowledge of our body. By touching different parts of the body we create a map of the different parts of our body, and feel our body image boundaries.

Our sensory impressions from our body must be organised by the brain to be able to create self-knowledge, understanding and a picture of our body – the body image. Our body image is the foundation for our body awareness and stays

in our nervous system, providing a foundation for all the planning and control of our movements (Langlo Jagtøien, Hansen, Annerstedt, 2002, p. 53).

The body image is essential to how an individual moves and how the body phenomenon is understood. It has a great influence on all interaction with other people; it is emotional and constantly changing. The body image is based primarily on kinaesthetic and tactile input (Duggan 1980, p. 49).

A positive and realistic knowledge and understanding of their body provides a confident personal identity and becomes decisive for all the mental functions. A person with a disturbed understanding, or a lack of awareness in this area has no possibility to interpret, judge or to try to influence the world around him (Grönlund 1988).

## **Take your partners...**

### **Wilhelm**

Wilhelm (assumed name) was born 1945 with the diagnosis congenital Toxoplasmosis. Wilhelm was born blind with a hearing loss. He uses his hearing aids, when motivated, like when he is listening to music e.g. if I sing a melody he can easily catch it and sing along with me, but not with words. But we don't know how much he understands. He was paralysed when he was three years old, which affects his ability to move his left side. His physical balance is affected by his injured knee. Wilhelm likes bodily interaction, assuming that he is motivated for it, and likes to take your arm and put it around himself.

The behaviour, caused by deafblindness, has made it difficult for the environment and community to understand his specific needs. Wilhelm has, from an early age, been separated from his parents. His history, like many of the congenitally deafblind people, has largely involved long periods in hospital and different medications. On account of the lack of communication and personal development he has never been able to learn tactile sign language. Using his body and the bodily interaction is the essential way that he communicates.

### **A session with Wilhelm:**

Because of Wilhelm's unstable balance we worked sitting on the floor during the sessions. This is a simple example of how body understanding influences all intervention and communication.

The sessions were based on a "namesong". The namesong could gradually change into a bodysong in different ways. Together, in a playful atmosphere, it is possible to explore the different body parts. The session's show how the concept of "self", "you", and "we" can be experienced using a namesong.

We worked using the room space with me moving into different positions, by sitting in front, at the side and back-to-back during the session with Wilhelm.

We worked with:

rhythm, using singing, clapping and body movement  
coordination, by playing with beanbags putting them on different parts of the body and let Wilhelm pick or throw them away from his body

perception e.g. the tactile and kinaesthetic perception in the physical body  
contact, playing with beanbags and the auditive perception by singing and by using different music instruments

contact, for instance by moving closer to me or moving away from me or start to join me in the song

teamwork, for instance by sitting back to back feeling each back pushing and leaning towards each other and creating trust and confidence

fantasy and expression, which has to do with joy. In a playful and trusting atmosphere we have explored the possibilities of the body by using sound, body movement, different polarities and mirroring and with different props. During the sessions, using dance and movement, Wilhelm built up a more expressive body language. To do this it is essential to dare to play together and to use the body as a sensitive instrument. Being playful and exploring together means you can be humble and creative in our way of thinking and doing. During the session we developed our interplay and I believe that Wilhelm's body image and his self-esteem had been invigorated. Wilhelm's body was looking more "whole" and during the last session, Wilhelm held his arms together and knew they were connected with each other. It looked like Wilhelm could allow himself to enjoy his whole body and soul, and to begin to take better care of himself.

### **And now...**

Nowadays, it is clear that Wilhelm uses his whole body when he is enjoying life! He is explosive, curious and playful. When he gets structure in his life and when he is treated in a sensible and equal way, Wilhelm shows that he is a charismatic person with a desire for physical body contact. He has gradually developed his body movements and body awareness. This has directly affected his ability to care for himself.

### **And finally..**

The project resulted in the establishment of new dance therapy sessions. Dance therapy happens once a week with groups of three congenitally deafblind people and their helpers. The purpose of the therapy is both therapeutic and educational.

To have had the opportunity to work with Wilhelm was very instructive and important; especially with the statement from the UN Standard Rules in mind “that ensure that persons with disabilities are integrated into, and can participate in cultural activities on an equal basis.”

From my own experience I know that dance therapy has a lot to offer to deafblind people and these cultural expressive forms complement all forms of communication.

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<http://www.un.org/esa/socdev/enable/dissre00.htm>

## **The consequences of age-related sight and hearing loss**

### **Ole E. Mortensen and Bettina U. Møller**

The Information Centre for Acquired Deafblindness, Denmark

The occurrence of dual sensory impairment amongst older people has proven to be much more widespread than previously believed. Statistically, between 3.8 and 6.8% of people over 80 suffer from such a high degree of dual sensory impairment, that they fall under the definition of deafblindness.

But what are the consequences of dual sensory loss? What impact does it have on the everyday lives of old people? And what are the problems they are up against?

Such questions have led to a series of studies published in scientific journals over the last 10 years. We have studied 18 of these in detail to analyse their findings.

Despite their different approaches and methods, the articles have many things in common and unanimous conclusions, which demonstrate that

1. a dual sensory impairment has a major impact on the way older people cope with life physically and psychologically, and
2. there seems to be a higher illness and mortality rate amongst them than others in the same age group with no sensory problems.

But as the studies also show it is possible for older people with a dual sensory impairment to avoid some of the negative consequences, and achieve better quality of life if the hearing and vision loss is allowed for and – as far as possible – compensated for.

## **Functional level**

ADL (Activities of Daily Living) and IADL (Instrumental Activities of Daily Living) are terms which are directly related to a functional level, and which are often the central themes when discussing older people and their ability to cope.

ADL refers to the activities which belong to everyday life. Focus here is directed on an individual's own abilities in relation to such activities as eating, bathing, personal care, dressing, going to the toilet, managing stairs without support and getting around in general.

IADL refers on the other hand to more demanding, and often outgoing activities such as going to the bank, talking on the phone, shopping, preparing food and administering their own medicines and finances.

In an American study entitled "Dual sensory loss and its impact on everyday competence", a group of 5,151 older people over the age of 70 was studied, looking at the everyday competencies they use.

Those who reported dual sensory impairment, generally indicated that it had a major impact on both ADL and IADL – not surprising specifically in the case of the latter.

Twice as many older people with dual sensory impairment reported problems getting dressed as those with no such functional loss. Getting in and out of bed was even worse – with 2.5 times as many older people with dual sensory impairment reporting problems as those unaffected.

On the issue of difficulties when venturing outdoors, the risk was 86% greater for older people with dual sensory impairment than those with no sensory loss.

When it came to IADL activities, the study indicated it was more difficult for older people with dual sensory impairment to communicate via the phone and to manage their finances.



(The study compensated for impaired cognitive function levels influencing the ability of older people in general in this area.)

### **Higher risk of falls**

Another American study, "Vision impairment and hearing loss among community-dwelling older Americans: implications for health and functioning" (2004) took a closer look at the relationship between the functional level and dual sensory impairment in the over 70 year-olds.

The combination of the two functional impairments is strongly linked to poor quality of life, physical disability (particularly with regard to IADL), balance problems, falls, hip fractures and increased mortality rates compared to people with only sight or hearing problems or with no problems with either.

Amongst older people with dual sensory impairment, the risk of falling was three times higher than those without, whilst the risk of hip fractures was twice as high. They also reported problems with walking 4.3 times more than unaffected older people.

It's obvious that impaired sight plays a larger role in such instances. But the risk of falling, hip fracture and walking problems was also higher in the group of people with dual sensory impairment than in the group with only a vision impairment, which means that the loss of sight is not the only cause.

More problems related to ADL and IADL for older people with dual sensory impairment is also the conclusion in the two American studies "The prognostic value of sensory impairment in older persons" and "The effect of visual and hearing impairments on functional status", both dating from 1999.

### **Restrictions to social life**

The American studies also showed that a dual sensory impairment puts a restriction on the social lives of older people. Whilst 74% with no sensory problems reported that they had visited friends during the last two weeks, only 63% of those with dual sensory impairment had done the same. Older people with dual sensory impairment also had only half as much telephone contact to their friends compared to those with no sensory impairment.

33.7% of older people with dual sensory impairment reported that they would like to undertake more activities in their social lives, compared to 25.1% with only hearing problems, and 31% with only vision problems.

The studies also clearly indicated that a vision impairment has a much heavier impact on ADL and IADL than does a hearing impairment.

### **Psychological problems**

Cognitive problems (memory loss, confusion and associated difficulties) and depressive symptoms are amongst the most prominent psychological problems

for older people. And just as there is a link between an individual's functional level and illness, there is also evidence of a link between dual sensory impairment and such problems.

In the aforementioned study "Vision impairment and hearing loss among community-dwelling older Americans: implications for health and functioning" of older people over 70, the occurrence of mild cognitive problems – described as "confusion" – was 2.8 times greater amongst older people with dual sensory impairment than amongst those with no sensory impairment. In comparison, the occurrence amongst the visually impaired older people was 2.2 times greater and amongst hearing impaired 1.4 times greater than those without any sensory problems.

An Australian study from 2006 "Sensory and cognitive association in older persons: findings from an older Australian population" used a test – the Mini-Mental State Examination (MMSE) – on the 3,509 participants to indicate whether there were cognitive problems. Amongst those participants with dual sensory impairment, there were six times as many showing signs of cognitive problems than those in the group unaffected. (Amongst visually impaired the occurrence was four times greater than those with no sensory problems, and amongst hearing impaired occurrence was twice as great.)

Thus, these studies underscore the importance of being more aware of the risk of cognitive problems amongst older people with dual sight and hearing loss, whilst at the same time being aware that a dual sensory impairment can also be confused with cognitive problems – and vice versa.

### **More depressive symptoms**

When you consider the enormous stress that living with a dual sensory impairment puts people under, it is not surprising that it is also linked to depressive symptoms.

A Finnish study from 2002 of 470 older people over the age of 75 ("Combined hearing and visual impairment and depression in a population aged 75 years and older") indicated occurrence of depressive symptoms (measured using the Zung Depression Scale) 1.6 times higher in the group with dual sensory impairment than in the group with no sensory impairment.

The same trend showed in the 2004 American study referred to above ("Vision impairment and hearing loss among community-dwelling older Americans: implications for health and functioning"), in which the occurrence of depressive symptoms among older people with the dual handicap was even higher – namely 2.7 times that in the group with unimpaired vision and hearing.

A very similar result was found in another American study ("The effects of single and dual sensory loss on symptoms of depression in the elderly") from 2005, which analysed data from a major interview-based study of older people, which

included a series of questions on mood, energy, worrying, self-worth and other areas that are affected by depression.

The increased risk of depressive symptoms prompted the researcher conducting the study to conclude the following: "It is vital that professionals working with sufferers of dual sight and hearing loss are aware of the increased risk of depression or depressive symptoms developing, and that they run screening tests for them. Early diagnosis of such problems can lead to treatment or rehabilitation which can help the patient achieve or retain a high degree of quality of life."

Two other studies from Italy ("Sensory impairment and quality of life in a community elderly population") and Hong Kong ("Combined effect of vision and hearing impairment on depression in elderly Chinese") have shown a link between depressive symptoms and dual sensory impairment which is higher than in older people with vision or hearing impairment as well as in those with no sensory loss.

However, it is important to note that these studies all discuss depressive symptoms, and not depression in the clinical sense, i.e. as an illness in which a number of symptoms of a certain degree have to present at the same time.

## **Illness and mortality**

As we get older, the risk of a number of other illness and health problems rises for the whole population. But several studies indicate that the risk of illness and accidents rises higher for older people with dual sight and hearing loss – and the same applies to the rate of mortality.

The aforementioned American study "Vision impairment and hearing loss among community-dwelling older Americans: implications for health and functioning" (2004) showed there was a higher rate of occurrence of a number of illnesses amongst older people with dual sensory impairment than amongst those unaffected.

In people with dual sensory impairment the risk of

- high blood pressure was 1.5 times higher
- heart problems was 2.4 times higher
- stroke was 3.6 times higher
- arthritis was 2.2 times higher
- diabetes was 2.1 times higher

than in those with no sensory impairment.

Such illnesses naturally also play a role in the mortality of the group. A 2006 American study of just under 117,000 participants ("Concurrent visual and hearing impairment and risk of mortality") indicated increased mortality amongst (white) men and women with dual sensory impairment. Mortality amongst white men with dual sensory impairment was approximately 1.2 times higher than

amongst with no sensory impairments, whilst it was approximately 1.6 times higher amongst white women compared to those without sensory impairments. A somewhat smaller Italian study from 1995 of 1140 older people between 76 and 81 (“Sensory impairments and mortality in an elderly community population: a six-year follow-up study”) also believed there was a link indicated between the dual sensory impairment and higher mortality rates – but in the case of this study, this was seen only amongst men.

