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THE MAGAZINE  
OF DEAFBLIND  
INTERNATIONAL

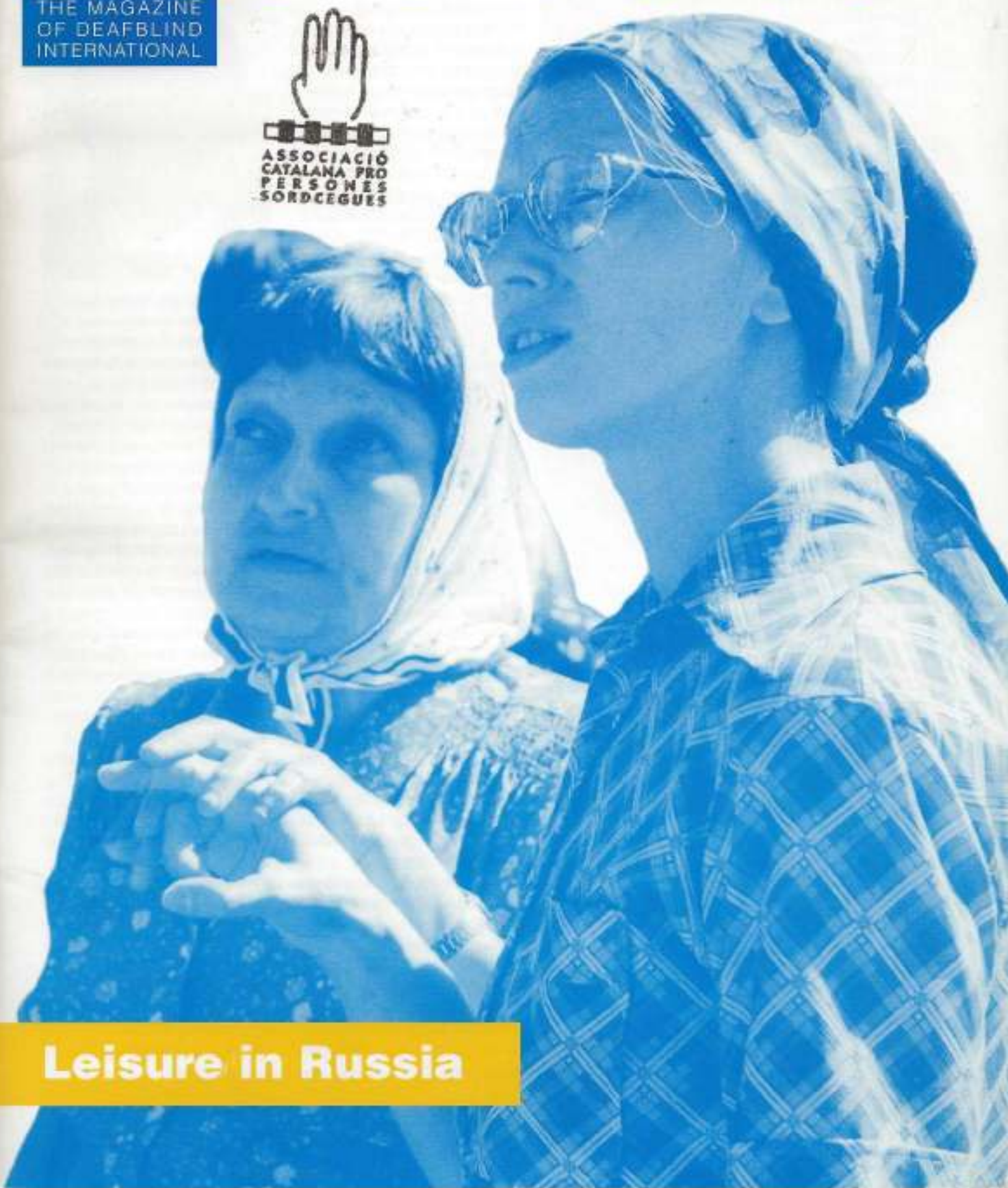
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Number 30 • July - December 2002

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**Leisure in Russia**



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

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

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

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

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

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Cover: Enjoying leisure activities in Russia.

## A message from the president

As I sit to write, it is the day after our Thanksgiving holiday here in the States, and most Americans are still recovering from this day of gorging ourselves on turkey and all the fixings, which we do annually in the name of gratefulness. Kidding aside, it is a favorite holiday for most Americans because we pause and reflect for at least one day on all the things we should be thankful for; our friends, our families, our work, our health and well-being. This holiday has none of the bombast of our Independence Day nor does it have the frantic anticipatory haste that Christmas seems to bring along. It is a day of feasting, thanking, quiet time with family, and reflection.

Our Dbl family also has a host of things to be thankful for. We have a wonderful managing board in the person of our Management Committee, and a very active Council. These individuals are extremely generous with their time, in making sure that we are a viable professional organization. We also have a top-notch newsletter, one that holds its own in comparison to what any disability group publishes as a worldwide publication. Thanks to our editor and her able staff for a job well done on a continuing basis. We have active network leaders, who look after the work being done cooperatively in a host of interest areas. Thanks to our loyal individual and corporate members, we have financial stability that allows us to maintain an organization at a much higher standard than in



past years. We have organization, Sense International, that allow salaried Secretariat to in a most productive, supported manner. We have improved our communications functions are currently in the process of significantly upgrading web presence.

All of the above are all matters pertaining to our over-arching information for which we can be and thankful. As I edit content of this current your hands, it also comes to me that we should be as well for the individual members of our organization who are always so contribute. I see and colleagues who have the time to write about Smart House in Sweden leisure activities in. They are typical of members who write contribute for ever the magazine: people real work with deaf people and willing their methods and approaches. We are thankful that this is about. I also see

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from a new contributor in Kazakhstan, a country that we are hearing from for the first time. We have a feature article about the Smithdas in New York, a couple that the entire field should be thankful to claim as part of us. This deafblind couple have been tireless advocates for a lifetime. And we see a fond farewell to a dear colleague, Anneke Balder, who steps away from deafblind work after several decades of service, and who was

instrumental in making our 1st European Conference such a success. Thanks indeed that we have had people like her in our ranks.

We obviously cannot thank every deserving person in this column. Suffice to say that we are thankful for who we are and who we have amongst us, and thankful that we have this close global community of people who comprise Dbl.

**Michael T. Collins, President**

## EDITORIAL

This edition of the Review has our usual mix of articles and news from around the world and we hope that you enjoy reading about the exploits and achievements of colleagues from so many different places!

Successful conferences and networking feature widely and there is no doubt that the notion of getting together and sharing information and support, not just locally and nationally, but internationally is having a hugely beneficial effect on the field of deafblindness. Electronic communications have made a difference and support our "talking to each other".

Here, at the Dbl Review desk, we receive almost all our material, including the pictures, through e-mail. This means that we are able to respond more quickly and more effectively! Many of you will be pleased to know that the Dbl website is now active again and Malcolm Matthews, who is Dbl Information Officer, will be planning and managing new developments over the coming months. Malcolm will be writing regularly for the Review to keep us all up to date and I know he will



welcome your comments and contributions.

We, too, are very grateful for the great support we get from our regular correspondents. Mike in Australia, Elin in Denmark and Stan in Canada have no idea how our spirits rise as we receive their contributions unrequested! Stan, Linda and the team will be working really hard in the next six months to prepare for our big Dbl event in Canada next summer. We wish them every success and look forward to seeing you there. And if you haven't written for us yet - what's stopping you? Get in touch!

Seasons Greetings to everyone!

**Eileen and Frances**

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# SmartBo - a "smart" house for people with disabilities



Gerhard Elger of The Swedish Handicap Institute, describes this groundbreaking project using new technologies to support independent living for deafblind and other disabled people. The project is financed by the Swedish Inheritance Fund and the Swedish Handicap Institute and has attracted support and sponsorship from private companies. The word Bo in Swedish means a nest and the name SmartBo is designed to create a feeling that a high tech house can also be a cosy warm place to be!

### Introduction

One activity of The Swedish Handicap Institute is to monitor and employ new technology for the benefit of people with disabilities. Through a number of pilot projects involving "smart houses" and computer-based solutions, we have learned how new technology can be made accessible for disabled people. Our experience from these pilots has created a solid platform for the SmartBo project. In a demonstration apartment we show working solutions serving as an example, as a source of competence, and as an inspiration.

### Aim of the project

The aim of the project is to build up knowledge and competence and share it with others. We investigated how information and communication technology (ICT) can be used to give disabled people a greater chance of an independent life, for example, how functions in the home could be automated or controlled by people with severe disabilities. We also want to

create interest in ICT solutions for the benefit of disabled people, and to demonstrate the need for new technology, acting as a source of inspiration for users as well as for professionals. Solutions and assistive devices are developed in co-operation with manufacturers.

### Target groups

SmartBo demonstrates the possibilities for mobility-impaired people, visually and hearing-impaired people and people with cognitive disabilities (developmental disability, brain injury, dementia).

Our target groups for information include disabled people, professionals working with assistive devices, private companies, the labour market, universities and colleges, local authorities, those involved in training health service personnel or special needs teachers, politicians, and other decision-makers.

### Methods

Based on our knowledge of target groups, we created scenarios where fictional

individuals with different impairments would live a rich and independent life in the apartment. Problems encountered in daily life were listed. We discussed how needs and ambitions could be fulfilled. During a seminar, scenarios were presented to disabled people and approved. Participants emphasized, however, that technical installations ought to be invisible or at least unobtrusive. The feeling of a home atmosphere was very important.

### What is SmartBo?

SmartBo is a two-room ground-floor apartment in a five-storey building situated in a Stockholm suburb. This house, together with several others, was built for a co-operative housing association for senior citizens. Consequently, entry is easy for disabled people; there are no steps or stairs to climb. The entrance door can be opened by remote control. The apartment is 78 sq m including kitchen with a sink area and a large bathroom. Outside the living room is a small private patio.

**SmartBo is a two-room ground-floor apartment in a five-storey building situated in a Stockholm suburb.**

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accessible through a door from the living room.

SmartBo is not fully adapted for any disability in particular. The project focuses on ICT and assistive devices and solutions made with computer technology and electronics. We want to show how disabled people can live an independent and rich life regardless of the type of disability. That means that many functions in an ordinary home must be possible to control and supervise for people with mild to severe disabilities. SmartBo is a home with facilities for relaxation and hobbies, for work and study.

Selecting installations to meet the needs of the users, we opted for standard equipment whenever available. Industry-standard products offer a better benefit/cost-ratio than equipment especially developed for disabled people. In that sense the installations in the apartment can be divided into two categories: one common to all users, one adapted for each group – even for each disabled individual.

The first category comprises basic systems enabling the user to supervise and control functions present in a home, e.g. windows, doors, locks, water outlets, electric power and cooker. The need to monitor and control such a large number of functions is most easily met by choosing a 'home bus system', which uses an intelligent building control system, particularly if you want to program more complex functions.

From experience, we know the EIB (European Installation Bus, which is able to control, regulate, measure, switch, sense and monitor) to be very reliable. Practically all

sensors giving input signals to the bus-system are ordinary standard components. Wall-mounted switches for lights etc. are EIB standard. A cable connects all sensors and all actuators in the apartment. (Sensors are input devices such as switches, motion detectors, magnetic switches, pressure sensitive switches, current sensing devices, water flow sensing devices etc. Actuators are output devices, i.e. relays for switching power, door automation, or controlling lamp dimmers.)

The following items are **sensed** by the system:

- ◆ all electric switches for switching lights and electrical outlets on and off;
- ◆ IR-receivers, one in each room receiving IR (infra-red) signals from remote control devices;
- ◆ entrance door and door from the living room to patio;
- ◆ doorbell at the entrance door and telephone signal;
- ◆ motion sensing device in the hall (used for automatic lighting of hall and bathroom);
- ◆ kitchen window and water tap;

- ◆ cooker;
- ◆ bed.

These items are **controlled** via the system:

- ◆ practically all lighting;
- ◆ most electrical power outlets;
- ◆ motorized lock of entrance door and door opener;
- ◆ motorized blinds and curtains and window opener.

These are the basic functions supervised and controlled by the system. But supervision and control must be made accessible for people with disabilities. The user interface of standard equipment is often inadequate. Every disability and every individual need may require a specialised solution for accessibility. This is the real challenge in a project like SmartBo where we strive to optimise accessibility for people with a wide range of disabilities.

Devices for the presentation of information to the user are the computer monitor plus recorded speech announcements. In addition, there are visual and tactile signalling devices, a text enlargement program, a speech synthesiser and a Braille display for visually impaired, blind or deafblind people. Input devices are



Jane Eriksen  
in the  
SmartBo  
home.

**SmartBo is not fully adapted for any disability in particular. The project focuses on ICT and assistive devices and solutions made with computer technology and electronics.**



**The goal is to give people control over their living in an apartment.**

different types of keyboards, alternative keyboards with overlays for pictograms etc., environmental control units (ECU) with infra-red signalling, speech recognition devices, a head mouse and standard and special switches.

There are basically three ways to control the system. Firstly via the computer (connected to the bus system with a serial interface), secondly via ECUs and the infrared receivers distributed over the apartment, finally via the standard EIB wall-mounted four-function switches.

The graphical user interface of the SmartBo computer program displays a bird's eye view of the whole apartment. Click to enter a room, or use the initial letter of the room's name (b for bedroom etc.), and see what objects are controllable and what their status is. For example you can see if a lamp is lit or not, or if a window is open or closed. You can switch the lamp on or off by clicking the mouse, pressing a letter on the keyboard, or touching the appropriate pictogram on the alternative keyboard. Open or close the kitchen window in the same way. For every controllable object, there is a range of alert levels to choose from.

For objects where a status change is important to ascertain, panels are shown on the computer monitor, sometimes with a voice announcement, when there is an alert, for example, the doorbell or telephone is ringing, water flow from a tap has gone on longer than desired, the cooker is overheated etc., the fire alarm is activated. For deafblind people, certain alerts are transmitted to a small vibrating device worn on a belt or in a pocket. There are four different patterns of vibration depending on the type of alert, e.g., doorbell, TDD or Braille-phone, fire alarm.

New client/server-based SmartBo control programs are developed in the BoMan-project run by Föreningen Furuboda. Financing is from the Information Technology In Practice programme. The first user interface created is a special text-based interface for people using the Braille display i.e. deafblind people. Responses from deafblind people working with the interface were extremely positive. Other interfaces will follow, i.e. graphical user interfaces for people with motor impairment and/or cognitive impairments.

A great advantage of this client/server-solution is that the client can be chosen for and adapted for maximum benefit for the user. You can use a palm computer, a notepad in a WLAN (Wireless LAN) environment or a normal computer, whichever suits you best.

