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THE MAGAZINE  
OF DEAFBLIND  
INTERNATIONAL

Number 28 • July - December 2001

# Review



**Deafblindness** *acquired and age-related*

## A MESSAGE FROM THE PRESIDENT

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

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

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

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

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

*Dbi Review* is also available 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: Louise Williams



It was about 23 years ago that I was appointed as Supervisor of the Deafblind Program at Perkins School for the Blind. A short while thereafter, we were visited by a young man from England. He had recently been recruited to head up the National Deafblind and Rubella Association of his country, which was at the time a small, fledgling organization struggling for survival. It was apparent that he knew very little about deafblindness, but that he was certainly anxious to learn. My recollection from that time is that his mind was like a sponge, soaking up every detail that might be useful to him.

He went onto build that organization into one of the most powerful, well established agencies for the deafblind in the world. Rodney Clark took this organization, which was founded on the emotional energies of a small group of very dedicated parents, and turned it into Sense, a national and international institution.

Similarly, Rodney helped Deafblind International to evolve from a loosely affiliated organization of educators, into an international association. The International Association for the Education of the Deafblind (IAEDB), as we

were known in the past, was primarily comprised of teachers and professionals concerned with the education of children. During Rodney's tenure as Secretary, he helped build the organization into a constitutionally based association of professionals, parents and deafblind people, concerned with services for children and adults. Having



served under four different Presidents (McInnes, Souriau, Suosalmi and Collins), Rodney has been the mainstay, the consistent presence, and often the guiding force in our development. His retirement marks the end of an era for us, a most successful era; it also leaves us with very big shoes to fill in the future of *Dbi*.

In the Spring, I had the opportunity to attend a send-off party for Rodney, at Alexandra Palace in London. An impressive collection of international visitors were present to wish him well in his retirement, and to thank him for his years of dedicated service. Such a fine, well-deserved tribute! How many of us will ever be able to say

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**Rodney Clark with H.R.H. The Princess Royal**

that we had Princess Anne preside over our retirement party??

Rodney, on behalf of Dbl, let me say we all wish you

the best in your new beginnings; may your life be full of the happiness and restful moments that you have earned so well.

## EDITORIAL

This issue celebrates the very busy time that Dbl and all its members and friends have had since the summer! In this issue we cover the life span – with articles about young children, adolescents and the elderly. We replay the European Conference in pictures and hear from Jan Jakes and Colin Bennett – with highly personal contributions. Mike has rightly recorded our thanks to Rodney Clark and later on in the magazine a number of other well respected and loved individuals are honoured too.

Our lead article, by Kolbein Lyng, discusses the work that he and colleagues are engaged in to identify elderly people with acquired deafblindness in Norway. He presents a splendid review of the literature and gives us all serious "food for thought". We hope you find it stimulating.

So, we are almost ready to take a short break here and we send you our very best wishes for a happy and peaceful New Year.

**Eileen and Frances**

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# Deafblindness in the future: acquired and age-related

*Kolbein Lyng is Senior Research Fellow at NOVA, The Norwegian Social Research Centre in Oslo, Norway.*

## Introduction

This summer at the Third European Congress on Deafblindness in Noordwijkerhout in the Netherlands the differences between the rich western world and the developing countries in the Third World was contrasted in one of the symposia. In the developing countries they fight to establish services for deafblind children in a community where people don't get old enough to experience even minor age-related problems with vision and hearing. In the rich western countries increased longevity and drops in the birth rates generate a large population of old people with severe age related loss of vision and hearing. For some older people the sensory losses combine into deafblindness.

The demographic changes will cause this group to rise in number in the years to come. In 1990 5.5% of the population was over the age of 75 years according to the OECD. In 2030 the same age segment will be 10.4% of the total population (OECD, 1996). The proportion of the population over the age of 65 within the OECD countries changes from 13.9 % in 2000 to a predicted 22.5% in 2030 (OECD, 1996). Such demographic changes are of minor interest to countries like Afghanistan or Somalia where the life expectancies for men are much lower – 43 and 45.4 years respectively.

With a possible prevalence of 1 to 3% of the population over 67 the majority of deafblind people will be old people with acquired deafblindness.

The usual reference group for deafblindness is children. The new group of old deafblind people is very different from this reference group, as they have all lived a life within a "normal" language society and gradually are excluded from it because of sensory losses. What we have learned from the study of children cannot easily be transferred to the work with the elderly.

Elderly people with acquired deafblindness do not recognise themselves as deafblind and they reject the use of the term deafblind about themselves. They may be

"hard of hearing with visual problems" or have "low vision with additional hearing problems". And they are right. They are very different from individuals growing up with a combined sensory deficit, where vision and hearing never have had full capacity.

The majority of work done within the field of deafblindness has been with children. Acquired deafblindness in old age has only recently been put on the agenda and I will therefore give a short and selective overview of the field. In this article I will start with an overview of ageing and sensory losses, combined losses and how they can be identified in old age. I will then provide a short description of an ongoing study of rehabilitation efforts for this group and conclude with some recommendations for future activities.

## Ageing and sensory function

A scientifically well-established set of age related changes has been described for both the visual and the auditory function (Kline & Scialfa, 1996). For both senses, it is demonstrated that an individual can expect an increased magnitude of sensory problems with increasing age. That does not mean that high functional ability cannot be found in old age, but that the majority of older people will experience a variable degree of problems with vision and hearing.