### **Possible explanations**

But what can a link between dual sensory impairment and physical illness and higher mortality rates be due to? The researchers point to two particular possible explanations.

The first is that these people may have been exposed to certain factors – such as smoking – throughout their lives, which can have an affect on sight and hearing as well as the development of certain illnesses.

The second is that dual sensory impairment has an impact on general quality of life, mood, functional level and social relationships, all factors which have been proved to have decisive influence on mortality amongst older people.

A third explanation is quite simply related to age. The occurrence of dual sensory impairment rises steeply with age, as does the occurrence of other serious illnesses. However, in the studies mentioned, the results were, of course, adjusted for age – i.e. allowance was made for this factor when calculating mortality – which means this cannot be the sole explanation.

### **Health-related quality of life**

Based on the concept of “health-related quality of life”, an Australian study from 2006 (“Association Between Vision and Hearing Impairments and Their Combined Effects on Quality of Life”) showed a clear link between dual sensory impairment and poor health-related quality of life.

Referring to a national study performed in the USA in 1994, the Australians point out that older people with dual sensory impairment have significantly lower health-related quality of life with a string of consequences, physical and psychological as well as their social abilities.

The American study “Vision impairment and hearing loss among community-dwelling older Americans: implications for health and functioning” is referred to several times because it describes the consequences in a number of different areas. This study also looked at health-related quality of life and highlights that older people who reported having a dual sensory impairment were significantly less inclined to report having excellent health” – only 7.7% of them did this, compared to 16.4% amongst those with no sensory impairment. Furthermore,

18.5% of those with dual sensory impairment reported to have decidedly “poor health”, compared to 6.7% of those with no sensory impairment.

The study “Surveillance for sensory impairment, activity limitation, and health-related quality of life among older adults – United States, 1993-1997” also indicated (not surprisingly) that chronic illness and functional impairment of for example vision and hearing, imposed severe limitations on activities and resulted in poorer health-related quality of life.

### **Focused action gives results**

The studies highlight in different ways the need for early action to compensate for the functional impairments which older people with dual sensory loss have to live with. A focused action is required that should lead to improving their general functional level and quality of life.

This is highlighted by – among others – the Italian study “Effects of sensory aids on the quality of life and mortality of elderly people: a multivariate analysis” which demonstrates that older people with visual and/or hearing impairments can be helped to enjoy old age despite the many obstacles encountered in their daily lives.

The study showed a clear link between sensory aids and quality of life, demonstrated in the form of a close relation between uncompensated sensory loss and poor quality of life – and on the other hand, between good quality of life and compensated (as well as possible) sensory loss.

One thousand, one hundred and ninety two (1192) older people between the ages of 70 and 75 living in their own homes took part in the study. They were those with:

- no vision and hearing problems
- vision and/or hearing problems who had received compensation
- vision and/or hearing problems who had not received compensation

Older people with the right sensory aids – even those with dual sensory impairment – indicated they were in a better mood, enjoyed a richer social life and had an easier daily routine than those who did not receive the necessary support and compensation, and who had to struggle harder to cope.

In fact, the study shows that the quality of life for older people with dual sensory impairment whose needs are compensated for as well as possible, is very close to the quality of life experienced by those with no sensory impairment at all.

For more information: [oem@dbcent.dk](mailto:oem@dbcent.dk)

## **Bergen welcomes**

### **7th Seminar of the Acquired Deafblindness Network**

**8-12 October 2008**

Activity, Ability and Participation: acquired deafblindness in all stages of life

Call for papers: the coordinating Committee would like to invite people to submit abstracts for the open workshops that will take place during the seminar. An Information pack is available in Braille, large print and CD Rom and gives guidance on how to complete your submission and what to do next

Our hosts: Statped Vest

Please contact: Grethe Nyborg: [adbn2008@statped.no](mailto:adbn2008@statped.no)

Closing Date: 3 March 2008

[www.deafblindinternational.org](http://www.deafblindinternational.org)

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**EDbN**



**Ricard Lopez**

## **EDbN (European Deafblind Network)**

The EDbN collaborated for the success of 1million4disability's campaign promoted by the EDF. Signatures were handed in to support disabled people at the EU.

Last 4th October, EDbN's representatives gathered together in Brussels with the other member organisations of the EDF in front of the European Parliament to hand in signatures to uphold the rights of disabled people. The Rond-Point Schuman witnessed the emotion of the audience when the exact number was announced: 1.232.771.

The campaign was promoted by the EDF (Disability's European Forum) and wants rights of disabled population to be protected in the European Union by means of effective legislation. It must fight against discrimination and must support the inclusion of 50 million disabled citizens in the European society. The EDF's president, Yannis Vardakas-tanis, emphasised that organisations need to work creating a "lobby" to defend the interests of disabled people and get an inclusive social model. Following the same patterns, Vladimir Spidla, European Commissioner of Social Affairs and Equal Opportunities, said that the common goal had to be an Europe without any difference between its citizens, regardless they had a disability or not.

On the other hand, the General Assembly of the EDF was held on the 5th October. Different matters and challenges for next year were discussed, such as working with the Paralympics Committee, citizens' access to health, creation of an Ethical Committee, disabled population's ageing, mental health and mass media, amongst others.

## **The Siblings Network**

### **Sabine Kersten reports**

During the the 14th Deafblind International World Conference in Perth/Australia in September 2007 the Special Interest Group on Families and Siblings provided a range talks and discussions about many aspects of the lives of families, including siblings of deafblind people.

Two siblings talked, in their presentations, about their experiences, offering advice for case workers, parents and siblings themselves. They were particularly supportive when it came to the sometimes delicate subject of sibling interaction. "The goal is to get siblings out of the dark and in people's thoughts as it is us siblings who will be responsible for our deafblind brothers and sisters in the future, and it will be us siblings that case workers and parents turn to when it comes to future programming" (Kathryn Weaver, Canada).

I think this illustrates the importance of services for siblings.

We are also very pleased and proud that the Sibling Network is now a member of the Dbl Council. I will be the representative for the Siblings Network. I think this will enable us to raise even more awareness for siblings and for the (special) family situation in which we grow up.

We have also made an information leaflet about the network, which was presented during the World Conference. If you are interested in receiving this, please contact me.

Our plans for next year: The family event "Listen to me" is scheduled for August 22-27, 2008 in Glasgow, Scotland. During this conference we will present a programme for siblings who will join their parents. The programme will be a mixture of workshops, discussions and leisure/sports activities. For more information, please check the Dbl website.

For more information, please contact:

Sabine Kersten

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## **Tactile Communication Network**

### **Bernadette van den Tillaart**

Over the last half year, we have been working on an application for funding to produce a DVD. We are very grateful to Sense Scotland, Perkins School for the Blind/ Hilton-Perkins Program and Andebu Dovblindesenter, for their positive answer and their contribution! The DVD is designed to inspire families and professionals in their efforts to meet the deafblind person in the tactile world. The DVD will be presented as a training tool as well.

In October 2007, during an intense working week in Glasgow, filmmaker Andy Crossan and manager of IT Gareth Alexander joined us for the technical aspect of our work. In January 2008 we will have our next meeting in Boston.

To find out more about our work by getting in touch by email:  
fgenugte-tillaart@tiscali.nlf

## **The Nordic Cultural Network**

### **Lone Poggioni reports**

#### **Conference for parents**

I  
n the first weekend of May 2007 the Nordic Cultural Network invited parents of deafblind children from the Scandinavian countries to a conference in Kungälv near Gothenburg in Sweden. The parents really looked forward to meeting each other every three years, not only to exchange good and bad news about their lives but to listen to some good speeches, take part in debates and especially for have some very nice days together with other parents. Many of the parents have known each other for quite a long time so they have become real friends. The title of the conference was this year “Parents as experts in collaboration with those around them”.

Marie Creutz from the resource centre Mo Gaard in Sweden gave the opening speech. She was honoured to be invited to talk to the parents, she said, and it was her wish that after this conference there would be a better understanding between the parents and the professionals. This is because so much more can be achieved for the deafblind child when professionals and parents co-operate! She focused – among other things – on how nice it will be to secure a good quality service in all aspects with the deafblind child. But – as she said: “Who decides what is quality and how do we recognize it”?

These questions started a very animated debate between the nearly 50 participants.

During Saturday and Sunday families discussed in small groups ideas about the role of parents, how to network and collaborate and positive communication and its value.

## **Courses for deafblind adults**

In 2007 we had 3 courses with a total of 30 deafblind adults' and 62 companions.

1. "Individualized art courses" on the island Gotland, Sweden. 7 persons from Denmark Norway and Sweden attended
2. "Nature sculpture course" at Johnsgaard Turistcenter, Sömådalen, Norway 9 persons attended
3. "The language as art in the music" at Slettestrand in Denmark and 14 persons attended

The Nordic Culture Network has organized courses for deafblind adults since 1996, and the deafblind person and the professionals look forward to participating. participate at one of the courses, because it means fun, meeting old friends, we meet in lovely places in a relaxed way.

We have been encountering funding difficulties this year and really hope that we will be able to find the support we need to continue to provide these courses, which are valued so highly. We are searching for a solution!

Acquired Deafblindness Network AdbN

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he Co-ordinating group of ADBN met in Lucern Switzerland on 1-2 December to make further progress on the programme for the 7th International seminar, which will take place in Bergen, Norway between 8-12 October 2008.

The title of the Seminar will be, "Activity, Ability and Participation in Acquired Deafblindness in all stages of life". The first announcement has already been issued, with a call for papers. These should be submitted by 3 March 2008.

The Co-ordinating group of ADBN looks forward to receiving papers and to hosting the 7th of its successful International seminars.

Ges Roulstone  
Chair, ADBN

## **12th Usher Study Group**

**Perth Western Australia Sept 24-25th 2007**

**Mary Guest writes this report but is retiring as contact person for the Usher Study Group, which she has helped to coordinate since 1985.**

'Out of isolation and into the worldwide Usher family', was an appropriate title for the 12th meeting of the Usher Study Group in Perth. As the planning got under way it was fortunate that we had the keen support of Robin Hamilton and Sue-Ellen Buckley at the Senses Foundation in Perth. Robin told us that they were only in contact with 14 people with Usher in the whole of W.Australia and that having the Usher Study Group come to Perth would help to end this sense of being so cut off.

The programme included advances in medical research, outreach in Venezuela, employment in Germany and the UK, building support groups, and some excellent personal presentations from 2 families with Usher in W. Australia. We had a strong contingent from ABLE Australia Services from Melbourne, Victoria with a dynamic presentation from Heather Lawson who has Usher 1.

Prof Claes Moller who has collaborated with Prof Bill Kimberling for many years working on the clinical and genetic aspects of Usher syndrome shared some findings from Swedish studies. More recent studies suggest that Type 1 Usher is present in 10% of congenitally deaf children. Some data indicate that Usher Type 2 is almost twice as frequent as Type 1 and although there are geographical variations worldwide (the prevalence of Usher Type 3 is much higher in Finland, for instance) the estimated frequency of Type 2 Usher is about 7.1 per 100,000. Prof Moller suggested that overall the frequency of all Usher types could be 'guesstimated' at > 10 per 100,000.

Prof Bill Kimberling, who works on the genetics of Usher syndrome in Omaha, left us with some positive thoughts from research said that, 'our understanding of Usher syndrome brings us to a new and exciting age where serious thought is being given to treatments that slow, prevent and even 'cure' this group of disorders'. At least two clinical trials are underway and there is a need now to develop and infrastructure to facilitate future trials. He expected 'significant progress to be made within the next 20 years'.

I hope that as a result of holding the 12th Usher Study Group in Perth that the folk in W. Australia feel that they are now part of a worldwide Usher family!

# **Usher Syndrome study group**

## **Living with Ushers**

**Lachlan Dainton from Western Australia gave this paper at the 12th Usher Study Group meeting in Perth, September 2007**

“Hello, I hope you are all benefiting from this workshop. I am already gaining a lot just by preparing for this talk.

I am 36 years old and I have Usher syndrome type II or III, right now I am not certain of which but I do know that I have both hearing and vision impairments. My hearing loss is at around 80% which is moderate to severe. The vision loss is around 30% of field vision, the eye condition is called RP (Retinitis Pigmentosa) but the central vision is pretty good for everyday use. The hearing loss occurred when I was about eight months old caused by German measles or rubella. The vision loss became noticeable when I was about 23 years old, so I had the benefit of some 25 years of clear vision.

The combined sensory impairments have impacted on me quite a lot in many different ways. The most significant is, as we all now know, common to deafblind people is communications or more importantly socializing. I find it very difficult in being comfortable in large group situations especially where there are total strangers. I have learnt and still learning that it's better not to assume the worst scenarios, not to think about the worst but the better aspects of things and people. Learn how to be on cloud nine! It is better to focus on something pleasant rather than think about the worst or the most negative thoughts. I find taking on these more positive attitudes really helps me to cope with difficult situations. Sometimes its best not to ponder, not to think at all, but just relax and hope for the best and learn how not to look for people's worst reaction. I am learning how not to be so negatively sensitive to others' reactions.