All computers in SmartBo are linked together in a wireless network. So you can move freely with a computer on, for example, your wheelchair, and control the apartment at a distance. Beside the bed and the

entrance door are small boxes with a button, a red and a green lamp and two holes underneath. We call them goodnight and goodbye boxes. Pressing the button when leaving the apartment, or at night, when going to bed, you get either an "Everything OK" message or you are told what you have forgotten to do. That may mean you need to close the door to the patio or the window to the kitchen, turn the cooker or the water tap off. Messages are oral, visual (by a red or a green lamp on the box) or tactile (by rods protruding from the underside of the box). In that way, information can be received regardless of disability. Deafblind people feel the rods. If they don't remember the cause of the alert they can read it on the Braille display.

For example, some complex functions of the system contribute to the safety of older people. When a person leaves his/her bed at night dimmed lamps light the way from bedroom to bathroom. If s/he doesn't return to bed after a pre-set time, helpers could then be alerted.

Still within the house, extending the use of the computer, there are a range of other facilities available. These include a colour-printer, a scanner and a OCR program (Optical Character Recognition) that blind and deafblind people can scan text from display as Braille) and a ROM-changer (so that severely motor-impaired blind and deafblind people can access encyclopedias, dictionaries, literature, modem and Internet software).

Assistive devices software in a second

## SmartBo





computer will assist people with mental retardation, brain damage or dementia. The goal is to give them control over their living in an apartment, support their activities by giving them planning capacity and reminders from the computer and help them to communicate whether they can speak or not. A universal terminal (video telephone + text phone + voice phone) for signing people (also for hard-of-hearing or mentally retarded people) is installed to support their communication. There is a video door-phone for motor-impaired and elderly people and a special door-phone for deafblind people. Users want to know who is ringing their doorbell and if it is someone they really want to open their door to meet!

## Discussion and conclusions

While ICT and electronics offer greater opportunities to live a better and more independent life for disabled and elderly people, systems could be employed to control and supervise people in an unethical way. The integrity of the individual must always be protected. Ethical aspects are of paramount importance when future living conditions are to be discussed.

The costs of installing and adapting an apartment with new technology might be saved by reduced expenditure on assistant staff. It can be a very positive experience to be able to cope with doing things on your own without having an assistant always at your side. Nevertheless, this is no excuse to deprive disabled people of personal assistance. Money is saved when elderly people can continue to live in a safe way in their own homes instead of

**It can be a very positive experience to be able to cope with doing things on your own without having an assistant always at your side.**



moving into institutions. Probably many people would prefer to stay in their homes if this is an alternative. This, however, should always be a matter for individual choice. In the optimal case, thanks to the use of modern technology an individual will enjoy a full and independent life in spite of severe disabilities; at the same time costs to society may be reduced.

SmartBo was completed in December 2000. A total of around 1500 visitors came from all over the world including deafblind people from Sweden, Japan and South Africa.

A very important outcome of the project is to share information and a package, including a video film and two CD ROMs, is available to buy. The video shows the house in use and the CDs contain detailed descriptions and an interactive tour. The video has English subtitling.

## SmartLab

The work on "smart" living is being continued at The Swedish Handicap Institute in a new activity called SmartLab involving all departments of the Institute. Knowledge, experience and equipment from SmartBo has informed this project.



**Door phone for deafblind people (left)**

Information can be found on [http://www.hi.se/english/smartlab\\_eng.pdf](http://www.hi.se/english/smartlab_eng.pdf)

The Swedish Association of the Deafblind (FSDB) plan to start a project in Spring 2003 – called Villa SmartBo – on independent living for deafblind people. Villa SmartBo will be powerfully supported by advanced technology to assist deafblind people to live independently and have an active social life!

## Information about SmartBo

The film with Swedish subtitling and two CD ROMs is SEK 200 (approx. €20) Order no: 01801. The film with English subtitling "People using SmartBo" is SEK 150 (approx. €15). Both can be ordered from the Swedish Handicap Institute Phone +46 8 620 17 00, Fax +46 8 739 21 52 or via [www.hi.se](http://www.hi.se)



## Sensory integration dysfunction in deafblind children

For most of us, sensory integration occurs without conscious thought. That is, the organisation of information received from our different sensory modalities is then used to enable us to interact effectively within the world around us. In this article Gail Deuce, an experienced teacher of deaf and deafblind children, explores these ideas.



Gail Deuce

**W**orking with deafblind children, I have become increasingly aware of a significant number within this population who appear to experience difficulties in this area. It is not unusual to hear a teacher describing the child who can use his residual vision effectively or use his residual hearing effectively, but not undertake both at the same time; or the child who has to stop walking to listen; or again the child who has to look away before reaching for a toy. More than this, some deafblind children appear to experience major sensory dysfunction, experiencing difficulty processing and integrating the information received from all their sensory modalities.

Ayres studied the process of sensory integration in children with moderate learning difficulties and equated it to information processing whereby:

*The brain must select, enhance, inhibit, compare, and associate the Sensory information [from different channels] in a flexible, constantly changing pattern.* (Ayres, 1989, p11)

Ayres (1987) developed a theory that emphasised the

necessity for integration of information from the tactile, proprioceptive and kinaesthetic senses. Michaels (2002) later identified children with dyslexia, dyspraxia or ADHD as being more likely to have dysfunctional sensory integration than other children.

Whilst this work does not relate to deafblind children I felt there may be some merit in considering the development of the proprioceptive, kinaesthetic and vestibular senses in deafblind children, exploring whether those children within whom these senses are underdeveloped lead to the child experiencing sensory integrating dysfunction.

This thought was reinforced when I was fortunate enough to work alongside David Brown (then Head of the Sense Family Centre in Ealing), and became involved with a young girl with CHARGE Association. It was felt that this child was experiencing difficulty developing her proprioceptive, kinaesthetic and vestibular senses and integrating the sensory information received. David suggested that we consider implementing a Sensory

Integration Therapy programme. This proved to be quite a difficult challenge as it was necessary to obtain the advice and expertise of a physiotherapist or occupational therapist who had undergone specialist training in this field. Eventually such a specialist was located and an individual programme established with immediate positive effects.

The success of this approach encouraged me to look further at the development of the proprioceptive, kinaesthetic and vestibular senses in deafblind children and to consider the possible implications for the child experiencing difficulties in these areas.

**For most of us, sensory integration occurs without conscious thought.**

### Case studies

#### Joshua

I first met Joshua at [redacted] and the following observations were made during a three month period:

- Joshua had established a series of repetitive behaviours around the home and the garden. Any change to the routine, such as moving the position of the dining chair, playing on the route) [redacted]



Joshua stopping and turning back to begin the sequence of actions again and again until he was familiar with the alteration made and could then continue on his 'journey'. As a result of this behaviour he had been given a tentative diagnosis of autism;

- ◆ Joshua had a moderate hearing loss and wore two hearing aids. He was only able to walk when wearing the hearing aids and would revert to crawling when the hearing aids were removed;
- ◆ when crawling, Joshua was not able to use diagonally opposite limbs. In addition he crawled with his hands fisted and his feet held off the ground to reduce the amount of information received;
- ◆ Joshua was fixated by bright lights and mirrors;
- ◆ Joshua was very limited in his ability to actively explore his environment in other ways. He was only interested in one video that was played repeatedly at home. He would also hold a long thin piece of flex between one finger and thumb of his right hand.

Large movement games (e.g. swinging and jumping with an adult) were introduced that Joshua really enjoyed, and jumping became the one activity that Joshua would request by reaching up and taking the adult's hands (almost endlessly). After a term in school there was little change in his behaviour and only limited progress made.

The advice of a specialist physiotherapist was sought. Eventually the school paid for a private therapist to work with Joshua as those therapists already involved

with children in school did not have the specialist training required. It was noted that Joshua was experiencing difficulty in a number of areas relating to his vestibular, proprioceptive and kinaesthetic senses.

An individual sensory integration programme was set up and implemented through eight sessions per week.

After six weeks many new skills were emerging, including:

- ◆ exploring playdough;
- ◆ beginning to mouth toys;
- ◆ more eye contact and social interaction;
- ◆ independent exploration of a range of toys;
- ◆ looking at his own reflection in a mirror;
- ◆ responding to object cues;
- ◆ simple problem solving (e.g. moving a book from his chair so that he could sit down).

## Harry

Harry is a little boy with CHARGE Association. He has a profound hearing loss, glaucoma and is registered partially-sighted. He has a tracheotomy and on-going health problems.

Consequently he has full-time nursing support in school.

Due to long periods of hospitalisation, Harry was not referred to the specialist teacher team for input regarding his sensory needs until he started school at the age of four.

Observations of Harry over time showed:

- ◆ he was reluctant to interact with others;
- ◆ the use of a Resonance Board was a huge breakthrough. Harry would become very excited and enjoyed experiencing strong vibrations. Use of this equipment supported the development of

anticipation, turn-taking and cause and effect;

- ◆ Harry was not able to transfer these skills to other situations despite consistent and frequent exposure to similar activities presented in other environments;
- ◆ sign support was introduced together with other augmented communication modes (e.g. use of object cues). Harry began to respond to some everyday signs but made no attempt to imitate the signs himself;
- ◆ anti-social behaviours began to emerge, including scratching and pinching.

It was initially suggested by Harry's teacher that these behaviours were the result of naughtiness and attention seeking. This interpretation of Harry's behaviour was reviewed and the suggestion made that these behaviours (although socially unacceptable) were Harry's attempts to obtain information from his world. This view was supported by observing that Harry pinched toys and objects given to him, and not just people.

Physical joint compression work was introduced under the guidance of an occupational therapist (specialising in sensory integration work) and after the second session Harry began to initiate these activities himself. When these activities were undertaken Harry's pinching and scratching noticeably reduced for a period of time afterwards. He was also felt to be much happier, smiling and willing to interact with others. At the end of the second session Harry imitated waving 'goodbye', a behaviour not previously observed. A more detailed

**The organisation of information received from our different sensory modalities, is used to enable us to interact effectively within the world around us.**



# Objects of Reference ... Objects for Conversation

## The Origins and Development of Objects of Reference in Europe

Marleen Janssen, The Deafblind Department, Instituut voor Doven, The Netherlands.

*In this article Marleen Janssen takes a brief look at the history of communication methods for deafblind people in the past and then focuses on the methods that inspired the staff at Instituut voor Doven in their work, past and present, to develop specialist provision. She discusses the people and the methods they used to support communication and the way in which objects of reference have been used in developing conversations with deafblind children. Marleen gives lots of practical examples and warns of the importance of the proper implementation of methodology in everyday practice.*



Marleen Janssen

### Conversations with deafblind people in days gone by

It is fascinating to see how much was already known about communication methods for deafblind people around a hundred years ago (Lenderink, 1907). Case reports on well-known deafblind people tell us that conversations with them and others took place using a variety of methods including, finger-spelling into the hand, Tadoma, tactile signing and a combination of all these.

We know the success stories of these well-known deafblind people. But what was it like before these deafblind people were able to communicate at a symbolic level, in other words before they had mastered these forms of communication – symbol systems?

A report about James Mitchell, the son of a Protestant cleric from Scotland, who was born in 1795, was one of the few deafblind children, who were recognised then, in whom both senses were limited from birth. This contrasts with the deafblind children I mentioned earlier, whose dual sensory disabilities were acquired as they began to grow up. This makes a great deal of difference for the development of communication.

From birth, James Mitchell was

totally deaf but possessed some residual vision. The nature of the cataracts affecting his eyes was such that he was able to distinguish a number of colours. He also had an extremely well developed sense of smell and sense of touch. His communication was limited but effective, as you will see in the following example. When a person came into the room, he knew immediately from the smell, this then led him to where

the stranger was standing or sitting, and the visitor was then immediately subjected to a tactile investigation. He also used his sense of touch to discover whether or not the stranger was wearing boots. James passionately loved horses, and the boots gave him a strong clue as to whether his visitor also shared this interest.

Anger, joy and sadness could be clearly observed in James; he showed these emotions by emitting discordant noises, loud bursts of laughter and by crying (Lenderink, 1907, p. 83-87).

So thanks to these individuals and their recorded cases we know a little about how the educators of that time struggled to engage in conversation with deafblind people and to provide a language to describe everyday events.



**Marie Heurtin using Tadoma, a method of speech reading using the hand.**



## The "Conversational" method of Dr. Van Uden

The task facing Jan van Dijk at the beginning of the 1960s was also a difficult one, namely to offer congenitally deafblind children a good upbringing and a good education at a special new department which was to be set up in Sint-Michielsgestel. Thirteen deafblind children were admitted to the department within a short space of time. Jan had trained as a teacher of deaf children and as a special educator. In order to be able to perform his new role successfully, he studied various methods which had been developed for deafblind people in other countries. He spent some time at Perkins in Boston, becoming acquainted with the methods used there.

He observed the "identifying method" as applied by Howe with Laura Bridgman. Communication was learned via the stimulus-response model, with the teacher always being the one who named the objects. For example, the teacher places a ball in the child's hand and says, "ball". Or the teacher shows the child a picture under which the child must place a written word.

Jan van Dijk also studied the methods used in the former Soviet Union by Sokolansky and Meshcheryakov. He learned from this how important it was to create opportunities and give children sufficient scope to build up representations of the world around them and to implant these mental images in their memory (Meshcheryakov, 1979; Enerstvedt, 1996).

But the most important source of inspiration for Jan van Dijk remained Dr. Van Uden's "conversational method", in which Jan had been trained as a teacher of the deaf, just like my own predecessors. The essence of this method lies in the child-centred approach during "the conversation". Dr. Van Uden developed the method of "seizing and playing a double act".

This method can be characterised as a natural didactic method that is also used by mothers of young children: the mother "seizes" the utterances of the child by repeating them in the right words and in the right sequence, and thereafter adds her own contribution. She does this in natural situations at moments when the child is motivated and awaiting her responses. Van Uden (1977) describes many examples of such conversation moments, e.g.

Mother comes to the cot, drawn by the sounds her baby is making. The baby immediately begins to move its arms, legs and facial features, half-crying and half laughing. The mother understands these expressive movements, these non-verbal expressions of "body language" and says "Are you hungry? Come here, my darling".

These two sentences represent a conversation: the first sentence contains the words which the baby would have uttered if it were able to talk: I am hungry", verbalised by the mother as "Are you hungry?" The second

sentence is the mother's own contribution to conversation. "Come here my darling". The baby does not yet understand this second sentence, but, through actions, the mother makes herself understood to the child out of the cot. In this way the child quickly comes to understand what the expression "Come here" means, and, for example, stretch out its arms when it hears these words (Van Uden, 1979). The method is based on an anticipatory approach to the motivation of the child; because the child is not yet able to build up expectations regarding the reaction of the mother. Repetition and predictability in the conversation routine play an important role here.

Afterwards, an important support tool in the method is the recording of the conversation moments in drawings and writing. The art was always to select the most characteristic elements, those that had the most impression on the child, and then to provide a language for those elements (Van Uden, 1977).