Life experiences also help one with maturity, and dealing with different situations more positively. Learning how to be a good giver really adds to ones sense of self worth. This also applies to being able to help others. There is always somebody who needs words of encouragement, words of insight or just simply sharing a harmless joke. Even better just helping them in some form or another is good. Always be willing to learn from others on their life experiences when you can.

I have been most fortunate in the things that have happened in my lifetime such as good education, good upbringing and plenty of good experiences to reflect on. I have several hobbies which I immensely enjoy which are woodworking and computing and have gained employment in these fields as a result. By doing the

hobbies as a job really helps in doing the work because you can do it better when you are naturally motivated and work hard at it. Being motivated and interested in the work also helps overcome some of the difficulties related to disabilities.

Right now I have two part time jobs, one job as an IT Support at a place called PEP Community Services and the other as a casual factory hand in a warehouse.

The IT job is one day a week at the PEP Community workplace which I am very happy to be associated with and have been for the last four years. I am most happy when I can solve problems and be of help to the organisation. The PEP staff treat me well and they are always very encouraging, it is a great pleasure to be there socially as well as for the work.

The other job is at the Trophy warehouse; my main role is preparing the wood blocks of different sizes and shapes by sanding them on the belt sander. It is fairly labour intensive and requires a fair amount of concentration. I have only been working there for the last month or so as a casual. It is nice to have the extra income and more money to play with. Due to my interest in woodworking I can do the work competently with good quality and consistent productivity which the boss really appreciates. From this casual job I have learned simple practical things that will make a big difference in my own workshop so it's been very beneficial working in the warehouse.

I have worked in many different fields, industries and different situations; my main aim is to do something that is intellectually stimulating and useful. I spend a lot of time on the computer, having completed an IT course. I could further my studies in this field which I may do at a later date. Right now I just want to create my own work at home in making lots of wood crafts with the hope of selling them. I don't think much about my disabilities because I have avoided my worst case scenarios and just plain sail! In other words I just enjoy the best that life can offer. There is no point in feeling sorry for oneself, no point in trying to do things that do not gel with you and your disabilities. Do the things that you know that you can do and improve on them. That's what I try to do by keeping myself occupied with things that keep my mind busy and focussed."

Email:

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### **Comment from Mary Guest, Principal Research Officer, Sense, UK.**

Lachlan's reference to Rubella as the cause of his deafness when the deafness was noticed at the age of eight months is not surprising. Many people who have

Usher syndrome have been told that the reason for their childhood deafness was because of maternal Rubella.

Although the symptoms of retinitis pigmentosa may occur before the age of 20 a diagnosis may not be made until adulthood. Thus the reason for the hearing problem and the vision problem may seem to have two differing causes when in fact in most cases both the hearing loss and the vision problems are caused by one of the Usher faulty genes.

Maternal Rubella is not the only reason given to families to explain their child's deafness. A difficult birth, 'blue baby', a virus in infancy, a bad bout of measles have all been cited by parents and people who have Usher as to why they are deaf. In spite of a firm diagnosis of Usher in later life these early beliefs in the cause of the childhood deafness often linger on in the family medical history. In a few cases, the cause of the deafness may not be connected with retinitis pigmentosa, but for the majority the cause of both early deafness and retinitis pigmentosa will be a form of Usher type 1 or Usher type 2 or another RP related syndrome. (In Usher type 3 deafness and RP seems to occur in adulthood). Professionals involved with diagnosis of retinal dystrophies need to think about the implication of hearing loss in the diagnostic process. If the answer to the question, 'do you' or 'does your son/daughter have any form of hearing loss' is 'yes' then this needs further investigation as it could lead to a more accurate diagnosis.

This in turn could lead to better management of the Usher or RP related condition and also to being aware of clinical trials and possible treatments in the not too distant future.

## **Working together towards Transition**

**This article discusses the importance of transition activities in school. The author demonstrates how through a single activity the priority needs of deafblind children can be met and how it is possible to weave in various learning experiences through an age appropriate activity.**

Dipti Karnad from The Clarke School for the Deaf, Chennai, India describes the principles and process she applies activities that support young people to make the transition to adult life and the world of work



## **Life is full of transitions**

For all of us life is full of transitions. It is the same for the deafblind child. He transitions from the security of the home, an early childhood education or preschool program, a centre based program either in a Special School or an integrated set up, from one educational setting to another (school to college) or from school to adult life in the community.

Attention to this transition should improve the relevance and effectiveness of educational services as well as ease the movement to other services after a student leaves school. Education should help the deafblind student to learn the skills he needs to lead a successful and enjoyable life as an adult.

Planning for transition to adult life should begin early.

In this planning process one should consider the young person's goals and dreams about adult life, his aptitude and preferences. Everyone should work towards the same dream. – an adult lifestyle based on the student's preferences, abilities, and network of support.

## **Transition to the “world of work”**

Transition is not only moving from school to work but there are other areas also that need to be considered as to why we work.

- We work for money : Work makes a person economically independent and contributing member in society.
- We work for social reasons: Most of our acquaintances are people we have met at work. Our co-workers become a social circle for us.
- We work to feel good about ourselves: Our self-esteem gets a boost when we are involved in competently performing tasks and we contribute to the world around us. Though there may be frustrating times in the workplace, the pride we feel from a job well done makes work a positive experience.
- We work to gain the respect of others – receiving the respect of the people around us not only helps us emotionally but also often influences the way others treat us.
- Work provides us with a stable routine – we know when and where we have to be in the morning and having a predictable structure for our day.

## **Types of Employment**

In the community there may be various types of employment, starting from self-employment to highly structured sheltered employment. The choice of jobs available could be highly culture specific or region specific. The job environment is also highly important since it is not only the working and earning for the self that is involved, but rather the opportunity to be with people that is of tremendous value.

It is during this stage that the team is involved in identifying the type of employment that is most suitable for a particular student. Sometimes the expectation of both the child and the family is to start an enterprise – big or small themselves. In such circumstances, depending upon the child's level of functioning, the family members play an active role in supporting the child. In this situation, the entire team then closely look at the factors involved in self-employment.

With the lack of a law to support transition planning in India, word of mouth and positive interaction with deafblind/blind multi handicapped students' play a substantial role in making breakthroughs for supported employment. In this case a specific job within a work site where the student can work with the support of professional staff and the available co-workers has to be considered. Many environmental modifications, social integration and mobility issues need to be taken care of.

A sheltered workshop is quite popular in certain regions. For the more severely involved students this works out to be the more viable alternative where they work with regular support in a highly structured environment. The special students could be a part of the workforce comprising of skilled or semi-skilled workers from the mainstream community. This facilitates social interaction in a more closely monitored atmosphere. Sometimes the deafblind/blind multi-handicapped students with different degrees of involvement comprise the entire workforce. They have specific duties to perform within the larger job demands. With regular inclusive activities during leisure time and community participation occasions, this arrangement also benefits the students.

There is also Open Employment – the most challenging job situation, wherein the students get training and eventually get a job in the open job market, with professional support gradually reducing to a level that is tolerable to both the student and the employer. The work area is clearly defined and the worker has an understanding of what is expected for output from him/her. However with the students with more severe involvement this arrangement may not work out to their best advantage.

### **Identifying Potential Jobs at School.**

At a time when one is looking for jobs in the community it is essential to expose the students to many 'job-like' situations while at school itself. Almost every school or training centre can think of many different errands or specific work that the student can learn to participate in and perform. These 'jobs' are routine work at school that is probably carried on by some of the other staff members. At times certain jobs can be created or further divided so that a student gets an opportunity to perform the same work successfully.

A cleverly designed functional curriculum makes use of many such job opportunities as training experience for the students. For example, a student may

be expected to pick up the class attendance registers and deliver it to the right class daily or she may be assigned to prepare tea at the canteen for the other workers or simply help in the serving tea, cleaning the cups and stacking them on the right shelves.

Allowing a student to have hands on experience of a job while at school leads to many advantages:

- The student begins his work experience in a familiar non-threatening environment.
- The rate and speed of learning and the coping mechanisms of the student is observed in a more closely monitored setting.
- The student starts developing the many prerequisite skills like reporting on time, being aware of ones own responsibility, taking instructions from the supervisor, asking for help etc. in a contextual manner.
- Gives the teacher an opportunity to strengthen the repertoire of job related skills e.g. time money management, mobility, self-care, leisure and recreation, communication skills along with the different types of specific trade skills.
- The whole team – child, family, professionals, gets a possible idea regarding the actual placement of the student.
- Learning the skills in the school environment will save time once the student is placed at the job situation. This would lead to positive experiences for both the employee and the employer.

## **Transition Planning**

Who takes part in the planning?

- The student
- Family
- Educational Staff
- Significant Community Members.
- Teacher Trainee

## **Whom are we talking about?**

The three young people

- Varun Govind who is a 15 year old boy with retinitis pigmentosa, cerebral palsy and mild learning disability.
- Vijaykrishna, a boy aged 15years, deafblind since birth, has light perception.
- Lokesh, also aged 15 years, totally blind with autistic features

**What is the activity?**

- **ACTIVITY** – making packets of groundnuts to be sold in the school at snack time.
- **TIME OF ACTIVITY** – One hour before snack time.
- **PLACE** – Vocational Class
- **PERSONS INVOLVED** – Three students aged 15 years with varying levels of visual impairment, hearing impairment and cognition.
- **STAFF** – Pre Vocational Teacher and Teacher trainee

**What are the priority areas to be developed through this activity for each young person?**

VARUN	VIJAYKRISHNA	LOKESH
<ul style="list-style-type: none"> <li>• <b>Fine Motor Skills</b></li> <li>• <b>Mathematics</b></li> <li>• <b>Orientation and Mobility</b></li> <li>• <b>Socialization</b></li> <li>• <b>Communication</b></li> <li>• <b>Money Concept</b></li> </ul>	<ul style="list-style-type: none"> <li>• <b>Communication</b></li> <li>• <b>Interaction with peers</b></li> <li>• <b>Functional Mathematics</b></li> <li>• <b>Work</b></li> </ul>	<ul style="list-style-type: none"> <li>• <b>Communication</b></li> <li>• <b>Socialization</b></li> <li>• <b>Orientation and spatial skills.</b></li> <li>• <b>Work</b></li> </ul>

Goals of activity

Long term goals-

- To work in a group towards transition each according to his own needs.
- To develop related skills required in a work set up through partial participation.

Short term goals

<b>VARUN</b>	<b>VIJAYKRISHNA</b>	<b>LOKESH</b>
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Student 1	Student 2	Student 3
<ul style="list-style-type: none"> <li>▪ Will learn to make paper cones first under supervision and then independently.</li> <li>▪ Will count the number of readymade cones.</li> <li>▪ Will move safely within the school premises to sell the groundnuts packets.</li> <li>▪ Will use appropriate language in order to communicate.</li> <li>▪ Will count the unsold packets and money received.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Will receive empty cones from Student 1 when he is touched on the forearm/wrist.</li> <li>▪ Will fill up the empty cones with a suitable measuring cup.</li> <li>▪ Will pass one the filled up cone to Student 3 by using suitable touch cues.</li> <li>▪ Will sit at the job for at least 30 minutes.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Will receive the cone from Student 2 when touched on forearm or wrist.</li> <li>▪ Will tolerate touch</li> <li>▪ Will fold the top of the cone.</li> <li>▪ Will place the cones from left to right on a tray.</li> <li>▪ Will sit at the job for at least 30 minutes</li> </ul>

Skills that will be developed through this activity

- Language and Communication
- Fine Motor Skills
- Gross Motor Skills
- Mathematics and money concept.
- Literacy
- Socialization
- Work Habits

- Orientation and Mobility

Working in a group

- Varun makes paper cones.
- Varun hands over the paper cone to Vijaykrishna.
- Vijaykrishna measures a certain amount of groundnuts to fill the paper cone. And tips them in to the paper cone.
- Vijaykrishna touches Lokesh's forearm and Lokesh is ready to receive the filled up paper cone.
- Lokesh stretches his hand to receive the filled up cone, while Vijay waits for the empty cone from Varun.
- Lokesh folds the top of the paper cone filled with groundnuts.
- Lokesh places packets in tray from left to right.
- Varun counts the packets.
- Varun sells groundnuts in the various units of the school.
- Varun counts unsold packets.
- Varun counts the money

### **Varun's Goals and outcomes**

<b>SHORT TERM GOALS</b>	<b>OUTCOMES</b>
<ul style="list-style-type: none"> <li>• Will learn to make paper cones first under supervision and then independently.</li> </ul>	<p><b>Through this activity the student has learnt :</b></p> <p><b>To make paper cones independently.</b></p>
<ul style="list-style-type: none"> <li>• Will count the number of readymade cones.</li> </ul>	<p><b>To count number of readymade cones.</b></p>
<ul style="list-style-type: none"> <li>• Will move safely within the school premises to sell the groundnuts packets.</li> </ul>	<p><b>The outlay of the building and move around safely in the school building.</b></p>
<ul style="list-style-type: none"> <li>• Will socialize with staff and students of other Units of the school</li> </ul>	<p><b>To socialize with the staff and students of the other Units of the school.</b></p>
<ul style="list-style-type: none"> <li>• Will use appropriate language in order to communicate.</li> </ul>	<p><b>To use appropriate language to communicate</b></p>

Will count the unsold packets.	To count number of unsold packets.
Will count money received.	To count money after selling the groundnut packets.

### Vijakrishna's Goals and Outcomes

SHORT TERM GOALS	OUTCOMES
<p>Will receive empty cones from Student 1 when he is touched on the forearm/wrist that is responding to and receiving a touch cue.</p> <p>Will fill up the empty cones with a suitable measuring cup.</p> <p>Will pass one the filled up cone to Student 3 by using suitable touch cues expressively.</p> <p>Will sit at the job for at least 30 minutes.</p>	<p>Through this activity the student has learnt :</p> <p>To communicate with others and to tolerate other peoples' touch.</p> <p>To measure out an exact amount of groundnuts -this is a skill in mathematics.</p> <p>To interact and work with his peers, that is receiving and passing on filled up cones (a beginning in working on the assembly line)</p> <p>To sit at a job for at least 30 minutes.</p>

### Lokesh's Goals and Outcomes

SHORT TERM GOALS	OUTCOMES
Will receive the cone from Student 2 when touched on	Through this activity the student has learnt :

<p>forearm or wrist.</p> <p>Will tolerate touch</p> <p>Will fold the top of the cone.</p> <p>Will place the cones from left to right on a tray.</p> <p>Will sit at the job for at least 30 minutes</p>	<p>To understand that others are communicating with him</p> <p>To tolerate others touching him.</p> <p>To fold the top of the cones.</p> <p>To place cones from left to right on the tray which is a pre requisite orientation and mobility skill needed for Braille reading.</p> <p>To sit at a job for at least 30 minutes.</p> <p>To do an age appropriate meaningful activity.</p>
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## CONCLUSION

- The students have started developing the many prerequisite skills: reporting on time, being aware of ones own responsibility taking instructions from the supervisor, asking for help etc. in a contextual manner.
- The teacher has got an opportunity to strengthen the repertoire of job related skills: time money management, mobility, self-care, leisure and recreation, communication skills along with the different types of specific trade skills.
- The whole team – child, family, professionals, have got an idea regarding the actual placement of the student.
- Through this activity there is a thrust to becoming an economically independent and contributing member in society.
- The three students have made a social circle among themselves.
- The appreciation from the teacher, parents and significant others from a job well done makes work a positive experience.
- These three students are receiving the respect of the people around them and this has helped them emotionally but also often influences the way others treat them.



- This activity has provided a stable routine and the students know when and where we have to be at a particular time of the day and to anticipate the activity to be done.

Thus through this activity, it has been our endeavour to develop skills needed for each student towards transition according to their chronological age.

## **Advocacy creation for deafblind people – a new initiative in Brazil!**

### **Márcia Maurilio Souza and Shirley Rodrigues Maia report**

Brazil is more than 8 million square kilometers in size, is divided in 5 regions and has cultural, as well as, development differences. The most developed areas are in the south and south east as the information arrives sooner there and as a result there are more educational and health resources as well as the established services for deafblind people.

To get over these differences the network called GRUPO BRASIL and AHIMSA – are developing a new course with the financial support of education ministry. This course offers knowledge on deafblindness and multiple disabilities in order to help create programmes and improve the services in other regions of Brazil. The courses are for special educators, government school coordinators, health professionals (doctors, physical therapists, speech therapists, and psychologists), sign language interpreters, family members and deafblind people. The participants are from the main cities chosen from 118 municipalities in the Brazilian states and they are offered the chance to pilot ideas about information sharing and to be trained in advocacy.

In 2006 we offered 3 courses. Two were in the north region and one in the north east. In all 156 people attended. This was very pleasing.

The course content is delivered in 60 hours of theory and practice. Some of the topics covered include: congenital deafblindness, the family, early intervention, acquired deafblindness, the guide interpreter, the intervener, O&M and reading and writing. The participants work as a group to evaluate the needs of the region and make an action plan for deafblindness and multiple disabilities. Also they have the chance to observe some services.

We had marvelous participation from professionals from GRUPO BRASIL with the coordinator, Shirley R Maia, and many of the other talented professionals. The result is that we have demand for the courses and we are getting the information through the reports of the action plan. The number of deafblind and multiple disabled children and young adults identified has increased and there are improvements in support.

Developments are ongoing in Brazil. In 2005 and 2006, through the educational ministry program called diversity and inclusion, the professional staff of Grupo Brasil offered seminars about deafblindness. As a result, of these courses for trainers were started and a school census by the educational ministry initiated. It showed that the number of deafblind children on the register in schools increased from 1.126 in 2005 to 2.773 in 2006; and from 66.000 multiple disabled children in 2005 to 74.405 in 2007.

For 2007 we have delivered 5 more courses in deafblindness and multiple disabilities for each region of Brazil. Two hundred people have participated. We now have a special office for professional guide interpreters, sign language interpreters and teachers of the deaf in the north, north east regions, and also vocational programs for congenital and acquired deafblind people, families with young children, and an information materials service.

We continue to press the government to assume responsibility for all deafblind people and their families.



# Co-Creating Communication with Persons with Congenital Deafblindness

## Theory and Practice

Wednesday 8th - Saturday 11th October 2008  
The Royal Armouries Museum, Leeds, UK

### The Programme

The conference will address four themes

8 October 2008 – Dialogicality

9 October 2008 – Joint Attention

10 October 2008 – Gestures and Mimetics

11 October 2008 – Language

*This conference will address four key aspects of human communication. Each aspect will be addressed by two lecturers: one who is an eminent specialist in the area of study and one from the field of deafblindness. On each of these topics, new insights are expected to emerge by bringing together the latest scientific developments and current practice in congenital deafblindness. This conference will build on the work already developed at previous courses and conferences on the topic of communication.*

*These four topics were selected because they help to describe how life experiences and emotions form and flow dynamically over time in the encounter between individuals and the external world. This is where dialogicality and joint attention are key concepts. It will also try to describe how this flow of thoughts and emotions projects itself in the body, thus presenting partners of congenitally deafblind people with visible bodily forms (gestures) that they can interpret and react to.*

*These exchanges between inside and outside or between self and other can lead to the co-creation of stabilised forms and organisations of forms that constitute languages. Therefore, special attention will be given to how, in the case of congenital deafblindness, gestures are formed and processed and on how language can emerge from them in a natural way. The question of whether the existence of a specific "congenitally deafblind language" is relevant, stimulating for scientific research and useful for educational purposes will also be discussed*

### Register Now!

<http://www.sense.org.uk/professionals/co-creating+communication+conference>

For further information please contact  
[conference2008@sense.org.uk](mailto:conference2008@sense.org.uk)

*We look forward to seeing you in Leeds!*

## **Talking about Communication!**

**Kitty Bloeming works at “De Brink”, which is a residential centre in the Netherlands. She is one of the first successful students on the Master’s course in Communication and Congenital Deafblindness, based in Groningen. She describes the benefit she has derived from doing it – as well as the value for the people she works with!**

“Last year I entered the new international Masters level degree in ‘Communication and Congenital Deafblindness’. When I started, I had some experience in advising caregivers who work with persons who are deafblind and have intellectual disabilities. My aim was to learn more about the theoretical insights, current in the field, in order to improve my knowledge and the quality of the advice I give. In this way I wanted to make a contribution to the improvement of the interactions between persons who are deafblind and their caregivers.

### **The course**

After having finished the master for two months now, I can say that it has been very valuable for me. The theoretical knowledge appears to be very useful. Part of the lectures consisted of video analysis. The theoretical concepts that we were taught about were illustrated in video examples of interactions between persons who are deafblind and their caregivers. It takes a lot of time to really learn to observe what happens during these interactions. Expressions can be subtle or very different from what you expect! At first I noticed very little from what was happening in an interaction and I needed many repetitions of the same example to see and understand what had happened. But the time that I invested in this has definitely repaid itself! I am now able to recognise the expressive communication of the deafblind people much more easily now. And, very importantly it appears to be possible to transfer this skill to the caregivers who are working with the persons who are deafblind. I think that this is a huge achievement; by noticing more expressions and responding to these, we improve the lives of the people we are working with. They can start to understand that they can tell us something in their own way and that they will be listened to.

### **Fit the course to your work place**

Another strength of the master level course is the free choice for a topic for the thesis. Because the thesis is a large part of the qualification it is possible to fit the

course to your own needs. The working place of the students can be very different. For example they are working with a wide range of people. Of course these differences influence the kind of topics that are interesting to study.

### **My study**

I have chosen to do an intervention study on expressions based on a bodily emotional trace. Part of the study consisted of coaching four caregivers. Their skills improved, which lead to the fact that the persons who are deafblind immediately profited from the study.

Right now, I'm working as a special educationalist at De Brink, a residential setting for persons who have intellectual and sensory disabilities. Some of the residents are deafblind. I believe that the master course improved my knowledge and skills with regard to deafblindness. As a result of this, it is possible to improve the interaction and communication between the persons who are deafblind and their caregivers.

And this is what it's all about!"

(Details of this course are on page 36).

## **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 ECN1 .

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

DbI European Communication Network

Curriculum coordinator: Dr. Marleen Janssen

Address

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

1 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 videos, 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.

## **Regional News**

### **Spain**

#### **1st Post-Induction Training Course for Intervenors for Deafblind People**

During July 2007 the first post-induction training course for intervenors was organised in Spain. Thanks to the support from Sense (with special thanks to Asunción Snow, Jenny Fletcher and Mary Foster), 20 selected professionals among the most experienced in deafblindness from the whole of Spain received specific high quality training. This group will be the first to train other professionals. Several observers from the Spanish Ministry of Education and the Education Department of the Generalitat of Catalonia attended the classes. The course was held in Apsocecat's Resource Centre for the Deafblind and offered all the facilities, including simultaneous translation. Co-ordinators were Apascide, Apsocecat and Apascide-Ceuta. It was designed for intervenors for the deafblind who work on one-to-one basis with deafblind children and adults or multi-sensory-impaired persons. The main objective was to provide the participants with the theoretical knowledge and practical application in order to carry out their task as intervenors for the deafblind.

Ricard Lopez, Spain

## **Apsocecat, Associació Catalana Pro Persones Sordcegues (Catalan Association for Deafblind Persons), opens its first Deafblind Resource Centre**

On 17 September the Councillor of Social Affairs and Citizenship of the Generalitat of Catalonia (equivalent to Minister of Health and Social Affairs) inaugurated Apsocecat's Deafblind Resource Centre in Barcelona in the presence of important guests from the political and social scene. It was an important day for the 2800 persons with deafblindness in Catalonia, their parents, the professionals and the volunteers involved.

The priority objectives of this Resource Centre which were submitted to the Councillor are:

1. Undertake a census of the deafblind population, including those persons with additional disabilities to their sensory impairment.
2. Ensure the availability of personal assistants such as "intervenors in deafblindness", specifically trained and on a one-to-one ratio, in day centres, residences, etc, in every place where there is a deafblind person.
3. Create the first specific pilot day centre / occupational workshop for the Deafblind in Barcelona. This model would be exported in accordance with the geographical needs as determined by the census.
4. Build a specific residential centre in Catalonia.
5. Create a "Reference Manual about Deafblindness for Social Services" to be distributed to all social agencies in Catalonia.

Ricard López, Apsocecat

## **Canada**

### **CDBRA elects Carolyn Monaco as its new President**

Carolyn Monaco was elected as the National President of the Canadian Deafblind and Rubella Association at its recent annual AGM and Board sessions. She has returned to the CDBRA National Board of Directors after a short absence. Carolyn had been a long standing Board member of the National organization and served as the Ontario Chapter President for 6 years.



Carolyn worked with students with deafblindness at the W. Ross Macdonald School in Brantford Ontario and as a provincial resource consultant to schools and families throughout Ontario.

Currently, Carolyn is teaching in the Intervenor for Deafblind Persons Program at George Brown College in Toronto as well as providing training and consultation nationally and internationally.

Carolyn was the recipient of the CDBRA National Cherry Bulmer Award in 2005 “for making an outstanding volunteer contribution to the organization at both the Chapter and National levels”.