## Symbol formation in the Van Dijk method

### Symbolic function

Dr. Jan van Dijk developed a communication method for deafblind children in which becoming aware of symbolic function is seen as a crucial process. In the development of children without disabilities, symbolic function separates thought from action and enables the child to evoke internal representations of things, people and events, even when they are not present. The child discovers that these representations can be named using a word.

In congenitally deafblind children the process of becoming aware of the meaning of symbols takes many years. The Van Dijk method is based on the idea that symbol formation must take place within a social context, in which the initiative lies with the child.

When developing symbolic behaviour it is essential at all times to try and match the child's spontaneous interest, to try and create conversation moments from the individual signs from the child as a starting point.

Like Werner and Kaplan (1963), Jan van Dijk believes that these signals must initially have something in common with the object to which they refer. For example moving the arm in a circle to signify "swing" or moving the upper body up and down to signify "swing". The essential point is that the child is to discover relationships for itself. Since at first children are usually dealing with symbols that involve simple actions, it is important to train the use of the symbols properly.

### The importance of pointing and reference

In addition to the development of natural language, symbol formation is also encouraged enabling the child to make references. In their communication, children are particularly when using words or gestures, to





conversation partners refer to things about which they have a shared knowledge. For example, the word "table" refers to a representation in the minds of both conversation partners. The word refers to something that is not actually present; it is a substitute for it. This can be called a representative reference.

Pointing is a preparation for this referential function of the word. A small child uses its finger to point to a photograph of the wall and begins to babble; the child's mother follows the finger and says, "Yes, that's Grandpa". The behaviour of the young child must be seen in the same way as pointing. For example, when the child picks up an object, holds it up and wants the other person to look at it. When people point to something they step outside of themselves, as it were, and make an appeal to the other person.

Since pointing with the finger can be regarded as an extension of looking at something, it is rarely found in those with a visual disability. Instead, this function is replaced, for example, by tapping gently on something, perhaps on a plate and then tapping the child for whom that plate is intended. This action is saying, as it were: "This plate is for Peter". Another example might be first

tapping the child's body and then tapping one's own body, as a way of saying: "You and me together". No words are used. Words replace a certain notion; the act of pointing does not. Although pointing refers to something, it does not replace it (non-representative reference).

Very clearly, the use of objects of reference is an extension of pointing.

## Objects of reference

When a child begins to succeed, after repeated experience, in forming a representation of how certain activities proceed, certain objects which are (or have been made) the most characteristic for the child can acquire a referential function.

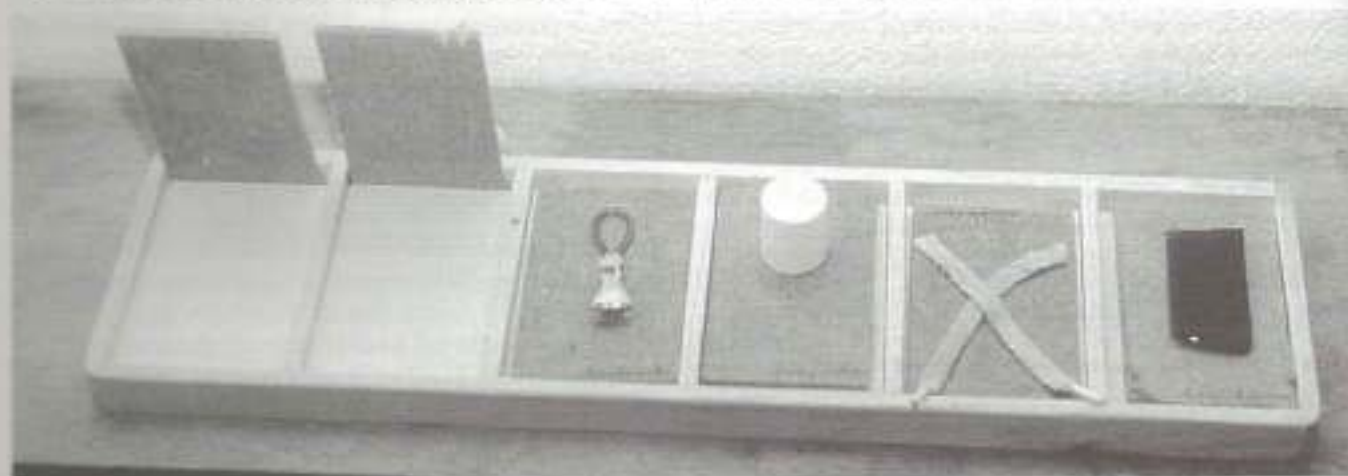
For example, when a certain beaker is presented at a certain time each day, the child will call up the representation of "I'm going to have a drink" when offered this beaker. In this situation the beaker refers to "having a drink".

Once the child has become aware of the referential function of an object, it can be taught to refer to the activity in question by taking the object, or using a schematised form of it. Abstracted objects of reference may be miniature objects or "a part of the whole". If the child wishes to cycle and the bicycle is not near by, it can be given the opportunity to refer to this activity by showing a "piece of a bicycle", for example to key to the bicycle lock.

## The importance of objects of reference

The importance of these objects of reference cannot be over emphasised. They give the language-less child an opportunity to express its wishes actively; the totally blind child does this using "tactile" symbols, while the partially sighted child uses drawings of the objects to be referred to in, for example a "reference book".

Using these objects of reference, experiences can be recorded in calendars and conversation books. The objects of reference offer something tangible – a concrete means of talking about experiences and events. Recording the events gives the child opportunity, for example, to look forward to a pleasurable event. The child can also express wishes with regard to the future, as well as being able to look back at events from the







past. The deafblind child is thus given an opportunity to become a person with a present, a past and a future.

## From signal to symbol

Objects of reference can develop into true symbols if they increasingly come to function in differing situations (decontextualisation). For example, the beaker is no longer solely that one object which is used in the morning and the afternoon, but is also an object which is used by other members of the child's group, which can be bought in the shop, which can have different shapes and colours, which is washed after use, and which you can talk about: "When are you going to buy a new beaker?" By allowing the object of reference to be used in a conversation in a range of different ways, often in combination with gestures or speech, the child abandons the idea that an object of reference must always lead to a particular action, but comes to realise that the object of reference can enable things to be given a name, for example: "That is a car". The child internalises this and realises that everything can be given a name. In this way it is possible for the child to detach itself from the purely pragmatic world.

## A symbol system

Once the child has discovered that people are able to participate in each other's worlds of action and thought, the need arises to do this systematically. A language system must be chosen. For deaf and deafblind children, development in the direction of sign language is the obvious choice. However, for some congenitally deafblind children it is possible to combine their own gestures with tactile symbols and Braille, and also with fingerspelling or writing (Van Dijk, 1965; 1967; Van Dijk & Janssen, 1993; Van den Tillaart, Janssen & Visser, 2000).

## Objects of reference in everyday conversation

In the 1970s my colleague and predecessor Mary Rose Jurgens described the important functions of objects of reference as being:

- the ability to characterise;
- the recording of experiences (Jurgens, 1977).

The characterisation of experience takes place by choosing a characteristic detail, taking the interest of the child as the starting point; this means that the characteristic detail can vary greatly from one child to another.

In the early 1980s ever more refined systems were being used with individual children. I began the Deafblind Department abstracting tactile objects of reference for a blind child in relief paper. (Janssen, 1984).

## Developments from the 1980 till now

In the early 1980s the number of deafblind children in our Deafblind Department had grown to 35. We developed all kinds of communication systems differentiated on the basis of the interests and capabilities of different children. The conversation always the central plank of these approaches, and objects of reference played a supporting role in establishing and sustaining the conversation.

In the mid and late 1980s, the use of objects of reference was becoming more and more well established not only for the deafblind, but also for other groups of children and adults with multiple disabilities.

## Research in the field

In 1989 Charity Rowland and Philip Schweigert studied the use of conceptually concrete symbol systems with deafblind children. Their studies showed that objects of reference were extremely useful for non-speaking individuals who were deafblind. The use of objects of reference is described in many publications within the context of "activity boxes", "anticipation shelves", "calendar systems", and often targets individuals who are deafblind. A number of augmentative and alternative communication (AAC) systems have been developed for use with non-speaking individuals since the mid-1980s. These have been thoroughly reviewed by Beukels & Mirenda (1998) and in the UK by Park (1997). These symbol systems require fairly well developed cognitive skills as well as good visual acuity.

Recently Rowland and Schweigert (2000) showed that the objects of reference are also useful for individuals with a broader range of disabilities: mental retardation, developmental disabilities, pervasive developmental disorders, severe visual impairment, severe orthopaedic impairment, multiple disabilities, and deafblindness. They have also demonstrated that tangible objects of reference can serve as a bridge to other symbol systems, including abstract systems (such as speech or manual sign language) and that learning to use tangible symbols does not interfere with the acquisition of speech.



## Implementation: back to the beginning

In our own Deafblind Department we have seen a development since the 1990s which corresponds with developments elsewhere. Our Department has doubled in terms of number of children (now 65), with the result that we have also acquired many new staff. The use of objects of reference, like the use of other forms of communication, demanded standardisation and accurate recording and transfer to the new staff members. We acquired five new communication chests in 1993, which contained standardised materials but which could be adapted for each individual child. One disadvantage was that we were unable to provide all those new people with adequate supervision and induction support in accordance with the original principles as related here.

The consequences of this were:

- ◆ when a new pupil joined us it was often the case that a communication chest had already been ordered before the child arrived, and before we had a chance to observe what that child's capabilities were and take them into account properly;
- ◆ attention was focused too much on planning and not enough on conversing;
- ◆ the initiative sometimes lay too much with the teacher rather than the child;
- ◆ there was too much of a tendency to drop into the fixed routine, without building in surprise elements and without eliciting conversational moments.

## So we learned the lessons ...

In conclusion therefore, I would like to stress that the use of objects of reference is only worthwhile if the educators (parents, teachers, caregivers and others involved in the child's upbringing) are well aware of the various functions of the objects of reference and know how they can use them. For us this meant going "back to the beginning" as regards implementation: explaining how objects of reference should be used in the context of everyday conversations. Good interaction and communication support and adequate training of educators proved to be a necessary condition for this (Janssen, 2001, 2002; Van den Tillaart, 2001) with which to have the impact it deserves.

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# Out and about in Russia ... is it just leisure?

From the moment that Usher Forum was founded we decided that we would create services both for deafblind people of different ages and for families with a deafblind member. Our organisation is nearly 5 years old and we are trying to develop our leisure programme.

**For some deafblind people the leisure programme became a return to the time of having good vision and hearing.**

**T**he leisure programme includes three strands of work:

◆ **communication club**

This is held once or twice a month and is open to every deafblind person or family member. Moreover, any of them can invite friends or anybody they wish to participate in the meeting.

◆ **parties**

Traditionally (we already have our traditions!) we celebrate birthdays and hold New Year and Spring parties with group competitions, quizzes and real fun.

◆ **excursions**

I will talk about our excursions in detail.

Every excursion has several targets to be accomplished. I will point out some of them. The one on the very surface is *visiting an interesting place*.

Being lonely, having mobility problems or being too busy in every-day life (in the case of family-members)

creates great problems when trying to visit the many historical and cultural centres and museums situated in Moscow and the region. Deafblind people have difficulties with communication, special guidance and interpretation (we do not have any interpretation services for deafblind people in Russia at the moment). So, voluntary guide-interpreters help people to visit these interesting places.

Another is that a visit represents a *real event* in their life. This is what we really want to present to all the participants of our excursions. Most deafblind people and their family members share with us their strong concerns that they don't have exciting events in their monotonous lives.

Both deafblind people and their family members feel they have a lack of stories to

share with their friends. This leads to the narrowing of communication circles around a deafblind person and around families who have deafblind members. Attending a real event provides a good opportunity to build content for future conversations with peers and colleagues.

The main participants in our excursions are adults with acquired deafblindness. They used to live much more active lives and had more opportunity for free time. Deafblindness practically closes that door to culture and this is not only because of their deteriorating sight and/or hearing. The situation within such a family usually becomes very difficult in our country and it is not for them to afford to go anywhere. The aim of the leisure programme is to return them to a *normal life* (in a way). Many people visit museums and galleries on Saturday and Sundays. We do THE SAME as everybody else does.

The deafblind people we asked stressed that the excursions gave them the opportunity to continue *learning*:

"I like going with you and learning new things" (Elena S.)

"I am fond of reading authors. It would be nice to visit museums of Russian writers" (Julia L.)





## LEISURE ACTIVITIES

*"When I was a school-girl I hated going to museums. I have mobility problems but nobody wanted to wait for me and I needed more time to see everything. Every time I went I got lost. I like to go with Usher Forum because I am not afraid of getting lost with you and you give me enough time for everything"* (Elena V.)

For some deafblind people these leisure programme tours became a return to the time of having good vision and hearing. For most of them it wasn't a painful meeting with the past at all.

*"Though I visited here when I was younger it was a pleasure to come back to a place that I liked to visit when I was young and beautiful"* (Nataly K.)

For the families of deafblind people we have some other targets. Firstly we offer them the possibility of *meeting different deafblind people* and seeing that it is possible to survive in such a situation; and secondly that there are different *methods of communication* that can be used with deafblind people.

Within the Leisure Programme it is quite common to find that when a deafblind mother cannot come with us, her sighted and hearing daughter and her husband will come with us instead. Sighted and hearing children of deafblind people often participate; mothers and grandmothers, their friends and relatives – we all know each other! The chance of an excursion provides a comfortable opportunity to get included in the group or to stay outside of the group but keep an eye on it. In our view, encouraging a mixture of different people creates a positive basis for accepting problems.



These excursions mean that parents get the rare opportunity to have a real rest, that very break which they dream about constantly. On a few occasions during a recent trip, mothers were able to absolutely relax. One of them smiled and said: "I don't even know where G. is now! I only know that I cannot be worried about him here – he is not alone here. He is safe" (Ella A.). Another mother was sitting alone on board the ship watching the passing trees on the other river bank. "Are you not feeling lonely?" I asked. "No, thank you. I am RESTING!" (Lilia H.)

Finally I want to tell you about our final trip of the year. Traditionally we close the season with some far-away tour. This year we went to the New Jerusalem which is a historical and cultural centre 75 km to the West of Moscow. A 17th century monastery was created as a copy of Jerusalem so that Russian Christians could visit the very important religious places – in Russia. When we visited it was the first day of summer and the weather was bright and happy. There were many new participants in the group. Victoria has Usher

syndrome, type 2. The family found us in February, but Victoria didn't want to come to the leisure club or to our parties. However, this time Victoria, her mother and aunt came with us. We were happy. Galina G. – Victoria's mother – said to us: "My daughter has stayed at home for four years. She didn't want to go anywhere. Here she saw for the first time that a person with Usher syndrome could meet other people and continue learning new things about the world".