She was also the recipient of the AER Division III Samuel Gridley Howe Award “for outstanding practice in services for individuals with deafblindness and their families”.

Carolyn is excited about her new appointment and intends to continue to carry “the torch” to advocate for quality Intervention services for persons who are deafblind in Canada, and elsewhere. Like her predecessors, Carolyn will be proud to promote CDBRA, both nationally and internationally.

Stan Monroe

## **Ireland**

### **Deafblind Ireland holds its inaugural meeting!**

On 10th November more than 60 people with deafblindness, their families and professionals working in this field gathered in Longford to launch Deafblind Ireland.

The new organisation was the brainchild of Carol Brill, herself deafblind with Usher syndrome. Dissatisfied with the lack of sufficient appropriate services in the Republic of Ireland she sought the help of other interested individuals in launching the new organisation.

The meeting heard speeches from families which told of their isolation and anguish in struggling alone to cope with the needs of a deafblind child. Despite the presence of some small specialist services in the Republic of Ireland large gaps exist in identification and response to children who are deafblind or support to families. Also no reliable data exists in Ireland on the numbers of people with deafblindness.

The new organisation hopes to provide a service of support, advice and guidance to anyone who is affected by deafblindness and professionals working with them. The group will shortly be registered as a charity in the Republic and will

campaign for improvements in early identification and service provision to both children and adults.

Contact Deafblind Ireland on [www.deafblindireland.org](http://www.deafblindireland.org)

## **Scotland**

### **Sir Terry Wogan Launches TouchBase Family Resource for Sense Scotland**

Sir Terry Wogan, a well known television and radio presenter, has just launched Sense Scotland's new Children and Family suite in TouchBase. It was made possible by the £333,783 funding from Children in Need (the BBC Charity that funds developments for children in the UK). The event was an opportunity for Sense Scotland and Children in Need to celebrate this wonderful new space and for children and families to sample this unique new resource.

As well as drama, arts and music workshops people were treated to performances from a junk orchestra and two music sets led by deafblind people who use Sense Scotland's services.

Based in Kinning Park, Glasgow TouchBase provides innovative and fully accessible resource for disabled people, carers, families and the local community. Facilities and services include a day centre base for children and families, drop-in resources for adults, music, visual and performing arts spaces, community offices, training and meeting rooms for hire and a community café due to launch next year.

Gill Morbey, Chief Executive of Sense Scotland said "It has been a fantastic journey for us since Sense Scotland started working from a tiny office in the early 80's. This accessible and friendly suite will provide children and young people with a place to meet, experience new activities and above all have the time of their lives." Helen Duffy, whose son Anthony is using day services at the children and families suite after school and at weekends was full of praise for the centre as he has been experiencing lots of different arts experiences and its really helping him to enjoy new things.

## **Slovakia**

"I spent the year 2006 in England and Scotland. It was my pleasure to work in Overbridge in Glasgow with great staff and gain the experience I could use in Majak, the first group home for adults in Slovakia. Also I was very happy to visit some services for deafblind adults in Leeds where I was the guest of Bob and Asuncion Snow at Sense North. This was a nice package of experience that I brought home for my new job.

I would like to introduce to you Majak. Majak means Lighthouse and it is the only group home for deafblind adults in Slovakia. The Lighthouse was a dream of the Slovak parents who wanted to ensure the life of their deafblind children in adulthood. It took long time to change a dream to the reality. Six deafblind people came to Majak in January.

I have spent my life working with children but in 2007 I had started with them as young adults! My head was full of questions. What can I expect from these young adults? I had a new building, new staff and young people who had new habits, new vices, but still they were my children. I knew them very well. The first two months were very hard for me and for my staff. The young people accepted the new building, new environment and also new staff very well, but my new staff were inexperienced.

We organized training on deafblindness, but it took several weeks to know all clients, to understand their behaviour, to learn sign language and communication with every individual. Two of staff decided to leave Majak. I let them go as they weren't born for this kind of job. Step by step we negotiated all barriers and after 10 months of running our group home I can say that we can see the first results. We created the real home, where the service users feel very good and comfortable.

We organize the time of service users according to their likes and dislikes, everyday we have the circle time which supports their relationships with each other. Thanks to the circle we develop everyone's communication. Through different activities we develop daily living skills. We travel to city Kosice and every trip brings new experiences and skills to our young adults.

We found some volunteers, who come to Majak and play chess or other party games. The volunteers took our service users on trips to the mountains or the Aquapark.

The staff communicate with service users by sign language. Martin, Juraj and Peter speak by sign language fluently and they like to talk to and discuss things with the staff. Martin and Juraj told me that they were in two different homes for mentally retarded people, but they had no possibility to talk or be listened to and understood. It is special feeling to know that our services are appropriate for deafblind young people and they realize that they receive from us what they need.

Majak was established by the parents association and we cooperate with parents very closely. We organized the Family Camp with our clients and their families last summer. It was great opportunity to discuss with parents and solve our

problems together. We have our plan for the future. We would like to find some job possibilities for our service users and some new and different activities, which will support their physical and mental development.

Majak has not only got young service users, but also a young and very capable director Henrieta Hajdeckerova, who loves all the residents and staff. We have created with the help of their parents one very nice family! I hope our enthusiasm will keep on going, because we need to fight for the recognition of deafblindness in our country and for legislation that creates more opportunities for services like Majak to be realised.”

Janka Sarisska

## **UK News**

### **Usher Study Group**

#### **Mary Guest gives an update on this research project**

Since I last wrote Dr. Zubin Saihan and Dr. Nell Rangesh have completed all the vision, hearing and balance testing. In all 220 people with Usher underwent clinical investigations, which has provided extensive knowledge on vision, hearing and balance function in Usher syndrome in UK families. The process of matching up the genetic results with the vision, hearing and balance results is now the main task. This phase requires careful checking and rechecking before a result is confirmed and before this information can be offered to the family with certainty. Possible outcomes for recruited families include:

- both of the mutations will be found confirming the type of Usher and the gene responsible,
- only 1 of the mutations has been found. This will indicate the likely type of Usher and the gene responsible,
- neither of the mutations has been found which could indicate that the Usher is caused by a gene which has not yet been discovered. Or that the Usher is caused by mutations that are not detected by the current methods and that the DNA from this person needs further analysis.

Dr. Polona le Quesne (formerly Stabej) one of our molecular geneticists employed on the NCUS comments. ‘Deciphering such a complex condition as the Usher syndrome demands a lot of careful work and an excellent communication between patients, clinicians and scientists. The NCUS Steering

Committee has done a wonderful job at leading and connecting all the people involved and it has been a pleasure and privilege to be part of the project'. As the pace of molecular genetic research quickens collaboration between voluntary agencies who work with deafblind people and centres for clinical and genetic research may well become more commonplace.

## **Australia**

### **14th Deafblind International Conference 2007**

Congratulations to Western Australia's Senses Foundation who hosted the 14th Deafblind International World Conference from the 25th – 30th September at the fabulous Burswood Convention Centre in Perth. All feedback suggests that it was a highly successful conference with participants reporting in particular, high levels of satisfaction with the Scientific Program, the Social Program and the many other conference related activities. An informative report of this major international event can be found at <http://www.dbiconference2007.asn.au/>

Some 460 people registered for the event. The final number of registrants was 381 people from 37 countries (or groups of countries ie United Kingdom)  
The excellent Scientific Program featured the following four Key Note addresses:

- Technology and Disability: Where have we come from and where are we headed?  
by Ray Kurzweil of Kurzweil AI Networks
- Genetics and Deafblindness – Where have we been and where are we going?  
by Bill Kimberling, Professor of Biomedical Sciences, Boys Town, National Research Hospital, Omaha, USA., and Claes Moller, Professor of Audiology, Sahlgrenska University Hospital, Sweden
- Happiness as the Key to Success – But What is Success? Health, wealth or wisdom?  
by Paul Hart, Principal Officer (Practice), Sense Scotland, Scotland; and
- Deafblind futures: a route map from the conference and Dbl strategy  
by Tony Best, UK

There were over 200 presentations in concurrent sessions over the four days of the Scientific Program. The conference included a number of social activities and a wide array of other conference-related activities.

## **Census data on disability**

Australia's National Disability Services (NDS) reports that approximately 822,000 Australians have a severe or profound disability; that is, they need daily assistance with one or more of three core activity areas (self-care, mobility and communication), according to the first release of data from the 2006 Census. Approximately 372,400 of these people are aged less than 65 years. The 2006 Census of Population and Housing was the first to include questions on disability. NDS had advocated the inclusion of disability questions for some years and was represented on an ABS group which advised on the development and testing of disability questions.

Although the Australian Bureau of Statistics (ABS) conducts a survey of Ageing Disability and Carers every five or six years, this does not provide the local area data valuable for service planning that the Census will provide. The first release of data on disability by local area is now available free of charge from the ABS website [www.abs.gov.au](http://www.abs.gov.au). The ABS will provide further information and analysis based on the 2006 Census over coming months.

Census data indicate that a higher proportion of Tasmanians (5%) and South Australians (4.8%) had a need for assistance than the national average (4.1%). For the first time the Census also asked a question on unpaid assistance to a person with a disability. It measured the population over the age of 15 years that, in the two weeks prior to the Census, provided unpaid assistance to a person with a disability, long-term illness or problems related to old age. Around 1.6 million Australians over the age of 15 provided unpaid care on this basis. 62% were women.

## **Electronic Voting**

Voting in Australia is compulsory and those who do not vote are fined. Electronic voting machines in 29 locations around Australia were made available for people who are blind or vision impaired in the recent national elections. Voters from any electorate were able to go to one of the locations nearest to them, since the machines accepted a vote for any electorate in Australia.

To cast an electronic vote, the voter listened to instructions through headphones and responded on a telephone style keyboard. The vote, printed in code, was then placed in an envelope before being put in the ballot box.

Voters were able to have a practice session with the machine before recording their actual vote, and a polling official was able to assist the voter to their seat and explain how the machine works.

Voters who were blind or vision impaired and were not able to attend a location with an electronic voting machine could cast an assisted vote at a polling place on election day, 24 November, an early vote at an early voting centre, or vote by post.

More information is available at the AEC website at [http://www.aec.gov.au/Voting/e\\_voting/index.htm](http://www.aec.gov.au/Voting/e_voting/index.htm)

## **Your tax dollar at work: but it's business as usual**

The Australian Government's new Raising Children DVD, which will be provided to parents of newborns over the next two years, is neither audio-described nor captioned. It is understood that some captioned versions are being planned, however, the possibility of providing audio-description is only now being explored. The Australian DeafBlind Council and our State's several Deafblindness agencies support the idea of the DVD, but are disappointed that, yet again, that accessibility has not been treated as an integral part of developing government information.

Information and the technology of information processing and transmission are central to modern social and economic life. In its effect on the social, economic and democratic participation of people who are deafblind, access to information is at least as important as access to the built environment or transport.

The NDS has called on all governments to support the concept of universal design which, when applied to information, would ensure that information systems and products are designed to enable access by everyone, including those with a sensory loss.

More information about the Raising Children DVD is available from [http://raisingchildren.net.au/raisingchildren.tv/tv\\_landing.html](http://raisingchildren.net.au/raisingchildren.tv/tv_landing.html)

## **Children who are deafblind or blind with multiple disabilities need help to reach their greatest potential**

The International Program of the Perkins School for the Blind in the USA is currently working in 170 countries to help children who are deafblind or blind with multiple disabilities to become literate. In a meeting with NDS, Perkins School President Steven Rothstein said that links were yet to be developed with Pacific Island nations.

The Perkins School International Program is dedicated to improving the quality of life for children who are deafblind or blind with multiple disabilities throughout the world. The program collaborates with a variety of local partners to provide direct services to children and their families; create innovative education programs; expand local and regional expertise; augment leadership skills in teachers and professionals; promote Braille literacy and advocate for lasting changes through education and disability policies. For more information, visit Perkins School for the Blind <http://www.perkins.org>

The World Blind Union (WBU) has endorsed the Australian Blindness Forum (ABF) proposal to pilot a recycled equipment exchange program in the Pacific-Oceania sub-region. This fits with the Perkins International Program goals to increase Braille literacy and provide a Perkins Braille to every person in the world who needs one. Perkins School has agreed to a link between its website and that of the ABF

More information from: Margaret Verick, Project Officer (Australian Blindness Forum), [margaret.verick@nds.org.au](mailto:margaret.verick@nds.org.au)

## **The 6th EBU Deafblind Conference**

### **Deafblindness:**

### **Equality and Diversity and The 2nd EDBU General Assembly**

**25 - 30 April 2008 Four Points Panorama Hotel, Zagreb, Croatia**

ORGANIZATION: Croatian Association of Deafblind Persons DODIR

Contact project coordinator at GSM: +385 91 382 1921

E-mail: [edbu2007@dodir.hr](mailto:edbu2007@dodir.hr) [www.dodir.hr](http://www.dodir.hr)

Come to Zagreb, you'll be most welcome!