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**"I like going with you. I like learning new things"**





# Inspiration and hardwork lead to a specialist Unit for the education of deafblind children in Greece

**T**he establishment of the first Unit for the education of the deafblind in Greece is a dream come true. The struggles of the Association of Parents, Tutors and Friends of the Deafblind have been worth while as the Ministry of Education, under the lead of the Director of Special Education, has established the first Unit for the education of the deafblind in cooperation with the Center of Education and Rehabilitation of the Blind (K.E.A.T.). The Unit will open up and start its work in the modern premises of the new building of K.E.A.T. in November 2002.

The process of the establishment of this Unit started about fifteen years ago, when Ms Argyro Raptou, a teacher at K.E.A.T., heard of Kosmas, a deafblind child who had been born with residual vision and residual hearing. Kosmas had been abandoned by his family and had been taken on by a state institution responsible for the care of abandoned children with multiple disabilities. Ms Raptou contacted her friend Calliope Karanikola who, up to that time had devoted her life to missionary work in various countries in Africa and Asia. Calliope Karanikola decided to foster Kosmas

and at the same time she started a struggle for his education. In the meantime, they discovered other children with similar problems and came into contact with the psychologist Mr. Jacques Souriau, from France. Jacques' help was invaluable, firstly in the educational advice he gave, and secondly in the advisory support he offered to the parents, tutors and professionals who were working with these children. Additionally, an in-service training program aiming at the specialization of the K.E.A.T. professionals started through visits to Deafblind Units in Europe and America. Following the enrolment of three deafblind children in the nursery school of K.E.A.T., and in order to answer the need for better awareness of the professionals working with the deafblind children and to keep abreast of the latest developments in the field, in-service training programs were introduced. Two K.E.A.T. professionals participated in these programs. This team of professionals comprised the core of the Association of Parents, Tutors and Friends of the Deafblind children. The first president of the Association was Calliope Karanikola. The next step



Photo courtesy of Greek Association of Parents, Tutors and Friends of Deafblind Children.

**Karanikola's dream was not only to see the Unit for the education of the deafblind children to be established, but also the establishment of halfway houses for deafblind individuals.**

was the aim of the members of the Association to establish a Unit for the education of deafblind children and to have this recognized as a separate independent, education department.

Until now, deafblind children in Greece have either been covered by "COMMUNICATION" - for blind children with additional disabilities - K.E.A.T. or by other units dealing with children with additional disabilities. Lighthouse for the Blind Greece has embraced the idea of a Unit for Deafblind Children from the very beginning, not only by providing the facilities of the offices of the Deafblind Association, but also by providing facilities for children's creative activities. Calliope Karanikola's dream was not only to see the Unit for



education of the deafblind children to be established, but also the establishment of halfway houses for deafblind individuals. Kosmas was growing up, and as she believed in the achievement of her goals, she fostered a second child named Apostolos. The Association had the full support of many specialists from the international field, including Dbl and EDbN, with their aims for a deafblind unit. The result of this cooperation was the planning of a series of seminars on subjects concerning the deafblind, which were organized with the sponsorship of K.E.A.T. and included five two-day or three-day seminars with total duration of 60 hours. There were 95 specialists – teachers, music, occupational and physical therapists, psychologists, mobility instructors and parents – who attended these seminars. The objective of the seminars was to create a network of professionals who would be able to deal with the support needs of deafblind children in various areas. The seminars were planned with the help of William Green, (Lega del Filo D'Oro), who also coordinated the seminars.

The seminar lecturers who were invited to come to Greece were experts in the field and came from many different countries. They responded enthusiastically to the invitation and gave their lectures free of charge. They contributed, not only in their input to the seminars, but also in offering their advice for the establishment of the unit itself. The honoured guests were: William Green (Lega del Filo D'Oro), Tony Best (Sense), Jacques Souriau (GRESAM), Inger Rodbroe (NUD Dk), Dennis Lolli (Perkins School for the

Blind), Emmanuela Storani (Lega del Filo D'Oro), Toulia Matsa (Greek Association of Parents, Tutors and Friends of Deafblind Children), Ursula Heinemann (Austria), Bernadette Kappen (Overbrook School for the Blind) and Mary Guest (Sense).

Mr. Stratis Hatzicharalampus, sociologist and member of the Board of Trustees of K.E.A.T., played a major part in the planning of these seminars and the establishment of the Unit itself. The Unit also had the unreserved backing of the President of K.E.A.T., Mr. Andreas Kravaritis. The seminars were brought to a close in September 2002 and their completion took on a festive air as it was accompanied by the formal announcement of the establishment of the deafblind unit, along with the simultaneous meeting of the Dbl members. The conclusion of the seminars together with the establishment of the unit for the deafblind children was hailed with a short speech by Mr. Michael Collins, President of Dbl, and Kevin Lessard, Director of Perkins School for the Blind.

The Deafblind Unit will start with five to six children and its educational program will be supported by eight to nine professionals in the framework of cooperation between the Ministry of Education and the Ministry of Health and Welfare. The educational staff will consist of: a psychologist; a music therapist; an occupational and a physical therapist; a specialist teacher; a kindergarten teacher; a mobility instructor; a child-care worker; a visiting nurse and the necessary domestic



staff. The needs of the children will certainly increase in the future and the aim is to be able to support all children as necessary. The staff continue their personal development in the field of special education by attending courses and seminars organized by foreign organizations. In the context of this collaboration, one of our occupational therapists, Georgia Pappa, is currently at the Perkins School for the Blind attending the Perkins-Hilton Program.

Sadly, Calliope Karanikola, the woman who inspired so many people in Greece, is no longer with us to rejoice at Kosmas' first day at his new school. She left this world in January 2000.

Today Kosmas is a member of Despina Mylona's family who continues Calliope Karanikola's difficult work.

**Menelaos Tsaoussis**

*Photo courtesy of Greek Association of Parents, Tutors and Friends of Deafblind Children.*



## CAUSE: A developing project

**W**e are now one year into the eighteen months of the CAUSE project and can see that the various elements of the project are really starting to come together.

CAUSE is funded by the EU Rare Diseases Programme and aims to promote work with CHARGE and Usher Syndrome across Europe. This will be done through:

- ◆ "Adapting to Change" – the CAUSE Conference: a joint meeting of the CHARGE and Usher Syndrome Networks.
- ◆ The production of information leaflets relating to the two conditions, which will be distributed in a variety of formats and languages and will also be accessible through the CAUSE website.
- ◆ Undertaking two key surveys: "Maintaining Independence" A Lifestyle Survey of people living with Usher Syndrome in Europe. "A Behavioural Survey of Children with CHARGE" – based on a wider dissemination of research projects currently being undertaken by Jacques Souriau in France and Tim Hartshorne in the USA.
- ◆ The production of a bibliography to include articles and other resources on both CHARGE and Usher.
- ◆ The development of an overview of the support and services currently available to families with CHARGE or Usher who live in the partner nations.
- ◆ The production of guides to good practice, which will aim to highlight new and innovative work with both conditions within the partner nations.

In Italy in October, the CAUSE project partners held their final meeting before the conference. This gave us the opportunity to



review the project to date and plan the detail of the conference and the information to be produced by the project.

As at previous meetings, the various representatives spent time in sub-groups to discuss specific aspects of the project as they relate to Usher and CHARGE. The CHARGE sub-group used some of their time together to write two of the information factsheets that will eventually appear in the CAUSE project folder. The Usher subgroup

very much focused on the programme for the conference.

CAUSE is about promoting awareness of Usher and CHARGE. The partners have identified broad target groups to receive information and the project workers plan to produce accessible, user friendly information resources to meet the needs of these groups. We plan only to produce a written report of the two surveys, but also to produce a video of interviews with people who have taken part in those surveys. The factsheet on functional effects of Usher Syndrome will, for example, be based on case studies to which we hope that people with the condition will be able to relate. The factsheet on resources will be based on findings of the Usher lifestyle survey; highlighting the services and resources that people with Usher from around Europe find to be of greatest benefit.

Throughout their three meetings the representatives from the p



Marylin Kilsby chairing the Usher Sub-group.



organisations have become increasingly aware of the strengths and gaps within their own information resources. Our aim is to produce a resource folder that will address some of these gaps, signpost further sources of information and be of equal interest and use to a professional working with CHARGE children in Germany as it is to a person with Usher in Spain.

## The CAUSE Conference "Adapting to Change"

The conference will bring together the CHARGE Network and the European Usher Syndrome Network. The two themes of the conference are "Adapting to Change"; which Dr Margaret de Feu from the UK will be exploring in her keynote presentation and "Identity and Being" which Carol Brill-Doran a member of the EUSN from Ireland will address from her individual perspective.

We are pleased to be able to confirm that David Brown and Dr. Tim Hartshorne will be flying in from the USA. David will be presenting

his paper "Sensory Integration: A special challenge for CHARGE", whilst Tim will be presenting the findings of the CHARGE Behavioural survey. There will also be an opportunity to learn about recent developments in Usher research.

The chair of the conference will be William Green, Vice-President of Dbl. A wide range of speakers and

workshop leaders specialising in both Usher and CHARGE will be taking part in the conference. Time is included for discussion and individual networking. The conference will also provide an opportunity for the two networks to look to the future. We hope that many of you will come and join us in March.



Marylin Kilsby, Jenny Towland, Hetty Bailey, Linda Linnett and Hanna Pittroff.



## The CAUSE Conference

27-30 March 2003

Hanover International Hotel, Hinckley, Leicestershire, UK

### Fees

Family rate: €250 per adult, €85 per child for up to 2 children, any additional children free.

Individual: €400

### For further information please contact:

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# Extraordinary People: Bob and Michelle Smithdas



Theresa Madden Rose, Ph.D is currently a Technical Assistance Specialist with The National Technical Assistance Consortium at Helen Keller National Center, Sands Point, New York, USA. Here she describes the achievements of two of her colleagues, Bob and Michelle Smithdas.

For more than twenty-five years, the staff of Helen Keller National Center in Sands Point, New York, has been privileged to witness extraordinary accomplishments by extraordinary people. Many people with deafblindness from all over the country come to The Center as students for periods of training during which they learn skills which assist them in their adjustment to daily life. Several other remarkable individuals who are deafblind are professionals on our own staff. Two such extraordinary people are Bob and Michelle Smithdas.

Bob Smithdas achieved notoriety when he earned not only a bachelor's degree, but also went on to earn a master's, and four honorary doctoral degrees. Hence he became Dr Bob Smithdas. His life story, however, began long before that. At the age of four and a half, he contracted cerebro-spinal meningitis and lost his vision and nearly all of his hearing. He later became totally deaf. In his first autobiography, 'Life at My Fingertips,' he noted that "unable to hear the sound of my own voice, I gradually lost my feeling for the pitch and stresses that give speech its human character." Dr Smithdas told me that he has "always been content to find out if I could overcome the obstacles of deafblindness for myself, and the challenges were the things that gave me my 'highs,' because they showed that everything is possible until you prove it impossible!

Besides I had a rather stubborn streak when I was a kid, and if you said I couldn't do something, I'd try to prove you were wrong and I was right."

He certainly has done that numerous times. We have all, especially people with deafblindness, benefited from his stubborn streak. With Helen Keller and Peter Salmon, Dr Smithdas played a vital role in the development of legislation in the USA authorising the establishment of the Helen Keller National Center for Deafblind Youths and Adults. At the age of 77, he continues to serve as Director of Community Education at HKNC. Bob's sometimes gruff, stubborn exterior is balanced by his sensitive poetry. In "Shared Beauty," he remarked, "I call it Life, and laugh with its delight. Though life itself be out of sound and sight." In addition to "Shared Beauty," Dr Smithdas is also the author of another collection of poems, "City of the Heart."

Michelle Smithdas was born hard of hearing and became totally deaf at the age of 15. After a snowmobile accident during her senior year at Gallaudet University, she lost her vision. Michelle met Bob when, in 1972, she came, as a student, to Helen Keller National Center. Three years later, they were married. Michelle is an instructor in the Communications Learning Department at The Center. In an interview printed in The Deaf American in 1976, Michelle said that she learned courage and determination from Bob. When



Michelle decided to acquire a cochlea implant in 1994, how Bob kept his opinion to himself after she had made her own decision. When the implant was turned on, the first sound she heard was Bob's voice. Michelle described the experience as "thrilling."

Like many Americans, Bob's garage filled with power tools which he uses to make repairs in the home which he and Michelle share. He is also a gourmet cook. Michelle is an excellent baker.

American television journalist Barbara Walters described her 1988 interview with Bob and Michelle Smithdas as the most memorable of her career. In the November 2001 'Power' issue of Ladies Home Journal, Ms Walters named Michelle Smithdas as the woman who most inspired her. On November 7, 2001, Barbara Walters presented the Helen Keller National Center Lifetime Achievement Award to Dr. Bob Smithdas.

Those of us who work in the field of advocacy for people with disabilities sometimes fail to recognize the achievements of our colleagues. Because of people like Bob and Michelle Smithdas, doors are open which had not even been approachable during Helen Keller's lifetime. That is truly extraordinary.



# Thank you Anneke!

As The Acquired Deafblindness Network met to hold their fourth Seminar in Switzerland, Anneke Balder reflected on its development over the years.

For the people who do not know the Acquired Deafblindness network already, I will start with a brief introduction of the network. We started in 1989 as a small group of isolated professionals who met each other during a European conference of the IAEDB (the former DbI). The IAEDB was founded as an organisation in which teachers and educators of deafblind children met each other at conferences and sub-committees. The subjects of plenaries and workshops in the conferences were all based on congenital deafblindness. That is not a surprise because this was the area of over riding interest at that time. In 1989 there was a slight change as some professionals, working with people with acquired deafblindness met each other during the conference in Warwick (UK). I was a member of this small group and we had several lively and sometimes emotional discussions about our work as most of us were "lonesome" cowboys in our own countries, who had to fight, in isolation, for a better life for people with acquired deafblindness. We decided that we wanted to meet each other on regular basis and our first "warlike" deed was to ask for official recognition as a sub-committee through the IAEDB. We succeeded and our association became a fact!

Because we were not more (and less) than some isolated professionals, the main subject during our first meetings was how to reach other isolated professionals and how to bring them in contact with each other. The idea of having a seminar was born! The first one was organised in 1994 in The Netherlands. In the program different aspects of acquired deafblindness were represented

and the best thing was that 60 isolated professionals felt less isolated afterwards as they met people with exactly the same problems.

Two years later, in Poltiers (France) we had a real theme: the United Nations Standard Rules for Handicapped people. Three sub-themes from these standard rules were the subject of the seminar: accessibility, rehabilitation and support services. There was a lot of discussion of working experiences and ideas about these subjects and a lot of participants got the feeling that they were no longer lonesome cowboys! Plans were made to do some things in co-operation. For our colleagues in France the seminar was a big success. Soon after the event they started making plans for a resource centre for acquired deafblindness and this centre is already successfully up and running.

During the third European seminar, the subject elderly deafblindness became a conference theme. The programme covered a wide variety of topics. Most participants went home with a lot of inspiration, but they also had a shared feeling of helplessness because this was a growing and unrecognised problem.

Now we are at the start of the fourth seminar. We have bigger ambitions than ever and there are a lot of challenging subjects:

- ◆ the growing number of old and very old people. We still need to know how to organise rehabilitation services and how to get elderly deafblindness on the agenda of the geriatric services.
- ◆ the international classification of impairment, disability and handicap of the World Health Organisation.
- ◆ the development of the continuing discussion with



**Anneke is making a career change and moving on after making a great contribution to putting this important area of work on the agenda.**

deafblind people and their organisations about all these matters, national and international.

Our mission will not fail as we hope this seminar will give participants the inspiration to go home with concrete plans for better services for people with acquired deafblindness. In order to do this we need you and your active contribution.

Now I want to share some personal thoughts and remarks. When I took the responsibility for preparing this keynote speech, I could not imagine that it would be my last speech in the deafblind world. Some of you know it already that I am going to leave this work with deafblind people to take on a new challenge. People asked me why did I take this decision. The answer is that there were organisational changes that made it impossible for me to continue. These kinds of thing can happen.

However, in all this change I would like to leave in my final words my legacy to you all. **"I wish that deafblind people and professionals will find a way to co-operate respectfully with each other to create a true dialogue."**

*This article was adapted from Anneke's address to the Seminar on Acquired Deafblindness in Zurich 2-6th October 2002*



## FAMILY CONFERENCE

The sculpture workshops used typical building materials including; cement, sand, polystyrene, wax and water.

◀ Kristina and her mother in a sculpture workshop.

from different countries in Europe communicated with each other. The daily "Beyond Words" sessions were run by the Nordic Culture Network and Sense Scotland who facilitated the possibility for deafblind participants and their families to express themselves through experimental sculpture workshops and music and light vibrations.

All participants said that they benefited from the time they had spent together at the conference. Ricard Lopez from Spain will be setting up an informal internet mailing list so that the families who attended can remain in contact with each other. There was good coverage of the conference on local television and media and a short film will be edited from this so that other people can share in the event. A follow up conference is planned for 2004 in Denmark and will be run by Lone Poggioni from the Nordic Culture Network.



◀ Music workshop



▲ Families from Slovakia and Czech Republic.



## Family event – 'Listen to Me'

**T**he recent European family conference on the 20–27th October 2002 at Bari in Italy was a great success. Over 90 parents, professionals and young people came from Western, Central and Eastern Europe to listen to lectures and take part in discussion groups, music sessions and sculpture workshops. The aim was to allow parents to discuss and exchange experiences and information on a wide range of issues concerning family life. The conference was made possible due to the financial support of Lega del Filo d'Oro, Hilton Perkins and Sense International. This sponsorship opened up



**Eliska (right) experimenting in the sculpture workshop**

attendance of the event to more families, particularly those from Eastern Europe. The event was also supported through

collaboration with a local disability organisation who many volunteers provided invaluable administrative help.

The location of the venue in Southern Italy was chosen with the intention of raising awareness of the service needs of deafblind people in that region. There are many families in the Puglia region who currently don't have access to specialised support. It is hoped that the local government officials who attended the event will be stimulated to provide appropriate support services for deafblind people in the future.

One of the highlights of the conference was the wonderful way that deafblind children and young adults



◀ **The music workshops used fans, electric light and streamers to make vibrations.**



# Developments in India ...

Akhil Paul, Director of Sense International (India), describes the background to raising awareness of the needs of deafblind people in India and paints a picture of exciting new service development.

## The situation in India

Disability has been a part of human existence from the beginning of life on this earth. In India, disability is sometimes referred to as the "result of wrong doings in the past life". This myth is gradually disappearing due to the awareness created by various non-government and government organisations. In India, there has been a lot of work done for those who have one disability i.e. those who are blind, deaf, mentally retarded and physically disabled, but when it comes to services for people who are multiply disabled the scenario is very different.

It is estimated that the number of people with a disability in India is over 90 million. There is no data available about the size of the deafblind population in India as, to date, there have been no comprehensive studies or research to determine the true incidence. Estimates, based on information gathered from community based projects, indicate that there could be more than 450,000 deafblind people in the country.

## The need for deafblind services

Prior to the establishment of Sense International (India), there was very little awareness about deafblindness. In this vast country there was only one pioneering school, the Helen Keller Institute for Deaf and Deafblind, Mumbai, catering to the needs of 23 deafblind students. The situation was such that neither the government, nor organisations working with disabled people were aware of a deafblind population. Lack of awareness of this unique disability meant, and still means, that many deafblind people are left without support or labelled incorrectly (for example as severely mentally retarded) and receive inappropriate support.

## National brain storming

However, a determination was building within the country to move things forward and with support from our international friends a start was made to the process.

Sense International India was founded and since then, we have been closely involved in the creation of about 25 services for deafblind people in 13 states of India, through support from local disability NGOs. The services are based on the model which is appropriate for that part of the country keeping in mind the regional needs. Some of the models are:

- ◆ vocational training units for adult deafblind people;
- ◆ national teacher training programmes;
- ◆ day care units;
- ◆ rural community based rehabilitation programmes;
- ◆ home based projects;
- ◆ residential training units;
- ◆ outreach programmes.

## Professional support

In addition to supporting the development of services, we work with each partner NGO to develop its capacity through the organisation of training programmes and workshops, which are facilitated by specialists in the field of deafblindness who come from all over the world. We are also supporting many other NGOs/ Schools and Government Institutions through our technical expertise.

## Government support

We realised that we have a campaigning role and have succeeded in getting recognition for "deafblindness" as a category of multiple disability by lobbying the Government. We have been successful in making the Government aware that there is a huge deafblind population in India,

which needs attention from all quarters of the society.

## Dissemination of information

The concept of deafblindness is new in India. There is neither literature nor information on deafblindness available. To fill this gap, we have set up a Resource and Information Unit. This Unit is the first of its kind in Asia and will cater to the needs of organisations and individuals who are interested in knowing more about deafblindness through specific handouts, articles, newsletters, leaflets and posters.

## The awakening

The beginning of the new millennium brought new hopes. The first ever Dbl Asia Conference was an amazing opportunity to share with and learn from colleagues from many nations. We are looking forward and planning to support them actively in the future.

## Sustainability

In all our programmes, the "sustainability" is a key element. In the last five years we have seen noticeable development in quality of services. We have succeeded in strengthening programmes through local specialists.

## The future

The past five years have seen some very exciting developments. Here, in India, there is a growing band of professionals and families who are determined to improve the lives of the hundreds of thousands of deafblind people in the country.

The original "Project" has grown into a "Programme" and now it has become a "Movement" – to support deafblind people wherever they live in India.

**Akhil Sukant Paul**

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Email: [akhil@senseintindia.org](mailto:akhil@senseintindia.org)



# The 'Dreams, ambitions and realities' conference a success!

"Wonderful atmosphere, as ever. Scotland has been welcoming and full of fantastic ideas."

Over 200 delegates attended the September 2002 conference with participants visiting from around the world. The conference received high praise from many of those who took part over the three days at Glasgow Caledonian University. The unique atmosphere of the event was largely due to the enthusiastic involvement of the children and adults using Sense Scotland's services and their families.

Delegate Marie Richardson said: "The staff team was great, from the top to the bottom everyone mucked in and made us feel really welcome."

Throughout the conference delegates took part in workshops, presentations from health

professionals, deafblind people and renowned experts of international standing. There were also a great range of social events including an exclusive preview of the Helen Keller Award exhibition and an evening of entertainment provided by a group of deafblind musicians.

Brian Abery from the University of Minnesota, USA took a look at issues of self determination and asked the question: "Would deafblind people choose to tell us more if we improved ourselves as listeners?"

The inaugural Tait Mitchell lecture, which will now take place annually, was presented by William Green, Lega del Filo d'Oro Italy and Vice President Deafblind International (DBI). In his presentation he used his experience of working with the deafblind community to discuss ethics and good practice.

The final plenary session saw Paul Hart from Sense Scotland use the music of Bach to examine communication between deafblind people and their seeing and hearing partners. His thoughtful and entertaining presentation proved that, in his words: "It does take two to tango.", while one of his key messages was that: "The essence of being human is being."

Gillian Morbey, Chief Executive of Sense Scotland said: "The conference has generated a fantastic amount of discussion and debate about real life issues for people with complex support needs. It was a rare opportunity for professionals, families and people who use services to share their own perspectives and to learn from each other. I know that people left the conference invigorated and full of confidence about their lives and the work they do."



For more information about Sense Scotland visit the website at [www.sensescotland.org.uk](http://www.sensescotland.org.uk)  
telephone: 0141 564 2444  
fax: 0141 564 2443  
textphone: 0141 564 2442



**Gillian Morbey, Chief Executive of Sense Scotland.**

**Brian Abery, Co-ordinator of School Age Services at the University of Minnesota, Minneapolis, gave the keynote speech.**



# Touching Bronze ...



International artist, Argyro Kondtandinidou, was specially invited to show her work in an exhibition timed to coincide with the Dbl Management and Council meeting in Athens. Mrs Kondtandinidou is a sculptress and has been actively working for the past 20 years. Her work is in galleries and private homes in Greece and abroad and she has most recently had work on show in Chicago, Atlanta and Illinois.

Argyro studied both technical design and painting and then went on to learn the skills of woodcarving with master craftsmen from Italy. This revealed a special talent in Argyro and UNICEF recognised this. As a result, Argyro has taught woodcarving to young people on a regular basis as part of its programme.

The artwork that was on show at the Council Meeting is a sculpted bronze domino. It consists of 14 pieces – each with the same dimensions. Each piece represents the private and public life of the four most important prehistoric civilisations: Greece, Egypt, Mexico and India.

This beautiful sculpted artwork can be placed on the floor, where people can walk on it and touch it. It can also be used as an educational artifact for deafblind children.

Diamanta-Toula Matsa, President of the Greek Association of Deafblind, Parents, Tutors of Deafblind Children and Friends invited Argyro because her work speaks to everyone about beauty and the culture that is common to all ancient civilisations.



Argyro Kondtandinidou works in Athens and her studio can be found at 4 Tripodon Street, Plaka. The Greek Association can be found at 27-29 Ragavi Street, Athens 11474.







## Latin America

## Resource Centre on Deafblindness: an answer to the information needs in Latin America



Marcela Forero reports:

In many developing countries, access to information about deafblindness is limited, particularly information relevant to local conditions. Information produced outside the local area is often inappropriate because it is not in a regional language and too often the achievements of deafblind people and/or professionals working at a local level go unrecorded.

Sense International (Latin America), with support from the UK's Community Fund, has spent the past year compiling information to create Latin America's first electronic information resource.

The Resource Centre on Deafblindness is a Spanish-language website designed to meet the varied needs of individuals, groups and organisations working with deafblind people, families and professionals. We are establishing contacts and links between health institutions, rehabilitation and education organisations, the deafblind community, educators, professionals, students, researchers, policy makers, managers, local communities and self-help groups across the continent. There is plenty of evidence that access to information at the right moment can mean the difference between the inclusion or exclusion of deafblind people in society.

The Resource Centre was launched as a pilot on September 6th 2002 in Bogotá, Colombia in an event attended by over 300 deafblind people, family members and interested professionals. It will be launched formally in

December 2002 after improvements have been made following a round of consultation.

### What information does the Resource Centre offer us?

- A A complete review of literature related to Deafblindness.** There are fact sheets on our site covering:
- ◆ Definitions, classification and causes of deafblindness (syndromes, genetic, others)
  - ◆ Information for parents (family, communication, education and sexuality)
  - ◆ Information for teachers and professionals (evaluation, communication systems, orientation and mobility, guide interpreters and training).

Fact sheets are easily downloaded and can be printed and distributed free of charge.

- B The users can access our Virtual Library,** ask for a copy or consult a database with around 500 publications including books, magazines, manuals and articles. You can also download some videos related with the topic (for example, a video on Helen Keller's life or communication systems)
- C The site has information about the organisations,** schools, associations and institutions from all Latin American countries, also a map listing key contacts in each country.
- D There is an area of the website given over to discussion forums.** It has sections including: "Deafblind Community",

"Youth network", "Forum", and "Ask for help".

- E Finally the Resource Centre documents the Real Lives of Latin American deafblind people.**

### How can we access the Resource Centre?

Information compiled in the Resource Centre can be accessed either directly, by visiting our website [www.sordoceguera.org](http://www.sordoceguera.org), or indirectly, by making contact with your local associations working with deafblind people (these organisations can print off materials free of charge).

In parallel with this project, three youth centres in Peru, Brazil and Colombia will be established, which will have fully accessible Information Technology enabling deafblind people with partial vision and/or sight to access the website directly.

### How do we know we are getting it right?

We have a Consultative Committee composed of 12 people from 8 different countries (including deafblind people, families and professional representatives). Their job is to help ensure that the Resource Centre stays up-to-date and to provide critical feedback on how it is being used locally.

### Future plans

Our future plans include getting the Resource Centre translated into Portuguese; creating discussion forums/networks for Guide-Interpreters and families; a Deafblind Job Link; and networking the virtual library with other countries where such resources exist.





## Slovakia

**The International Family Camp with Deafblind Children in Sabinov, Slovakia**

**Janka Sarisska,**  
Director of  
Evangelical  
Elementary  
Special School  
for Deafblind  
Children,  
Cervenica,  
Slovakia reports  
on exciting  
developments in  
Slovakia ...

With financial support from Hilton/Perkins International we organized the sixth Family Camp in Slovakia. The first three Family Camps were organized for the Slovak families with deafblind children and the last three included families from abroad.

This year the camp was held in the small town Sabinov in the East Slovak Region. We had 15 families and 86 participants in all!

The families which were invited were from the Deafblind School in Cervenica and three new families with multi-handicapped children. In addition there were families from East European countries – Hungary, Czech Republic, Romania and Bulgaria. Six professionals supported the activities with the deafblind children, siblings, parents and teachers. One of them was Gillian Morbey from Sense Scotland, who is also the mother of a 27 year old man.

The participants created 4 groups – deafblind children, their siblings, parents and teachers. Their programme was divided into 4 areas:

- ◆ Educational work on communication, art therapy, music therapy, sign language and special pedagogical and psychological counselling.
- ◆ Cultural and sporting

activities which were tailored individually to the needs of each deafblind child. There were activities like walking into town, visiting the museum, shopping, taking a trip to the old castle, travelling by train or bus to enjoy the natural world. Everyday we had the swimming pool, gym and sports ground available to us. One of the nicest activities was sitting together around the campfire toasting our toes by the warmth of the flames. The children relaxed in this new environment.