**14<sup>th</sup> Deafblind International World Conference**  
**Perth, Western Australia, September 2007**

**Photographs from the Conference on DVD**  
**and**  
**Conference Proceedings on DVD**

**Available Now!**

**Visit the conference website at**

**[www.dbiconference2007.asn.au](http://www.dbiconference2007.asn.au)**

## **Venezuela**

### **Maria Luz Troconis**

#### **Day Of Deafblindness 27th June 2007**

S

OCIEVEN, the organization for deafblind people and their families in Venezuela that's day-to-day work is to promote action to improve the communication and quality of life of deafblind people asked the people of Venezuela to join with them on the day of Deafblindness. They asked everyone to unite with joy and make the day a very special one and celebrate as much in Venezuela as in the rest of the world. Socieven also mused this opportunity to express its profound gratitude to all its supporters for being with them in this beautiful cause.

Socieven invited everyone to see the television film, Conoceme, (get to know us) which was going to be screened twice on the 27th!

[www.socieven.org](http://www.socieven.org)

#### **ICT for deafblind users – a survey in Denmark**

##### **Ole Mortensen writes:**

We have done a questionnaire survey among Danish people with acquired deafblindness asking them about 29 day-to-day activities like finding their way in the street, recognising people that they know, communicating, using e-mail. We have asked them to rate these activities on how important each activity is to them and how well they manage the activity.

The rationale is that if they claim to manage it poorly and they find the activity important, then this is a problem for them. This has given us an indication of how these respondents evaluate their situation themselves.

## **Next Steps**

The next step is to contact some experts – both here in Denmark and abroad. We need to explain the situation that deafblind people find themselves in, describing the particular problems that they encounter, which senses can be used and how etc. We need to challenge them to come up with ideas or suggestions of ICT based solutions that might work for deafblind people as well, with little or no alteration.

Can you help?

The experts will not only be from within our field – the idea is to have input from technology professors, future analysts, product developers, inventors, gadget nerds and others who might have an inspiring idea –however crazy! Our intention at this stage is to publish their ideas in a “21 ideas on ICT for deafblind users” type of booklet. We are in the phase of identifying the experts to ask, so if you have any suggestions, from inside, or outside, the deafblind field, I would be very grateful to hear them.

Please contact Ole on email: [oem@dbcent.dk](mailto:oem@dbcent.dk)

## **Foyer group**

### **Development and deafblindness – Dbl members create a new forum**

A new group emerged from the conference at Perth, made up of many Dbl members and friends from the developing world who have strong interest in following up on the UN convention and other relevant issues related to development and deafblindness.

The “Foyer group” intend to develop their shared interest keeping each other informed about developments and asking for support and advice, using electronic means. In order that the exchange can have a focus, 5 Key Areas of Work were highlighted, to include:

- Education. Including early Intervention; educational provision (formal and non-formal) and teacher training

- Health. Including, medical aspects of the work / research / developments, as well as awareness raising regarding the prevention of some of the causes of deafblindness

- Advocacy.

- Policy. Information sought on the new initiative for projects, e.g. Government of Kenya. What is happening regarding the ratification of the UN Convention

- Work and Employment. Lessons learnt from the South to the North

- Technological advances

Regular contact will be very much encouraged, particularly cross regional/national/continental! Other opportunities to meet and share expertise will be explored.

If you are interested contact Sian Tesni from CBM who will add your name to the list of contributors:

sian.t.roberts@btinternet.com

# NORDIC CONFERENCE



## What's so special about deafblindness?

September 10 - 14, 2008

Hanaholmen Kulturcentrum - Espoo near Helsinki, Finland



### Programme

The conference will focus on three main topics:

- Communication
- Identification
- Documentation/Information

Invited plenary speakers will provide input to the work on these topics. The workshops will be placed in streams, which each will address one of these topics.

The language of the conference will be Scandinavian with interpretation to and from Finnish and Icelandic. NUD furthermore wishes to open up for participation from the Nordic countries' adjacent areas such as the Baltic States and Northwest Russia. Therefore, all plenary sessions and some streams will be interpreted into English.

### Workshops

Please submit abstracts before January 14, 2008. A more detailed "call for papers" will be available shortly.

Updated information about the conference will be available at [www.nud.dk](http://www.nud.dk)  
You may also contact us at [nud@nud.dk](mailto:nud@nud.dk) for further information

NUD welcomes you to join us in wondering:  
"What's so special about deafblindness?"



Nordic Staff Training Centre for Deafblind Services  
Slotsgade 8 - DK-9330 Dronninglund - Denmark  
Tel.: +45 9647 1600 - E-mail: [nud@nud.dk](mailto:nud@nud.dk) - [www.nud.dk](http://www.nud.dk)



Swedish National Institute for Deafblindness



## **World Health Organisation and UNESCO**

### **Lex Grandia with Ann Thestrup report**

#### **Meeting the Director General of World Health Organisation**

Lex met the Director General of WHO, Dr Margaret Chan. She is very committed to implementing the measures of the Convention in her own organisation as well as in the WHO regional and national offices and their programmes. Lex presented three messages on behalf of the International Disability Alliance (IDA) which he is Chairing at the moment. Disabled People Organisations expect to be involved in policy making of UN agencies, involving and affecting persons with disability. Their messages are:

- “Nothing about us without us”
- DPO’s favour a social and human rights based concept of disability rather than the medical model
- disability is not a disease but a human condition
- mainstream disability into all parts of the WHO system and have one unit responsible for disability related matters (rather than now splitting it up in smaller groups, as it is now.)

It was a very fruitful meeting and Dr Chan recognised the DPO’s and their role in the Convention, understood the issues around the medical model, and promised to take a more holistic approach. She reaffirmed that medical aspects of disability will still be at the centre of the work of WHO. She promised to establish a task force within WHO to mainstream disability issues into the organisation and to work on implementing the Convention. She gave her full commitment and promised co-operation to work in tandem with DPO’s in future, on an equal basis.

#### **WHO – Disability and rehabilitation seminar**

Lex had a full day at a partners seminar with the DAR ( disability and rehabilitation) team of WHO, other experts from different parts of WHO, the 8 major international disabled peoples organisations, major service providers/ development NGOs, and government representatives from major donor/ funding countries in the disability field like US, Japan, Finland, Sweden, New Zealand

and a few more countries .The purpose of the seminar was to explore how these 4 groups of stakeholders can work together to implement the Convention. It was a very interesting day. A formal report will be out later.

## **UNESCO**

Lex had a full day with UNESCO on Education for All and the flagship called “Towards inclusive education for all”. This project is working on guidelines for policy makers from all over the world about inclusive education.

This project is also developing a web site on inclusive education, supported by the University of Jyväskylä, Finland and the web master is urging us to send material, reports, and announcements of events and resources of all kinds on inclusive education. [markku.leskinen@edu.jyu.fi](mailto:markku.leskinen@edu.jyu.fi)

## **IDA meets again in 2008**

In February 2008 the next IDA meeting takes place in NY. It is connected to the next session of the UN Committee for Social Development, and IDA will seek to have meetings with ILO, UNDP, DESA, UNICEF and other UN, New York, based agencies.

WFDB has now got consultative status with the UN, so has the right to attend all meetings in the ECOSOC strand. WFDB would be happy to brief DBI on what is going on and consult with Dbl on possible ways of working together on influencing developments and other relevant matters related to the UN.

## **Deafblind Guidelines on Service Provision**

**Malcolm Matthews reports on how the guidelines are being used and advises on how to use the Dbl Guidelines to bring about change in your state or country**

### **Introduction**

The Dbl Deafblind Guidelines on Service Provision is available in English at [http://www.deafblindinternational.org/guidelines\\_services.pdf](http://www.deafblindinternational.org/guidelines_services.pdf) and in Spanish at [http://www.deafblindinternational.org/guidelines\\_services\\_spn.pdf](http://www.deafblindinternational.org/guidelines_services_spn.pdf) It outlines Deafblind International’s recommendations for service provision and is intended as a statement of the particular needs of deafblind people. It is a set of guidelines

for all those seeking to implement best practices for the population, and applies to governments and public and private service providers. It aims to contribute to deafblind people receiving and achieving their rights – which will require recognition of deafblindness and access to specialized services and support.

## **The summary**

The summary of the Dbl Deafblind Guidelines states that deafblindness is a unique disability and gives a description of deafblindness. It states that deafblind people are often among the most isolated disabled people and excluded from participation in society. It goes on to state that if deafblind people are to have full human rights then there must be specific planning and services.

The summary then goes on to list aspects of planning and services that must be provided if deafblind people are to have their human rights.

These include

1. recognition of deafblindness as a category of sensory impairment
2. identification of deafblind people
3. functional assessment undertaken by someone who is specifically trained
4. a workforce that has specialist knowledge
5. awareness training
6. the needs of deafblind people to be specifically addressed when planning services and support for disabled people
7. specialized services including technological solutions and human support
8. the deafblind person and what they want being at the centre of planning and provision
9. involvement of families
10. availability of one-to-one communication support / human support services.

## **The full guidelines**

The main document has sections that develop the arguments for the above. The idea is that the full document could be used in planning what action to take or in lobbying for policy change OR sections could be extracted depending on what it is that needs to be developed or changed.

## **Examples in the appendix**

An appendix to the main document articulates in more detail the roles of human support service providers and the way these have been developed in different countries to meet needs in different settings.

Underpinning the document is the view that deafblind people's human rights are denied unless they are recognised as a group in their own right. But recognition is not enough. They cannot be full citizens unless there are changes to the way



society treats people who are deafblind and – most critically – there is provision of specialized support that enables them to be equal participants in the mainstream of life.

## **Bringing about change**

But how do you get recognition for deafblind people and policy change that makes a difference at a national level? Achieving change is usually a long process. It involves informing policy makers, developing allies and supporters, proposing policy changes, pushing for change, and then maintaining awareness. The Dbl Guidelines provide some arguments you might use in this process. It might be helpful to be able to state the views of the world organisation, Deafblind International, to give credence and weight to the points you are making.

Sometimes being able to talk about how deafblindness has been recognised in other countries, about how the Dbl Guidelines have been implemented, what policies exist elsewhere and what services have been developed, can make a big difference when making arguments nationally or locally.

In England and Wales there is “statutory guidance” from central government about the social care of deafblind children and adults and, as such, there is legal requirement to provide by those local authorities that have responsibility for social care. Having said this, there are 10% of localities that have totally failed to implement any aspect of the guidance!

The statutory guidance in England and Wales came about following years of raising concerns about deafblind people’s needs and the production of a number of documents on needs and how they might be met. The guidance was agreed following a long campaign by deafblind people and organisations called “Yes to Access”, a “Deafblind Bill” being tabled in Parliament, a government consultation that was a response to the campaign, and a period of negotiation. One of the arguments made at the time of the campaign was about the better provision in some Scandinavian countries.

This statutory guidance covers points 1, 2, 3, 7 and 10 of the Dbl recommendations

Although this guidance in England and Wales exists, Sense continues to respond to government consultations and raise issues related to deafblindness for both adults and children. At the moment this involves a campaign called “Fill In The Gaps” about the needs of older people who have difficulties with both sight and hearing.

### **Some examples of use of the Dbl Guidelines:**

The Dbl Guidelines have been referred to by Sense International, India, when preparing reports, papers, demand letters and presentations for negotiations with Government and other disability and development organisations.

In Massachusetts, the Dbl Guidelines have been used to advocate for a broader view within the Commission for the Blind, to expand their definition of who should be included as deafblind and to have them broaden the services that they offer.

In Argentina, the Guidelines have been shared at different levels in order to promote deafblindness as a different and unique disability. This has included promotion to the Argentina Congress and suggesting changes to existing laws that take the Guidelines into account.

(Everybody in the Latin America Network has access to the Dbl Deafblind Guidelines as they were translated into Spanish and Portuguese.)

### **The Guidelines have also been used in other ways:**

“10 indicators for good quality services” have been developed based on the Dbl Guidelines by Sense International India. The indicators are used internally to assess the quality of the services that they support. They are also used as a self assessment document by partner organisations to help inform them of their own practices and to make improvements.

Any new organisation in India considering starting deafblind services, will ask the questions:

- What does this entail for us as an organisation?
- What do we need to do to develop a ‘model’ service?

Sense International India’s response is to share the Dbl Guidelines, so that stakeholders are well informed about deafblind services before they take any decision about developing services.

### **Might the Dbl Guidelines be used in your country? In deciding about this you might want to consider the following:**

- Is deafblindness adequately recognised in my country in policy and legislation?
- Does the situation in my country warrant using the Dbl Deafblind Guidelines to try and bring about change?