- ◆ Siblings of deafblind children. They worked as 2 groups: one of younger children and one of older ones. Except for the leisure time activities they worked very actively with a sign language teacher and Gill.
- ◆ Parents. They had some lectures related to social and psychological development. The parents visited all the therapists and had the opportunity to discuss things with them. The Parents Association also had a meeting. They discussed the current problems about the development of a group home for deafblind adults. At the end of the stay the music therapist and the psychologist had a

therapeutic session with parents and it was very successful!

One of the highlights of the whole week was our "performance" with both the deafblind children and their siblings. We invited the parents and people from the town to this performance. It was wonderful! Especially impressive was the last part when the siblings sang a song and their deafblind brothers and sisters also sang "with their hands". Even a tiny 3 year old was signing!

The Family Camp was 6 days long and every day had a structure. We worked from 9 in the morning until 6 in the evening. It was demanding but everybody knew that the time we spent together would be useful for the families in the future. Throughout the time there was regular evaluation of how things were progressing! All the families were delighted with the programme. They learned a lot about working with their child at home and in school. Perhaps best of all were the relationships that were developing between the families. The siblings from Slovakia and the foreign families experienced no barriers at all, even though they didn't speak same language! There was wonderful co-operation between everyone – the professionals and the families.

**A home for life**

The Parents Association, the School for Deafblind Children in Cervenica and Blind Union in Kosice are all working together on the project to create a Group Home for

deafblind adults. The Slovak government has recognised the needs of the deafblind population in the national programme of care of deafblind people. The

national programme, ordered by government, is an unique opportunity to start more systematically to solve the problems of deafblind people in our country.





## Slovakia

## Visitors from abroad

continued

The 27th of October 2002 was a special day for the Deafblind School in Cervenica. Director, Janka Sarisska, with staff and students welcomed the group of 7 Americans to the

School. They were President of the Hilton Foundation, Steven M. Hilton, Vice President, Dayanne M. Hayes and Robert Buckley, M.D. with his son Brian Buckley. They were

accompanied by Hilton/Perkins International's Michael Collins, Director of Perkins School for the Blind, Kevin Lessard and Eastern Europe specialist, Dennis Lolli.

## Australia

## National Conference



Mike Steer reports on recent developments in Australia

The 6th National Australian DeafBlind Conference was held at Lidcombe, Sydney from 12-15 July 2002. There were 226 participants with 30 presenters and exhibitors. There was high level of participation by people who are deafblind (both in numbers and involvement in discussion) with delegates from all Australian states and territories (except Northern Territory). A contingent of eight people from New Zealand attended, as well as presenters from Japan and the USA with delegates from NSW Department of Ageing, Disability and Home Care (both management and community workers).

31 of the delegates were deafblind, seven were deaf and six were blind. There were 35 interpreters and 40 volunteers supporting delegates. Two volunteer bus drivers ensured that delegates were safely delivered from the airport, to and from their accommodation and the conference. Muscular relief for delegates was provided by four volunteer massage therapists and for those who needed child minding support there was a volunteer childcare worker.

New Zealand is now a member of the Australian DeafBlind Council following the AGM held during the conference. Australian

Commissioner for Human Rights, Dr Sev Ozdowski opened the conference, drawing attention to the rights of Australians who are deafblind and the current discrepancy in services and funding for people who are deafblind. Mr Shin-ichiro Kadokawa from Japan (himself deafblind) spoke of his battle for education and the work he now does in Osaka to (a) improve conditions for people who are deafblind and (b) to promote peer support by people who are deafblind in Japan.

Five speakers from the United States spoke on a variety of issues. These included Education, CHARGE Syndrome, the important factors in interpreting for people who are deafblind, the function of communication in behavioural problems and the role of grandparents in developing communication. Local and Interstate speakers also addressed areas of education, interpreting, rights, networking, mentoring, personal & community participation, sensory problems in aboriginal communities, medical issues and technology.

A copy of the proceedings on CD, costing A\$20 can be ordered from: Janne Bidenko [dbconference@gpo.com.au](mailto:dbconference@gpo.com.au)

Janne also has long-sleeved very smart Aussie conference T-shirts for sale at A\$22 each and short-sleeve T-shirts available at

A\$16 each. Both have the conference logo on the front and fingerspelling and Braille alphabets on the back (dark blue with yellow printing). Caps with "touch" in Braille on the front and yellow conference logo are available for A\$15. Conference bags are available for A\$12 each. All items plus postage.

## Unmet service needs

Margaret Verick, the Australian Blindness Forum's professional lobbyist based in Canberra reports that the Australian Institute of Health and Welfare (AIHW) has recently indicated that A\$519 million in extra Commonwealth and State/Territory funding for unmet needs in disability services over 2000-1 and 2001-2 is proving effective.

AIHW undertook a study for the National Disability Administrators group to examine the effects of new funding and estimate the remaining unmet need in Australia for disability services. The study provides information for the next Commonwealth-State/Territory Disability Agreement funding negotiations.

Australia has a population in excess of 19.2 million. Of this number approximately 18% are estimated to have a disability or impairment. Results of the survey reveal that on a 'snapshot day' in 2001, due to the unmet



**Australia**

continued

needs funding, an additional 900 people were receiving accommodation support services, an additional 2,350 were receiving community support services and 2,425 additional people were receiving community access services.

However, conservative estimates are that nationally, 12,500 Australians with disabilities and impairments still need accommodation and respite services, 8,200 places are needed in community access services, and 5,400 people need employment support. The report summary can be visited at the AIHW web site [www.aihw.gov.au](http://www.aihw.gov.au)

There is no indication of the number of these unserved people who are deafblind,

**National Council News**

The Australian Deaf Blind Council (ADBC) committee for 2002-3 consists of Irene McMinn, Sven Topp and Di Hartman representing people with deafblindness, and three other members – Mike Steer, Sharon Barrey Grassick and Meryle Trentini. The committee has re-elected Irene McMinn as President, with Sven Topp as Vice-President, Sharon Barrey Grassick as Secretary and

Meryle Trentini as Treasurer. ADBC is still seeking a parent representative to serve on the committee.

**ADBC farewells John Finch**

It was with much regret that ADBC said farewell at its 2002 AGM to one of its founders, motivators and benefactors, John Finch, CEO of Victoria's DeafBlind Association. ADBC members world-wide sent him best wishes for a happy and healthy retirement and look forward to reading the history of deafblindness he is compiling.

**John Finch retires**

**Sharon Hillman  
adds her tribute**

John Finch, Chief Executive of The Deafblind Association in Victoria, Australia retired in July 2002.

Mr. Finch, who for 17 years has been the Association's CEO said it was with mixed feelings that he had announced his retirement.

"I am very proud to have been involved with such dedicated staff and volunteers. Their commitment to improving the lives of people within the deafblind community is second to none. I will miss the challenges and satisfaction associated with working in such a rewarding environment."

Mr. Finch's personal contribution to the Association has been outstanding. His dedication to raising awareness of the deafblind community within Government and the general public has continued unabated. Under his leadership, Mr. Finch has seen The Association grow significantly in size and

stature within, and external to, the not-for-profit community reshaping the organisation in order to service people with multiple disabilities.

"The Deafblind Association has established an exceptional reputation for making a difference to the lives of people with deafblindness or multiple disabilities. In retirement, between my four-wheel drive expeditions and travel plans, I intend to share my experiences by documenting the history of DBA."

The Deafblind Association's Board is pleased to announce Celestine Hare, The DBA's current General Manager, will assume the position of Chief Executive Officer from 1st July 2002.

Ms. Hare has been with The Association for fourteen years – in the position of Deputy CEO for the past seven and a half years, and has managed The Association's Direct Client

Services area for five years.

The Deafblind Association's Board is confident of a seamless transition, as the hand over process is currently under way. "Mr. Finch and Ms. Hare have shared a commitment to The DBA over many years and I am confident that the future of The Association is in excellent hands. I look forward to continuing our close working relationship," explained Mr. Eddie Keir, President of The Deafblind Association.

**Celestine Hare**





## Czech Republic



Holidays of deafblind people are moving across Europe!

Jan Jakeš

## Wanted! Holiday Hosts for Summer 2004 in Europe!

The 5th holiday for deafblind people took place in Croatia in June 2002, hosted by Croatian Association of Deafblind people: DODIR. The next one will be held in Poland next summer. So now we are looking for an organiser for the year 2004 and for the years following.

Since 1997, European deafblind people have had an opportunity to spend holidays together attending international camps. The holiday camps programme is aimed to offer social, cultural, creative, sporting, and other recreational activities. There are social games, dancing, excursions, and visits of monuments, museums, and interesting or beautiful places. The deafblind participants from various countries and their interpreters have time for informal chatting, friendly discussions, informal gatherings, and the chance to share personal life experiences. It is really exciting to discover and get acquainted with people and to get new knowledge and skills in communication. The other activities are fun and challenging too! For instance we tried water skiing in Switzerland and learned diving in Croatia.

The fact that the deafblind people share and enjoy all the camp events together, helps them to improve their mood and morale while learning new things that make life exciting.

Till now, deafblind people have attended and enjoyed five international camps, which were hosted by national deafblind organizations. Here they are!

- ◆ **Czech Republic, Paprsek and Prague 1997.** Hosted by LORM, organized by Jan Jakeš and Věra Husáková. Attended by 17 deafblind participants from 7 countries: Belgium, Czech republic, France, Italy, Sweden, Switzerland, and United Kingdom.
- ◆ **France, La Rochelle, 1998.** Hosted by Association Loisirs/Vacances pour Sourds-Aveugles, organized by Florence Chevallier and Jean-François Guérineau. Attended by 18 deafblind participants from 6 countries: Czech Republic, France, Italy, the Netherlands, Sweden, and Switzerland.
- ◆ **Belgium, Lampernisse, 2000.** Hosted by organization EURO 2000, organized by Peter Vanhoutte and Koen

Amerlynck. Attended by 16 deafblind participants from 9 countries: Belgium, Czech Republic, Denmark, France, Italy, The Netherlands, Poland, Sweden, and Switzerland.

- ◆ **Switzerland, Monthey (Suisse Romande), 2001.** Hosted by ARSA (Association Romande Sourds-Aveugles), FRSA (Fondation Romande en faveur des personnes Sourdes-Aveugles) and UCBA (Union Centrale Suisse pour le Bien des Aveugles), organized by Julia Roessler, Françoise Gay-Truffer and the Centre des Marmettes. Attended by 16 deafblind participants from 5 countries: Belgium, Czech Republic, France, The Netherlands, and Switzerland.
- ◆ **Croatia, Bol (Island of Brač), 2002.** Hosted by Croatian Association of Deafblind Person DODIR, organized by project co-ordinator: Elizabeta Tarčay, and assistants: Davorka Dragojevič, Maja Levar, Lidija Milošević. Attended by 24 deafblind participants from 8 countries: Belgium, Croatia, Czech Republic, Denmark, Finland, Italy, Sweden, Switzerland; there were 13 deafblind persons from abroad and 11 deafblind persons from Croatia.

Proposals, offers, questions, comments, and correspondence can be addressed to:

**Jan Jakeš,**  
VIA Association of the Deafblind  
K Vodojemu 29,  
150 00 Praha 5,  
Czech Republic  
E-mail: jajakes@volny.cz





**Kazakhstan Meyrim** – the first foundation of deafblind people in Kazakhstan

**Galina Frolova,**  
President of  
**Meyrim,**  
writes ...

The first and only charity helping deafblind people in Kazakhstan was founded at the beginning of 2001 by a group of individuals. It is called "Meyrim" – The Public Foundation of Social Support and Rehabilitation of Deafblind People. The Foundation is located in the city of Almaty, the former capital of Kazakhstan. Galina Frolova, a deafblind woman herself, is the President of the Foundation.

Since the beginning the Foundation has worked on a voluntary basis. It has good relations with the associations for the deaf and for the blind in the region. At the moment there are 60 deafblind adults and 40 deafblind children living in Almaty who are on the Foundation's registration

list. All of them have different causes of deafblindness. The Foundation already has information about other deafblind people living in different regions of the country that aren't on this registration list.

The Foundation has managed to establish good contacts with most of the registered deafblind people and families with deafblind children. We have a one-room office where regular meetings of the communication club of deafblind people takes place. These meetings have become the first step in solving the most complicated problem for deafblind people – communication and getting information.

Thanks to donations by the Canadian embassy, the

Foundation has been able to purchase the equipment and furniture we need. Other donations have given us the opportunity to finance parties and leisure activities for deafblind people and their families, something they had been greatly missing.

We still need information and materials on how parents can educate and teach their deafblind people. We also need consultations on how we can support people with different causes of deafblindness.

We would love to hear from you. Please write to:  
**Galina Frolova,** President  
Foundation "Meyrim"  
Bogenbay batyr str., 214  
480012 Kazakhstan, Almaty  
tel./fax (3272) 93-76-42  
e-mail: meyrim@nursat.kz

**Romania**

**Cristiana Salomie,**  
Director of Sense  
International  
Romania,  
writes ...

Our major priority for this year, (apart from the partnership with the Romanian Government), is to set up a day centre for a group of 29 deafblind adults in Timisoara county. We have just elected the co-ordinator of the group and are very pleased with the appointment. Geta-Cristina Manderscheid is 34 and is from Timisoara. She has profound hearing loss and tunnel vision and is married to a deaf man. Geta-Cristina graduated from the Vocational School for the Deaf in Timisoara, where she was trained in reeling. She worked in a factory for a short time, but as she has severe sight problems, it was difficult for her to do her work and had to resign. She likes to paint and is very gifted. She attended a school of arts for one year, but didn't have enough money to finish the course.

Her greatest difficulty has been to communicate with

others. Although she attended a school for the deaf, she didn't get an education that was appropriate for her complex disability. She has always felt isolated and frustrated about not being able to communicate with others the way she would like to. Geta has told us that the new Timisoara Day Centre represents an oasis in her deserted life. She has already got involved in all the activities run at the Day Centre and, due to her enthusiasm and her husband's support, she acts as the engine of the whole group of deafblind adults from Timisoara. As she has leadership qualities as well, she has become the co-ordinator of the group. She is a very active person, optimistic, sensitive, full of charm and has a great sense of humour. She sees herself as a deafblind woman and is

aware of her very special needs. We are very pleased with our new appointment and hope that the group will flourish under her leadership.

We have also recently elected Geta-Cristina to be a member of the SI(R) Advisory Committee. She is very pleased that she has been elected as a member of our Committee. She recently attended one of the meetings and she communicated through her interpreter that she was very happy that we have treated her as one of us and that she will be able to represent deafblind people in all the activities of the Advisory Committee.

**Cristiana Salomie,** Director  
Sense International  
(Romania)  
Blv. Timisoara 27  
BI D, sc B, et 5, ap 23  
Bucharest  
Email:  
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## Sweden

**Sensation, Perception and Formation of Meaning**Anny Koppen,  
NUD

In co-operation with the Dbl Working Group on Communication and Congenital Deafblindness Nordic Staff Training Centre for Deafblind Services (NUD) organised a conference on Sensation, Perception and Formation of Meaning in Congenitally Deafblind Persons. The event took place in Gothenburg in Sweden from August 27 to September 1st and gathered

around 80 persons. The Working Group on Communication and Congenital Deafblindness has for some time been exploring the formation of meaning in communicative interaction with persons who are congenitally deafblind and has suggested to focus on two essential concepts: narratives and blending. In an encounter between the world of research and the world of

deafblind education these two concepts were examined from different points of view resulting in in-depth discussions, new and shared focus of interest and new co-operating partners for the Working group of Communication.

Papers from the conference will be posted on NUD's website [www.nud.dk](http://www.nud.dk) under publications.

## India

Akhil Paul, Binali Sundahani and Sumitra Mishra report ...



Akhil Paul

Binali  
SundahaniSumitra  
Mishra**Refresher Workshop for Educators of Deafblind People**

Sense International (India) organised a refresher workshop for educators and project coordinators of all its partner organisations from the 16th – 18th September 2002 at Mumbai. The major focus of this workshop was to update the skills of professionals working with deafblind persons. More than forty professionals from all over the country attended the workshop. The participants and the faculty enjoyed many interactive sessions on topics such as assessment, curriculum planning, and working with families and so on. One session was dedicated to capacity building initiatives for the participants. The participants had many practical concerns to discuss about the deafblind people with whom they were working. The importance of building good quality programmes was highlighted throughout the sessions and all participants have gone back with clear cut action points that they are now going to implement in their respective programmes

**Deafblind Teachers Network**

Educators, field workers and project co-ordinators met on the 19th of September and after discussion formed the first Deafblind Teachers Network! The network will provide an opportunity for professionals working closely with deafblind children to share their successes and concerns and learn from each other's experiences. The network will provide a platform for the professional growth of its members through information sharing, training opportunities and mutual support from like-minded colleagues. The activities of the network will be determined by its membership. The next network meeting is scheduled in February 2003.

**Deafblind awareness visits**

Team members from new deafblind programmes have been visiting organisations working with deafblind children for a few years now. The visits are organised primarily to gain practical experience related to running

a deafblind programme and assessing the requirements and logistics for setting up a sustainable programme. Such exchange programmes, between two organisations, help form a mechanism for sharing ideas and experiences on a long-term basis.

**What are the benefits?**

The staff from the visiting organisation gain information and knowledge on various aspects of working with children and families and practical and successful examples of resource mobilisation in the community. At the same time the host organisation gets an opportunity to increase its skills in developing programmes for the visitors. It also gives them an opportunity to reflect back on their own activities and review their actions and roles. In the last few months' five organisations have been involved in such a programme at different times.



**Sense International, together with Sense Scotland, will be running its 5th Professional Development Programme (PDP) in September 2003**

The PDP is a six-week long training and development programme, based in the UK, which provides an opportunity for professionals throughout the world to develop their skills in a specialist area in the deafblind field. As part of the programme, you will spend 6 weeks in the UK during September and October 2003.

Since its launch back in 1996, the Sense International PDP has enabled more than 22 professionals from 13 different countries to take part. Leela Agnes from India and Stella Kamau from Kenya both took part in the 2001 PDP.

*"The PDP has given me such wide exposure to a variety of different programmes."*  
(Leela Agnes, India)

*"The PDP has opened my thinking of the delivery of services to deafblind people in a whole new way."* (Stella Kamau, Kenya)



**Participants from the 2001 PDP Programme. From left to right: Monica Marin, Andrea Hathazi, Leela Agnes, Stella Kamau, Sumitra Mishra**

**The PDP provides professionals with the opportunity to:**

- Increase knowledge and skills in a specialist area relating to sensory impairment;
- Visit/observe different specialist services throughout the UK;
- Discuss work and plans with professionals experienced in similar work;
- Produce a project related to their work at home with the support of specialists in the UK.

For further details on the PDP and information on how to apply, please contact Emma Fisher at [efisher@senseinternational.org.uk](mailto:efisher@senseinternational.org.uk). The deadline for applications is 28th February 2003.



INVESTOR IN PEOPLE



## Networks

### ACQUIRED DEAFBLINDNESS NETWORK

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### CHARGE NETWORK

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### CONGENITAL DEAFBLINDNESS IN ADULTS NETWORK

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### EMPLOYMENT NETWORK

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### EUSN - EUROPEAN USHER SYNDROME NETWORK

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### USHER SYNDROME STUDY GROUP (USSG)

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### INTERPRETING DEVELOPMENT NETWORK

c/o Kersti Erik  
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### MULTIPLY DISABLED VISUALLY IMPAIRED EUROPEAN NETWORK

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### NORDIC CULTURE NETWORK

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### TACTILE COMMUNICATION WORKING GROUP

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## NETWORK NEWS

# Employment Network News



Following a very good meeting in Holland last year a bid was submitted to Europe for funding to allow the members of the employment network to meet and develop the links we had established. Unfortunately, although the bid was accepted as being valuable, not enough money was available so it was not funded. This has left us in the position of valuable work being done in a number of countries but few opportunities to share with each other.

This is where the employment network can have an effect. Employment is so important in the day to day life of deafblind people that we need to share our experiences and knowledge. I would like to hear from anyone who has an interest in employment issues so that a way of sharing information can be developed. Maybe we could use the internet to share ideas. It is possible to meet in a web community and discuss ideas and issues. If you are interested in trying this out please e-mail me at

[captaink48@hotmail.com](mailto:captaink48@hotmail.com) and we will set up a link.

The network was set up to develop and promote good practice in employment. We have been asked to produce a document which could be used by DBI to do this so I would like to hear from anyone who would like to share their ideas with others.

Recent work in the UK, has focused on:

- ◆ Identifying the barriers to employment, in consultation with disabled people and employers.
- ◆ Providing support for people with disability in applying for employment.
- ◆ Providing support for employers.
- ◆ Providing support to those becoming disabled whilst in employment.
- ◆ Developing models of employment.

If you are doing similar work, or would like copies of the documents developed during the projects, please contact me.

Tony Kirk

# EUSN Network News



Carol Brill Doran, Secretary of the EUSN and Marilyn Kilsby, a member of the EUSN are very involved in the planning the CAUSE conference, which takes place in Hinckley, Leicestershire, from 27-30 March 2003.

We hope that as many members

of the EUSN as possible will be able to attend this conference, as it will be a wonderful opportunity to expand the EUSN, both in terms of membership and in terms of its future plans.

Marilyn Kilsby



# The Nordic Cultural Network

**N**orway, Sweden and Denmark have a long tradition of co-operating in all kinds of projects, problems and arguments. The governments from the 3 countries have closely collaborated and many NGO organisations in Scandinavia regularly meet each other to exchange information and to solve problems that they have in common.

Therefore it was also natural for the Nordic parents organisations of the deafblind to create an association. It started formally in 1993 and in 1998 it was decided to establish the Nordic Cultural Association for the Congenitally Deafblind together with professionals and practising artists.

In 1999 The Nordic Cultural Association was asked – as a Network-group – to become a Dbl board member. We were very honoured and accepted at once.

The Association is run by a Board consisting of 2 representatives from each of the Nordic Parent Associations. It has several objectives.

- ◆ To collaborate and exchange experiences between the Nordic parents of congenitally deafblind people.
- ◆ To help to formulate a meaningful content for the future of deafblind people in Scandinavia.
- ◆ To organise a Nordic parents conference every 3 or 4 years.
- ◆ To co-ordinate when one or more parents from the Nordic Cultural Association participate in international activities.
- ◆ To offer cultural activities for congenitally deafblind adults from all the Nordic countries.

It is a great pleasure for the Association to give congenitally deafblind people the opportunities to work with and develop creative talents, therefore giving him or her the opportunity to learn, experience, express themselves and to

## Lone Poggioni reports



**Board members of the Nordic Cultural Association Else Gro Segerblad from Norway, Lone Poggioni from Denmark and Lena Johansson from Sweden**

communicate with the outside world in a new and different way. But why is it so important to give deafblind people this opportunity? Because deafblind people are just like you and me.

Every one of us is – in one way or another – striving to find a pattern for life, or a pattern in life. A deafblind person has their special way of life and way of experiencing the environment like everyone else. We are sure that deafblind people experience more contradictions, conflicts and paradoxes in their life than we ever will experience.

For that reason, feelings of discontinuity and chaos are



**Some of the parents at the conference**

perhaps the most prevalent feelings for deafblind people.

We wondered whether there would be a chance for them to live out their passions, protests and dramas and develop these expressions in artistic directions. It is often thought that artists are very special and not ordinary people. Therefore we asked; why shouldn't special people who are deaf blind also become artists?

For the deafblind person to be an artist means fun and friendship and he or she is sure to find a better quality of life.

And, in the course of 7 years, we have seen this to be true.

We started in the summer 1996 with one course. It was a sculpture course in Gothland with 6 participants and it was a big success. So in 1997 we offered two courses – one in sculpture and one in dance. Both courses were held in Gothland in Sweden. 10 deafblind people took part.

Each year we have expanded our courses and this year 5 courses in Sweden, Norway and Denmark will run covering sculpture, dance and drama, music and nature sculpture. About 34 deafblind adults have taken part this year making a grand total of 140 participants who have been involved since the start.

## Our Conference

This year we held our 3rd conference. Held in Sweden, 54 parents attended from all over Scandinavia. Its theme was exploring the essence of deafblindness and what is important for parents of deafblind children. It also focussed on collaboration between parents and professionals and communication through common experiences.

**The Nordic Cultural Association  
Lone Poggioni  
Denmark**



# Congenital Deafblind Adults Network

**W**e are very happy to announce that the Congenital Deafblind Adult Network (CDBAN) is alive and well. On the 9 and 10 November 2002 a group of interested people from Scotland, Italy and France met and drew up a working plan for a series of Network activities leading up to 2007. This action plan includes preparations for our network day in Toronto and a strategy to gather information via video taped interviews with parents, service providers, professionals and, where possible, Congenitally Deafblind people speaking for themselves. The questions we are posing are in two main areas; service provision and structure, and quality of life indicators. We have agreed that it is very important to investigate the needs and resources of congenitally deafblind

people and to use this information to form the basis of future action by this group. This information will be made accessible to all interested parties. We are also considering a project looking at Congenitally Deafblind people becoming adults and any impacts on ageing that could exist.

We are intending to include some more permanent members to our Network, both families and professionals and, where possible, service users. We hope to see many people in Toronto for our network day.

For more information please contact Dominique Spriet via email: [spriet.dominique@wanadoo.fr](mailto:spriet.dominique@wanadoo.fr) or fax: 33(0)1 45 89 03 00. Alternatively you can email Paul Hart at: [phart@sensescotland.org.uk](mailto:phart@sensescotland.org.uk)

# MDVI Network News

## Kent Lundvist reports

A Workshop on Visual Assessment for Multiply Disabled Visually Impaired Children and young people was held between 11th and 15th December at the Resource Centre Vision/Ekeskolan Örebro Sweden.

Practitioners, working with visual assessment on a daily basis with MDVI children and young people were welcomed. The aim was to invite two members from each founder organisation within MDVI Euronetwork. They would use the time to meet and share best practice concerning methods, aims and practical consequences of visual assessment with MDVI children and youth.

A full report will appear in the next issue.

# Usher Study Group

**S**ince 1985 a group of people interested in improving knowledge and understanding of Usher syndrome has met every two or three years in Europe. With the Dbl World Conference being in Canada in 2003, the Usher Study Group Network of Deafblind International (Dbi) considered it an opportunity to attract participants from North America to meet and study together about this disability. People with Usher, families and professionals are invited to participate in a two-day seminar devoted to sharing about living with Usher and current medical and scientific research on the issue.

## Time and Venue

The Usher Study Group two-day seminar will be held at the Delta Meadowvale Resort and Conference Centre in Mississauga, Ontario on Saturday August 02 and Sunday August 03, 2003, just prior to the 13th World conference on Deafblindness being held August 05, 2003.

## Seminar Programme Themes

Day One will be devoted to medical and scientific research and, in particular, the issue of families involved in research programmes. Day Two will be devoted to ways and means of living with Usher.



Mary Guest

During the two days, a free exchange of views and debate in order to stimulate further thinking and good practice, will be encouraged.

Discussion will also occur about fostering the organising of a North American Usher Study Group and encouraging international liaison through Dbi.



**Bernadette van den Tillaart reports**

# Tactile Communication Network



In May 2001, 40 staff workers from different European deafblind departments were invited to a meeting with the European Working Group on Communication. At that meeting the initiative was taken to form a group of educators who would be interested in how deafblind children learn and communicate through the tactile modality. These educators are; Barbara Bettenmann of Helm Tanne, Switzerland, Barbara Miles from Vermont, USA, Bernadette van den Tillaart of the Instituut voor Doven, The Netherlands/ USA, Gunnar Vege of the Andebu Dovblindesenter in Andebu, Norway and Gabi van de Ven, of the Instituut voor Doven in Sint Michielsgestel. During the following year we formulated the general aims and ideals of the working group and an application for network recognition. We felt very supported when the Dbl management committee honoured

our request to become a Dbl Network group.

In May of 2002 we met at the invitation of Ton Visser of the Instituut voor Doven, The Netherlands. For three days we talked about our experiences of how congenitally deafblind children use touch, proprioception and kinesthetic modalities in order to learn and communicate. Our discussions led to the formulation of a research question which we intend to address during the course of the next few years. The broad question we are addressing is this: *How do congenital deafblind children develop social concepts through the tactile mode?*

We intend to use case studies and detailed video-tape analyses of interactions in order to better understand how congenitally deafblind children come to see themselves as members of social systems. We are grateful to Hans van Balkom of The Instituut voor

Doven, The Netherlands, who has supported us in setting up this project and finding funding.

In December 2002 we will meet at the Andebu Dovblindesenter in Norway, hosted by Knut Johansson. The Tactile Communication Network will maintain relations with the European Working Group on Communication to share our developments with each other.

We would like to share our ideas, experiences and information. We invite members of Dbl to contribute their observations, literature suggestions and questions related to our research topic. We do this in the hope that we can make our research useful to the broad community of educators of deafblind children and adults.

**Contact address:**  
Dbl – Tactile Communication Network  
Bernadettevandentillaart  
@tiscailmail.nl

# The Communication Network

**Jacques Souriau reports**



The Communication Network recently met in Gothenberg, Sweden, on the 1st September 2002 after participating in the 'Sensation, Perception and Meaning' conference organised by NUD. As a result of this meeting, NUD are now running an information update on the internet about the network.

The activities carried out by the Communication Network are made

possible thanks to the collaboration of NUD (Nordic Staff Training Centre) and CNEFEI (French Staff Training Centre for Teachers of Children with Special Needs). Many other organisations also contribute: Skadalen (Norway), IvD (The Netherlands), Spermalie (Belgium) & CRESAM (France). It is important to note that the majority of the European organisations addressing congenitally deafblind people are

involved in letting their staff participate in the staff development activities.