If you decide that there is a need to work on this you may then want to consider:

- What change is needed? What is the priority?
- What might be done to bring about that change?
- Who can I work with to achieve change?
- How might we use the Dbl Deafblind Guidelines to bring about that change?
- What is our plan of action?

In preparing a plan of action you might want to consider the following:

- Are there useful lessons from the experiences in other countries of seeking to change policy and what are they?
- Will similar action work in my country?
- Who might support us in this activity?

Contact [malcolm.matthews@sense.org.uk](mailto:malcolm.matthews@sense.org.uk) with any comments or examples of use of the Dbl Deafblind Guidelines.

## **11th EUROPEAN DEAFBLIND HOLIDAY**

**Hotel Sopron\*\*\*\*, Sopron, Hungary**

**4 to 11 August 2008**

**Hosted by Hungarian Deafblind Association**

Dear friends,

We are pleased to invite you, deafblind adults, to participate in the 11th European Deafblind Holiday.

We prepare a range of social, cultural, sporting and recreational activities. There will be walking, swimming, working in clay, trips and other activities. There will also be music and dance events, visits to local places of interest, shopping trips and other excursions.

An opportunity will be given to participants to exchange their knowledge and opinions in all areas in a friendly atmosphere. It will be fun just to socialise with

other deafblind people. Or you could just relax and do whatever you want to in this lovely part of Europe.

The official language of the holiday event will be English. But if you don't understand this language please don't stay at home! There will be a range of communication methods so that all of us will be able to communicate with everyone else!

### **Our Hotel**

Accommodation is Hotel Sopron\*\*\*\*. Close to the centre. At the hotel there are mainly double rooms and some triple rooms. Single rooms are available for an extra cost. Please try to have room-mate(s), because the cost of a room for one person is the same as for two persons. Thank you for your help! We hope this won't put you off coming!

The rooms are beautifully furnished and they have bathroom with tub, telephone, remote control satellite TV, radio, refreshment-centre, hair dryer. Most of them have their own private balcony and air-conditioning.

The hotel has a bar, wellness centre and open-air swimming pool, a conference room as well as a restaurant where you can eat good Hungarian food, wine and beer.

Check out the hotel website: [http://www.hotelsopron.hu/\\_old/english/index.htm](http://www.hotelsopron.hu/_old/english/index.htm)  
Sopron

Sopron is situated near the western borders of Hungary, at the foot of the Alps, 60 km from Vienna and 220 km from Budapest. It is one of the oldest jewels of architecture in the country. Sopron merges past and present in itself. The air is clear and the natural environment, calm. The hiking routes of the wooded hillsides, the view towers, the mountain springs, and the proximity of Lake Fert make Sopron one of the most beautiful and most pleasant holiday resorts of Hungary.

Tamas Gangl (President)

Please fill in Registration Form, Accommodation form and Travel Plan on Dbl website and then return them, not later than 30 April 2008, to:  
edbholiday2008@gmail.com or email Tommy for further information. Postal address: Siketvakok Orszagos Egyesulete, 1146 Budapest, Ajtosi Durer sor 39. Hungary

### **Strategy for our future direction**

**Tony Best has been chairing the Strategic Planning Group and their proposals are outlined here. The group conducted a detailed consultation with members over a period of 15 months before putting forward these recommendations for our future direction**

### **What should Deafblind International do over the next 5 years?**

Should it continue to organise networks and conferences, or are there other activities that are more useful? It has a website, but how should that be developed and what sort of information should it contain? Dbl is very active in some parts of the world, so should it continue to work there, or is it time to provide more help for colleagues in other regions?

The answers to these questions were agreed at the international conference in Australia in September. But the long term direction of Dbl ('The Strategy') was developed through ideas from Dbl members over the previous 12 months. A 5-person strategy development group has been working since May 2006 to collect opinions about the future of Dbl from individuals, networks, corporate members and from associated organisations. The group had over 70 discussions with people on their ideas and around 20% of subscribing members contributed to the consultation.

In its report, the group proposed 5 ways in which Dbl should change over the next 4 years, and put forward 18 recommendations for action. However, what had been clear from the consultation was that Dbl was highly regarded within the field of deafblindness, and there was tremendous respect and approval for what it was doing. The changes were to build on strengths and to increase, if possible, its influence and activities.

### **Major changes**

#### **In what ways should Dbl change?**

1. Provide a little help for many or a great deal of help for a few?

Dbl is currently concerned with supporting a wide range of people who are involved with a range of people with deafblindness. It was hoped that the organisation will become more inclusive, while recognising that this might result in our limited resources being stretched.

In terms of deafblind people, it is hoped that we will do more in relation to elderly people who lose their vision and hearing, and ensure we include people with vision and hearing impairments and multiple disabilities. In terms of professionals, we should work actively to include more medical professionals, particularly as more deafblind people define themselves in terms of their medical

conditions (often genetic). However we must remain primarily a support for practitioners, as well as retaining strong links with families.

## 2. Treat the symptoms or deal with the cause?

Dbl accepts the fact that deafblindness exists and supports those who work with deafblind people. It was felt that this emphasis was about right, although it is hoped that a limited amount of work will be devoted to help removing medical causes of deafblindness. This support was asked for from a few specific regions, where Dbl could support national health projects and local campaigns.

## 3. Provide direct services or advocate for change?

Most Dbl resources are focussed on providing direct activities for members and professional colleagues. However, there is a strong wish that Dbl now develop its political role and becomes more engaged in campaigning for change. In the recommendations, this is translated into changes in ManCom roles, developing public policy and position statements, and links with International development agencies (INGOs).

## 4. Focus on established work or diversify into new activities?

Networks events and international conferences are well established as the major activities of Dbl, with the excellent information services based on Dbl Review. It is felt that Dbl should now actively explore a wider range of activities to achieve its purpose. This would include exploring the use of webpages, perhaps for on-line training, as well as the provision of information (in written and video formats) and the use of regional meetings and conferences. A number of other, more radical, ideas were suggested such as member mentoring and commissioned research. It was recognised that these developments would all require additional resources, including people and money.

## 5. Hold to core mission or seize opportunities to get new resources?

It is felt that Dbl should continue to fulfil its original core mission in relation to people with deafblindness. It should therefore resist opportunities to divert scarce resources into activities, campaigns and areas of work that, although praiseworthy, do not impact on the lives of deafblind people and their families. They should remain at the centre of everything that we do and therefore this is an area where there should be no change.

## **Next steps**

In order to make the changes, the strategy group made 18 recommendations for action. The next step is to develop a timetable for implementing these recommendations over the next 4 years, and to decide which of these recommendations should be implemented first. The ManCom is working on this

task and has already decided on the priorities. These are some actions in relation to Networks, changes in the information services and income generation. However, it is clear that members of the ManCom will need the help of members to implement the strategy and so there will be a number of opportunities to become more involved in Dbl activities over the next few months. Those members who have taken time to work on Dbl activities have almost always thoroughly enjoyed the experience, and have benefited in many ways. So the strategy group does urge all members to consider offering to help with these projects as they are announced.

## **Detailed recommendations**

### **Members**

1. Individual membership continues to be open to all who are interested – professionals, family members and deafblind people. It is clear that Dbl is not an organisation of deafblind people, but supports all people involved with deafblindness.
2. Individual membership should be on a term (4 years) basis and not annual.
3. Corporate members should continue to be recruited and should pay an annual subscription. Dbl should recognise the considerable contribution they make, and ensure there is an appropriate package of benefits.
4. The fee structure should be re-examined, in order to improve access to Dbl membership for people from developing regions.

Although there are only a few hundred subscribing members of Dbl, there are strong reasons why we recommend developing the membership scheme. What is the thinking behind these recommendations?

Dbl needs to be able to show that it represents the deafblind world if it is to have an increased 'political' role, and individual membership is a powerful way of achieving this. The collective knowledge of members is a valuable resource for Dbl and is more accessible if people feel part of a membership scheme. For members, it is probable that membership will become more important as more large centres (e.g. special schools whose staff enjoy the benefits of corporate membership) are replaced by individual staff dispersed in small services throughout the community. Members can feel a sense of support through access to information, opinions and the exchange of ideas, particularly when there are developments in the members' only website and in members-only events. In addition, members, by paying their subscriptions, can benefit colleagues in less developed areas, by enabling them to receive the support which is often commonplace in countries of The North. This 'sponsorship' of colleagues, if

made a transparent scheme, may be a powerful motivation for many members of Dbl.

## **Networks**

5. Dbl should identify the networks it needs to put the strategic intents into operation.

6. Dbl should re-examine their requirements on networks to ensure there is planning, implementation and reporting on activities.

7. Networks should establish preferential benefits for Dbl members.

8. Dbl should provide a network development and support function.

Networks are seen by members as a core activity of Dbl and no-one has questioned the continuing relevance and importance of this activity. However there are some developments that members would like to see, to improve the effectiveness of networks and to more adequately meet changing needs.

There was some concern that there are no specific benefits for members who attend many network activities. Indeed, some 'network' activities were attended by many people who were not even members of Dbl and certainly not 'members' of the network. This, it was felt, needed attention if activities were to continue to be part of Dbl.

The solutions to this problem could be to ensure members received many activities at a lower cost than non-members; some activities, particularly materials development, could be restricted to Dbl members; other events could be specifically designed to be open activities but would include an effort to recruit members.

At present a number of networks exist but are not active. It is suggested that one outcome of the strategy could be the identification of the key networks that must exist in order for Dbl to fulfil its strategic intents. At present it seems likely that a systematic approach to supporting work with elderly people who lose their vision and hearing could be a new development priority.

Network activities are mainly in the form of meetings or conferences. However, these take considerable time and skill to arrange and, perhaps as a consequence, only a few of the networks are very active. Others seem to recruit largely from one geographic area (often Europe). While this is excellent for those who join in, other members have expressed concern at feeling excluded and this apparent inequality could be addressed.

To increase activity in all these ways may be idealistic, but would be made more likely to happen if there were an extended Network Development and Support Group, providing technical know-how rather than administrative support, but actively engaged in managing all the networks.



## **Information**

9. Dbl creates a development plan to increase the website as a key information resource to members.

10. Funding or sponsorship be obtained to ensure an active and up-to-date website.

11. Dbl develops a language policy in relation to the provision of information in languages other than English.

The provision of information is seen as the second core activity of Dbl, with Dbl Review being very highly regarded. The newly emerging website is considered the major new area of growth and a key method by which Dbl can support its members in the future. However, it is recognised that the provision of information which is up-to-date and reliable, is dependent on people with time and contacts to make it happen. At present much of this is provided pro-bono (i.e. at no charge to Dbl) by some of the corporate members.

The aspirations for the website include areas for networks, discussion forums between members, information from conferences, workshops and meetings, on-line training, links with other resources. If funding is required, then seeking sponsorship and advertising has been suggested.

A concern that is emerging is about translation. For example, at present there are very few Dbl members who speak Spanish, in comparison to the number of professionals in the field. Although the official language of Dbl is English, it seems very beneficial for Dbl to find a way to provide a parallel website in Spanish to give access to professionals and families who speak Spanish. There is no easy way to achieve this, although we have gone some way through the voluntary contribution of a corporate member.

## **Staff development**

12. Dbl and related INGOs should meet to clarify their roles in relation to staff development and help Dbl define its contribution.

13. Networks should think of their work as contributing to staff development and to the development of new knowledge, and organise activities to achieve these purposes.

14. Dbl should ensure the development of expert workshops for experienced people, so the field can grow in its knowledge and in the expertise of individual members.

15. Dbl should consider contributions to staff development as a worthy category for awards.

The role of Dbl in relation to staff development is not clear although most of its current activities are designed to share good practice and help individuals grow professionally. Part of the confusion over staff development comes from the lack of clarity over the work of the major related INGOs. Several of these organisations are closely linked to Dbl but it is not always clear when Dbl is

providing support or when it is the work of one of these agencies. It is therefore suggested that the roles be clarified, perhaps through one 'partnership' meeting. Networks are the paramount way for Dbl to deliver staff development. Networks therefore should be encouraged to develop this role, perhaps through activities that focus on specific problems that members need solving, through the focussed examination of topics to develop new insights and knowledge (as the Communication network has done so successfully), through the introduction of 'master classes' for experienced members.

This latter idea, which could perhaps be developed in discussion with the INGOs, could spread and develop best practice as well as helping to develop future leaders in the field.

## **Advocacy**

16. Dbl should develop public policy statements to support campaigning work.

17. Dbl should develop its research activities to support the public policy and campaign work.

18. Dbl should examine the possibility of obtaining external funds, using universities and Dbl members to support the necessary research, authoring and direct support work.

It is recommended that this be developed into an important area of activity and so it is described here in some detail. It was felt that Dbl is well placed to become a significant organisation internationally to influence the development of services for the benefit of deafblind people and their families. To achieve this, Dbl needs to extend its role in campaigning through the development of information, and through providing people able to support campaigns at a national and international level.