Our future plans include an expert workshop to take place in May 2003 which will investigate questions around communication and meaning-making. We also plan to deliver an international course, however, the exact content and date of this has not been decided yet.



# The Acquired Deafblindness Network

Anneke Balder reports ...



From 2 – 6 October the Acquired Deafblindness Network organised our fourth seminar in Zürich (Switzerland). Nearly 100 people from twelve different countries participated in the seminar. The theme was "Problems of acquired deafblindness and the services of professionals today". Plenary sessions and workshops were presented on this theme. During the first two days the focus of the discussions was on making an inventory of the problems. On the third day the subject of the discussions in the workshops were problem solving and future planning.

The following extracts from the workshops will give you an idea of what we discussed.

## Screening materials for identification of elderly deafblind people

This workshop looked at screening materials and in particular a study about the impact of severe combined sensory impairment on living conditions and quality of life in old age in Norway. Although we are always proclaiming that we have to identify older people with dual sensory loss, what do we have to offer them after this identification? Are there services available and if so, which ones?

Another very important point was that the health system looks at problems with eyes and problems with ears, but hardly anyone realises that a problem with eyes and ears in the same person is not two single disabilities, but is actually one severe disability.

## Creating awareness

This group discussed the different levels of awareness of deafblindness and the importance of deafblind people being the central focus in the process of creating awareness. Training

programs can help to combat the fear of deafblind people of professionals who have little awareness of deafblind people. Deafblind people must play a central role in these training programs. Giving information about deafblindness and deafblind people was stressed as fundamental.

## Interaction between deafblind people and professionals

This group looked at the problem of the natural conflict between deafblind people and professionals. There is a big gap between the expectations of the deafblind person and the competencies of the professional. A deafblind person has questions about their life; the professional will help him/her with a theoretical background. The challenge is to get more balance in this conflict situation.

## Relationships between professionals

This discussion was mainly focused on elderly deafblindness. Collaboration between professionals is hindered by several facts:

- ◆ The problem of definition: old people do not see themselves as deafblind people, their identity is 'old' or 'very old'.
- ◆ The definition of deafblindness is influenced by the client rather than the professionals.
- ◆ There is a lack of knowledge about dual sensory impairment among all categories of professionals (except the real deafblind specialists).
- ◆ Medical doctors, rehabilitation staff and daily carers are not used to working together.







The consensus of opinion was that we should be taking initiatives that would put this problem on the international agenda. This could be done top-down by campaigning in the media and bottom-up by staff development activities for carers and families. In the whole process the GP was recognised as a very important person, because s/he is the one who is involved in the first diagnosis.

## **Support services**

This workshop explored the 'contactperson' system that occurs in Denmark. As a special law of social services, all deafblind people in Denmark have the right to a contactperson. Because the roles of the contactperson are so many and varied, everyone (the deafblind person and the professional) must know what the tasks of a contactperson are and what they are not.

## **Environmental services and technical aids**

This group looked at the problem of technical aids and equipment not being interesting for big commercial enterprises to get involved in. Therefore the market is very small. It is important to co-operate between different countries as giving information to each other about technical aids that have been

developed will prevent the same thing happening in two or three places.

## **Communication with elderly deafblind people**

Theoretical presentations and examples from daily life allowed this group to discuss the following ideas:

- ◆ that knowledge about the context of the communication makes the understanding much easier;
- ◆ that deafblind people, like other people, like to talk about the stories of their lives. Elderly deafblind people have a lack of contact with others that can mean they have little new to say when there is an occasion to

express themselves. However, when people are deprived of contact with others for a long time, then they stop developing inner thoughts and remembering their stories.

- ◆ that memories can be brought back through the use of photos and going to places to trigger thoughts related to these places.
- In summary: success in communication depends enormously on taking into account the narrative aspects of exchanges and being sensitive to the deafblind perspective.

## **Rehabilitation**

This workshop focused on a case study of a 69 year old woman with Usher type II. She had mobility problems.

A rehabilitation model in which the client's question is the basis of the rehabilitation make this kind of situation difficult to handle.

The first step is the development of trust and confidence between the deafblind person and the professional. You are then able to create a situation in which the professional can give information about the mobility problems. After this, the deafblind person can choose rehabilitation in mobility or not. Professionals always have to respect the wishes of the client, however difficult it can sometimes be!

**Anneke Balder**





## 13<sup>th</sup> Dbl Conference 2003



The Canadian Deafblind  
and Rubella Association

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

### Welcome from the 13th Dbl World Conference President

On behalf of the Canadian Deafblind and Rubella Association and the Dbl Conference Planning Committee, I invite you to come to Mississauga, Ontario, Canada next August 5-10, 2003 to attend the 13th Deafblind International (Dbl) World Conference on Deafblindness.

We are excited to host this event and to welcome colleagues, families and people with deafblindness from around the world to come to this event in Canada, where it is being held for the first time.

At the time of writing there is about eight months left for us to do the planning to make this conference an event you will truly remember.

The Scientific Committee promises to have a full and diverse program for you as a result of its incredibly successful Call for Papers, which generated well over 200 applications from individuals from 27 countries representing 6 continents. Reviewing these papers from around the world further reinforced in my mind how similar the issues are with this disability and how together we are internationally!

We have facilitated an interesting array of Pre-Conference events, including:

- Two day (August 02-03, 2003) Usher Study Group Seminar organized by Mary Guest and Constance Miles
- Five day Course (August 01-05, 2003) "Communication and Intervention for those who are Congenitally Deafblind"
- Seminar (August 05, 2003) on Independent Living Options for Persons with Deafblindness in Canada

While the Conference Program is in its early stages of development, I will share with you the titles of the proposed Plenary Sessions: "Celebrating Communication Around the World", with presenters from Eastern Europe; Latin America; Asia; Africa and Canada; "Communicating Research to Practise and Practise to Research"; "Relationships are the Key to Communication"; "Communication and Collaboration are the Keys to Advocating for Quality", and the Closing Session - "Opening Doors to the Future".

I just want to remind you that there are some important deadline dates that you should observe:

- April 30, 2003 for Early Registration Fees
- Copies of Presentations and Handouts by April 30, 2003
- Hotel reservations must be made by July 4, 2003
- July 15, 2003 the final date for Registrations
- Airport Shuttle Information required by July 15, 2003
- Conference Registration August 5, 2003

We expect that a Preliminary Conference Program will be available by April 1, 2003 and will be mailed to Conference Registrants.

Watch for a Conference mailing before the end of the year and check out the Conference Website for updated information.

**Linda Mamer - Conference President**



# DbI website update

Malcolm Matthews is DbI Information Officer and has responsibility for editing DbI's website. Malcolm will be writing a regular column to update readers of DbI Review and to encourage your involvement.

"We really want to make the website a useful information source and tool for people working in the deafblind field around the world." The website is at [www.deafblindinternational.org](http://www.deafblindinternational.org) Technical support is provided through Sense International India.

## What's new?

- ◆ New information just uploaded to the website includes a section on the CAUSE Project. This is about CHARGE and Usher Syndrome and includes material in French, German, Spanish and Italian.
- ◆ A new section on research projects is to be created. The idea is to list research activities

that relate to deafblindness with links to websites and contact details. If you have any information on research activities please let me know.

- ◆ We have plans for further development and promotion of the site. This will include more content for the gallery or deafblind arts section. We are collecting photographs of artwork produced by deafblind people and links to other deafblind arts pages on the web. Please let me know about any creative achievements that you are aware of that we could promote on the site.

In the future, a new area to be developed will be on the recognition of deafblindness and promotion of deafblind issues in different countries. The aim is to provide materials that will help people to plan campaigns and lobby for recognition of deafblindness and the need for deafblind services in

their own countries. Often information on what has happened elsewhere can be really helpful when trying to bring about change in your own country.

Most of [www.deafblindinternational.org](http://www.deafblindinternational.org) is in English. However, we hope that there will soon be a version of the site in French. More information will be available on this when it is launched.

We have other ideas but what happens next will depend on your contributions! See you in cyberspace!

## Malcolm Matthews

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# DbI Awards 2003

With a DbI World Conference fast approaching, nominations for the DbI Lifetime Achievement Award and the DbI Distinguished Service Award are being actively sought.

## Lifetime Achievement Award

At each World Conference, a Lifetime Achievement Award will be made to an individual/individuals who has/ have made a distinguished contribution to services for deafblind people on a national and international level. This award is recommended to be given towards the end of one's working life and will be given only occasionally and when deemed necessary. This is a new DbI award and has never been given before.

## Distinguished Service Award

This award will be given more frequently than the Lifetime Achievement Award. It will be presented to people who have significantly contributed to the deafblind field, or DbI, internationally. These awards will be presented at any Regional or World Conference. Previous winners of the Distinguished Service award are: Joan Shields, Edward Waterhouse, Jan van Dijk, John McInnes, Rodney Clark, Sonja Jarl, Norman Brown, Anthony Best, William Green, Mike Collins, Jacques Souriau, Beroz Vacha, Sadako Imamura, Dietrich Bunck and Marjaana Suosalmi.

## Nominations

The Management Committee has appointed Richard Hawkes and William Green to be the Awards Committee. All communication on this subject should be sent to them via the DbI Secretariat ([dbi@sense.org.uk](mailto:dbi@sense.org.uk))

The deadline for nominations is **15th February 2003**.

To nominate someone please submit a brief summary giving details of who you are nominating and why. You must also attach a biography of that person.

This information must be sent to the DbI Secretariat ([dbi@sense.org.uk](mailto:dbi@sense.org.uk)) by 15th February 2003 at the latest.

**William Green**  
(DbI Vice-President) and  
**Richard Hawkes**  
(DbI Secretary)  
September 2002





**Mike Collins, President (centre) and William Green, Vice-President (left)**

## Management Committee and Council news

We are delighted to announce the birth of Dbl Secretary Emanuela Brahamsha's baby daughter, Scarlett, on 16th September. Congratulations to Emanuela and we wish her and Scarlett all the best. In Emanuela's absence, Richard Hawkes will be standing as Acting Secretary until further notice.

The latest Management Committee and Council meetings took place in Athens, Greece, on 20th and 21st September. Both meetings ran very successfully and coincided with two very significant activities: firstly, the opening of the very first deafblind unit in Greece, notably the Unit for the Education of the Deafblind; and secondly, the running of a number of deafblind training seminars for specialists.

For further reading on both these activities, please refer to Menelaos Tsaoussis' article earlier in this Dbl Review. Dbl would like to say a very big thank you to all the staff at the Greek Association of Parents, Tutors & Friends of Deafblind Children and all the staff at the Center of Education and Rehabilitation of the Blind (K.E.A.T) for their warm hospitality during their stay in Athens.



**Council members at the meeting in Athens in September**

## Changes to the Dbl Constitution

Further to discussions during the recent Council Meeting, members unanimously agreed a proposal from the Management Committee to amend the Dbl Constitution – to increase the number of elected Dbl Vice-Presidents from one to two. The Constitution has now been changed and 2 new Vice-Presidents will be elected at the Dbl World Conference in Canada in August 2003.

## Dbl Elections 2003

New Council Members will be elected at next year's World Conference held in Canada. A Nomination's Committee has been set up to facilitate the process. If you would like to have your say on who gets elected, you must become a voting member today! Contact the Secretariat now at [dbi@senseinternational.org.uk](mailto:dbi@senseinternational.org.uk) to find out how to register your organisation as a corporate voting member. All nominations must be received by 31st December 2002.

## Awards section

With the next Dbl World Conference fast approaching, nominations for the Dbl Lifetime Achievement Award and the Dbl Distinguished Service Award are being actively sought. Please do read the Awards section highlighted in this Dbl Review issue. The deadline for nominations is 15th February 2003.





Argyro Raptou and Mike Collins

## Membership Update

There are currently 564 members from 76 different countries. A reminder to renew your membership fees for next year will be circulated in January 2003. It is imperative that you renew your membership registration for next year as early as possible. Members who do not re-register their details will be removed from the database.

## The DbI Secretariat

If you have any DbI queries, please feel free to forward them to Emma Fisher at the Secretariat. Emma can be contacted by email at [dbi@senseinternational.org.uk](mailto:dbi@senseinternational.org.uk) or by post to: DbI Secretariat, 11 - 13 Clifton Terrace, Finsbury Park, London N4 3SR.

## DbI Website

We are pleased to announce that the website is now active again. Visit [www.deafblindinternational.org](http://www.deafblindinternational.org) for the latest news and information on DbI.

## Strategic Planning Update

Following on from the recommendations put forward by Marjaana Suosalmi, it has been agreed by Council and Management Committee members that DbI submits an application to the UN for consultative status. We hope that this will give DbI greater worldwide recognition. In addition to this, and as part of the process, the DbI Information Officer, Malcolm Matthews, will be putting together a number of position papers and fact sheets. These will include case studies

outlining the way things have progressed within individual countries, as well as posing questions on the extent deafblindness is recognised in such countries.

## Could you host the World Conference in 2007?

It may seem a long way off but we are currently inviting organisations to submit applications for hosting the World Conference in 2007. If you are interested in hosting this event in your Country then please contact the Secretariat for details on how to apply. All applications must be forwarded to the Secretariat by 15th February 2003.

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

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

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

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

*Large Corporates:*

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

*Small Corporates:*

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

Corporate Members can be nominated to sit on the Council.





DEAFBLIND INTERNATIONAL

## Non-Voting Membership

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

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

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

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

Please debit my ☐ Visa ☐ American Express  
☐ Mastercard

Expiry Date

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

Please find enclosed my Postal Order ☐

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

Surname \_\_\_\_\_

First name \_\_\_\_\_

Organisation \_\_\_\_\_

Job Title \_\_\_\_\_

Address \_\_\_\_\_

Town/City \_\_\_\_\_

County/State \_\_\_\_\_

Post/Zip code \_\_\_\_\_

Country \_\_\_\_\_

Tel: (please include country & area codes) \_\_\_\_\_

Fax: (please include country & area codes) \_\_\_\_\_

Email: \_\_\_\_\_

### DbI Review (tick one box in each category)

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

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

### Please return to:

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

## Corporate Membership

There are now two tiers of Corporate Membership:

### Large corporates:

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

### Small corporates:

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

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

We submit an annual fee of US\$ \_\_\_\_\_

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

### Method of payment (must be made in US dollars)

☐ Cheque or international postal order

☐ Bank Transfer

Name of Bank: RABOBANK

Address of Bank: Sint-Michielsgestel, Netherlands

Account Name: Instituut voor Doven: INZAKE DBI

Account Number: 11.29.09.825

### Member Details:

Organisation \_\_\_\_\_

Representative \_\_\_\_\_

Date of Bank Transfer \_\_\_\_\_

Address \_\_\_\_\_

Tel: (please include country & area codes) \_\_\_\_\_

Fax: (please include country & area codes) \_\_\_\_\_

Email: \_\_\_\_\_

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





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