There are several reasons why this development, at this time, is seen as important. The recent UN Convention on the Rights of Persons with Disabilities is a major development and will be followed up by many governments in the next few years. If deafblindness is to be included in those discussions, then there is a need for materials to guide governments on the rights and needs of deafblind people and their families. There are several other current global initiatives, such as Education for All, which also require a voice on deafblindness if the lives of children and adults are to be improved as part of the outcomes.

Dbl is the only professional organisation well placed to develop a role in global representation of the field of deafblindness, and there is evidence that some of the Dbl policy statements that have been produced previously were valuable in generating interest and influencing governments.

A major element in the development of advocacy will be the production of documents on what is needed. The kind of topics that will need to be covered includes specialist services in assessment or education, the right to employment and inclusion within mainstream services, identification of disability, the right to aids, appliances and equipment.

In order to develop and use these policy papers there needs to be two supporting developments. The first is the identification of people able to work with Dbl members who seek the support of Dbl. It seems likely that this development could result in improved opportunities and services for many hundreds of people, so it is a very effective use of the limited resources available to Dbl.

Dbl also needs people able to write the policy documents. While there is a concern over the imminent loss of some experienced Dbl members, here this can be turned to an opportunity. Recently retired people could give a little of their time to preparing documents or even to supporting the use of documents at a national or international level. Some of these people may be ideally experienced to provide this support, and may well be very willing to contribute their time and experience.

The second supporting development is in 'research' – evidence to support the policy documents. This evidence may be from externally funded projects, and the results can give valuable guidance on numbers, needs and good practice. It may be collected by short-term working groups, set up by Dbl to answer specific questions, and who can use the powerful resource of Dbl members as a source of data. It may be possible to identify universities who are carrying out studies and who may be persuaded to address some of the issues that are important to Dbl

The impact of this development work could be to raise the profile of Dbl internationally with global institutions such as the UN, UNICEF and WHO and with INGOs. Members have expressed a strong appetite for more involvement in work of this kind. However, they also made clear that this change in Dbl activity should not be achieved through a significant reduction in the direct support to professionals working with deafblind people.

## **Organisation**

To achieve the results described above, it is recognised that there will need to be greatly increased human and financial resources. At present the reality is that Dbl survives on the good will of volunteers who have the time and resources to support Dbl activity. This is not going to change dramatically in the next strategic period, and therefore we will continue to depend on some of the large corporate members to provide people to work for Dbl. There is a wish that Dbl continues its move to be more democratic. While it is desirable to move towards a stage when our processes are based on fully democratic choices, we recognise that it is not possible at present, and we do not recommend any changes at present to the

processes for selection to Council and to officer posts, nor in the composition of Council

Money is needed to support the work and there is a necessity to diversify the donor base. Many of the activities can be seen as projects and might be sponsored or funded externally to Dbl. It is possible that some of the INGOs in the field would respond to requests from Dbl for them to carry out some of the projects – for example materials development, research, sponsoring meetings, writing policy papers. However, if Dbl seeks to secure external funding, this is likely to put Dbl in competition with INGOs in the field who seek funds from the same sources. Those INGOs might contribute some technical know-how in generating funds for Dbl, but again it is recognised that there could be a conflict of interest. This is a known problem in other fields of international work, but no clear solution has been identified.

Therefore, it might be necessary to have a person on ManCom, to be responsible for income generation. The principle underpinning these financial issues could be stated as ‘Dbl wants work done- but does not mind if other organisations do it. It will still fulfil our paramount ambition- to benefit deafblind people and their families’.

## **Conclusion**

The recommendations and strategic direction described in this article indicate the sort of organisation Dbl could become, and some of the changes needed to achieve this. The recommendations do not provide operational details of how these changes should be achieved – that is for the individuals asked to lead those changes.

We envisage a process that is a transition rather than a transformation, moving Dbl from a residual dependency on a few organisations to fuller representative democracy, replacing the current uneven development with uniformity and equality of development, and moving from a dependence on the goodwill of volunteers to a sustainable professional development. This, we believe will be to the benefit of professionals working in our field and, through their work, will increase the benefit to deafblind people and their families. Now we have defined our future, the work needs to start to achieve it.

Tony Best

Chair

Strategy Development Group

Members:

Isabel Amaral

Maria Graciela Laynes

Akhil Paul

Sergei Sorokin

## **DbI Awards –**

**presented at the World Conference**

**Introduced by Bernadette Kappan, DbI Vice President**

### **DbI Distinguished Service Award**

This award recognizes a DbI member who has significantly contributed to the deafblind field or to DbI internationally. This award honors an individual who has demonstrated outstanding contributions to the field professionally, has developed or promoted innovative practices, has made extra ordinary contributions to DbI, has authored professional publications, offered staff training or provided leadership on an international level which has promoted or improved services to individuals who are deafblind and their families.

### **Penny May Kamau**

“This individual is spirited, well organized and focused on the needs of individuals who are deafblind from childhood to adulthood, from pre-school to vocational training. She looks at each person as being an important member of the family and society with abilities, gifts and rights.

For many it may be difficult to remain spirited in an environment where basic health care services remain poor and unaffordable in some regions, where there continues to be gender inequality, traditional taboos and discrimination against individuals who are deafblind. This individual has devoted the past 17 years to making sure that deafblind services expanded and were of high quality. In her approach she included parents, siblings, teachers, medical professionals, governments and as many stakeholders as possible.

The highlights of this individual’s career include:

- starting parent groups and forming The Parents of Deafblind Association. This began in Nairobi and later expanded in Uganda and Tanzania.
- offered workshops for siblings to share their challenges and achievements.
- developed services in Kenya, Uganda and Tanzania.
- established vocational services for adolescents and ensured that they would have appropriate communication.
- started teacher exchange programs where teachers in East Africa would spend one week in another program sharing skills, seeing programs in operation and then returning with new ideas.

- made sure that students were medically screened, had their glasses repaired and provided transportation to appointments for poor families.
- established yearly meetings between the administrators of the programs for deafblind children and the district education officers and the Ministry of Education.
- provided an opportunity for adults who are deafblind to meet, socialize and receive services.

Wow, what an incredible career! Penny May Kamau has done so much for individuals in Africa but it is her spirit that makes all this possible. She has accomplished wonderful things but her vision and her ability to see the beauty in every individual who is deafblind is what makes her so special”.

### **Barbara Miles**

“This individual is a quiet, gentle, soft spoken person who probably doesn’t realize how much she has done for the field of deafblindness.

Her career spans over 20 years and she continues to grow and develop and always shares her knowledge with professionals and families. As a teacher she loved the closeness with the children and always worked to find the best way to communicate with every child she came into contact with.

Literacy, communication and tactual communication are areas that she is best known for. In the early years so many professionals were taught to guide the students with hand over hand instruction. After many years of work and carefully observing students, she experimented and studied how the students used their hands. She guided us to look at the hand as an important part of communication. She taught us to gently guide the child’s hand with hand under hand instruction. Her work always focused on giving the students opportunities to make choices and decide for themselves.

She has lectured throughout the United States and around the world. Her writing has been used to train staff in the best practices for deafblind children and young people.

As a founding member of the Tactile Communication Network she continues to work with colleagues to research, develop and share ideas on communication. The field of deafblindness will always be thankful for this devoted, motivated and caring professional”.

### **Graciela Ferioli**

“This individual has worked tirelessly to provide high quality services to individuals who are deafblind and their families. She has worked in her region to create awareness and encourage local administrators to provide services. She travels widely across the region providing training to staff and families. Her

enthusiasm and gentle manner has been so encouraging to everyone she has come in contact with.

She has been involved in many firsts. Her organization and pure grit helped pull off the Dbl World conference in Cordoba. Through her efforts the new Latin American network is up and running. On a regular basis she has advocated for professional literature in Spanish and she has often provided the translation. A constant advocate for individuals who are deafblind, parents and staff from developing countries. Throughout her time as part of the ManCom she has reminded everyone of the needs of this group of individuals. As the Vice President of Dbl she encouraged the group to establish clear responsibilities for all the jobs and assisted with a variety of committee assignments.

Her talents and skills are many but her constant focus on respect and communication are traits she will be remembered for. She has an undeniable enthusiasm for her work and this is always being communicated to others. Work is so important and she does this in a fun way. Whenever there is a chance she is ready to celebrate and is the first on the dance floor. Her friendly and kind manner gets her into many doors to open services for individuals who are deafblind. Latin America is so fortunate to have such a wonderful person and advocate for individuals who are deafblind”.

## **Dbl Lifetime Achievement Award**

The Lifetime Achievement Award is given to an individual who has made a distinguished contribution to services for people who are deafblind on a national or international level.

This award is given to someone towards the end of his/her working life.

Distinguished contributions could be in the area of publications, research, development of new techniques or procedures, practical application of teaching techniques, training staff and parents, advocacy; and dynamic leadership.

Norman Brown

“Tonight Dbl is pleased to present the Lifetime Achievement Award to an individual who was a father of a son who was deafblind, was a tireless supporter of people who are deafblind and their families, an advocate, a teacher and an inspiring speaker and writer.

Shortly after the birth of his son, he became involved with the National Association of the Deafblind and Rubella Children (Sense) and from that time on he was an inspiration for everyone in the UK and around the world.

He worked hard to make the needs of adolescent and adults known and to create high quality services for these individuals. He shared this knowledge with other

parents and encouraged them to work on behalf of their children. When the Dbl world conference was held in Argentina he offered training in three countries in South America. He was a presenter at many conferences and was always encouraging parents and teachers. In the later years of his career, he was the co-coordinator of the Diploma and Degree courses in the Education of Children with Multi-Sensory Impairment. He inspired and taught a new generation of teachers.

In addition to his work with the deafblind, he was involved in theatre groups – writing, acting and directing. He sang in local operas and at one time managed a number of bands.

This exceptional individual was an outstanding professional and will be remembered for his contribution to the field of deafblindness but most of all we honor tonight a gentleman, an advisor, a friend, a fun loving and thoughtful person who had the best smile

Tonight Norman as you look down on us from heaven, we honor you. Please watch over us and help to do what is best for individuals who are deafblind. Thank you to the many members who took part in recommending their colleagues world wide for an award this time.”

Bernadette Kappan

## **Management Committee News**

The Dbl Management Committee and Council meetings were held respectively on 24 September and 25 September, at Perth, coinciding with the Dbl World Conference. The General Assembly was held on 26 September.

The new Dbl Strategic Plan was ratified by the General Assembly. Implementing the strategic plan will be a priority for the council members. Following successful elections we now have our new office bearers – William Green as the President, Bernadette Kappen and Akhil Paul as Vice Presidents. The newly elected Council met on 27 November for their first meeting.

The Secretariat has put in its resignation and the process of appointing a new Secretariat has been initiated.

## **Dbl World Conference**

14th Dbl World Conference held from 25-30 September 2007 at Burswood Resort in Perth, Western Australia was a grand success. 381 participants from 37 countries participated in the conference.

The Scientific Committee did a wonderful job in developing an excellent scientific programme. Proceedings of the Scientific Programme would be soon available with the secretariat.



The local Planning Committee managed the show very efficiently. Pre conference workshops, family activities and tourist day activities were well organised. Volunteers were there to support the participants throughout the event.

The 15th Dbl World Conference in 2011 will be hosted jointly by Blind People's Association and Sense International (India) in New Delhi.

## **Membership Update**

All those members who have not renewed their Dbl membership in 2006 will no longer be included in the mailing list for Dbl Review. Corporate members, if you have not renewed your membership, you will not find your names in the Dbl membership lists. Your contribution is valuable to Dbl and we therefore request you to regularly renew your membership.

Individual members are requested to regularly update their membership in order to continue receiving regular updates from us.

Members, please note that the credit card payment facility is now activated and functional. Please visit online at:

<http://www.deafblindinternational.org/standard/membership.html> to make your payment. Also remember to quote your specially assigned membership number in all communications.

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

## **Dbl Website**

The Dbl website is regularly updated with information. We welcome new submissions. We also have developed Dbl promotion materials that you could use to talk about and promote Dbl at meetings, seminars, events and so on organised by you.

## **The Dbl Secretariat**

The Dbl Secretariat is always aiming to improve the service that we offer.

If you find any difficulty in making an online payment, please get in touch with the Secretariat, right away.

Please contact Sumitra Mishra/Parag Namdeo at:

[secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org) or post your query at: Dbl Secretariat,

Post Box No: 9601, Janakpuri, New Delhi – 110058, India. Dbl is a vital network

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

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

Non-voting membership costs 30 a year or a discounted 100 for four years.

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

There are now two tiers of Corporate Membership:

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

Small Corporates: Annual Fees between 300 and 1,500

Corporate Members can be nominated to sit on the Council.

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