## Vision

The typical age related changes in vision, *presbyopia*, is characterised by reduced visual acuity, reduced accommodation and reduced contrast sensitivity. The impairments are related to changes in both the optical media of the eye and the neural basis for processing visual information (Kline & Scialfa, 1996).

Presbyopic changes are manifested in many everyday visual problems. Low levels of illumination, glare, small print, and low contrast all cause typical problems reported by old people (Kosnik *et al*, 1988). Under optimal illumination and contrast with refractive

corrections, age related changes in the visual system do not usually cause serious functional problems in everyday life.

Severe functional visual impairments are primarily caused by diseases in the eye. *Cataract*, *macular degeneration* and *glaucoma* are the main causes for severe visual impairment and blindness in old age (Patterson, 1995). Cataracts are usually treated successfully surgically with implantation of artificial lenses (Elam, Graney *et al.*, 1988). The prognosis of glaucoma is better if the condition can be detected early and prevented from developing. Senile macular degeneration is still the most common cause for blindness in old age. The wet type can now be treated medically with success. Unfortunately this type represents only 5-10% of the cases.

The prevalence of visual problems depends on the criteria used and the populations studied. Longitudinal studies show that prevalence of visual impairment increases with age (Keller *et al.*, 1999). Between 10 and 27% of the population over 70 years old show serious visual impairments (Horowitz *et al.*, 1991). The frequency depends on age and a higher proportion is found among elderly adults living in institutions than among home dwelling individuals. Peterson & Kirchner (1980) reported as many as 42% of residents in institutions and 48% of the population in nursing homes had some visual disability as measured by visual acuity. Among frail adults as many as 18% show impairment of 20/70 or worse (Keller, Morton, Thomas & Potter, 1999).

Perceived impairment shows more or less similar figures. In a telephone survey among adults aged 45+ from Lighthouse (1995) 17% reported moderate to severe impairment, increasing to 25% for those over 75.

The disabling impact on everyday life depends on the type and level of visual loss. The loss usually

compromises self-care capacities and leads to social isolation (Horowitz *et al.*, 1991). Major depression is found among 3.8% of the visual impaired over 75, and higher figures (16%) are seen among institutionalised old people (Valvanne, Java, Erkinjuntti, & Tilvis, 1996).

## Hearing

The typical age related changes in auditory functioning, *presbycusis*, belongs to the sensorineural type of hearing loss, and is characterised by a gradual elevation of thresholds for pure tone high frequencies (Garstecki & Erber, 1998). The condition is irreversible. Because temporal resolution of auditory stimuli is diminished, speeded and distorted speech is more difficult to perceive. Presbycusis is therefore particularly sensitive to adverse listening conditions and is disruptive for communication. This is amplified when speech is distorted or speeded (Wingfield, 1985). Reverberation also contributes to the distortion of speech. Studies of hearing in daily life show distinct groups of problems connected to the basic age related impairments (Slawinski, Hartel & Kline, 1993).

Hearing loss is the fourth most common chronic condition affecting adults over 65 years (Garstecki & Erber, 1998). The prevalence of hearing impairment in old age is estimated to be somewhere between 13 and 96%. The figure depends of the age of the groups investigated, the frailty of the subjects investigated, and the criteria used.

About 30% of adults between 65 and 74 years old and 50% of those between 75 and 79 years have some degree of hearing loss (US Bureau of Census, 1997). When pure tone audiometry (PTA) is used a higher proportion of hearing loss is found compared to self-reporting. While 19% of adults 65 years and older is

## About Kolbein Lyng

Kolbein Lyng started his research as a psychologist working on language development and later as a clinical psychologist he worked in the care of people with learning disabilities. He has also designed and supervised training programmes for teaching sign language to deafblind children.

Since the middle of the 80's he has been engaged in research into ageing.

His main research interest is how and to what extent ageing influences perceptual and cognitive processes. Most recently he has been engaged in projects on how to identify elderly people with acquired deafblindness, and how effective interventions can be determined that improve functional abilities and quality of life.

If you would like information about the checklist and questions Kolbein can be reached at:



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found to have some degree of hearing impairment when speech audiometry is used, only 8.1% of a non institutionalised population report that they have a hearing impairment.

When high frequency loss is used as a criterion, 35% of a community dwelling population (age 55-74) show hearing impairment. Only 14% is found when self-reporting is used (Reuben *et al*, 1998). When nursing home populations are examined the prevalence rises to 42-77% when audiometric measures are used (Garahan, M B *et al*, 1992; Sturmer, Hickson & Worrall, 1996). The discrepancy between subjective and objective measures may be explained by compensatory mechanisms in the environment. Other people usually raise their voice when communicating with a hearing impaired person, thereby compensating for the impairment.

The consequences of age related hearing impairment is primarily related to the social and communicative function (Hull, 1995). While speech often can be discriminated under optimal conditions, adverse conditions like background noise, reverberation and unclear diction may make speech perception impossible. This is amplified by lack of additional cues from visual input like facial expression and lip reading.

## Combination of severe visual and auditory loss; deafblindness

Beside congenital deafblindness and some defined conditions like Usher syndrome, that lead to dual sensory loss, age related diseases in the visual system might combine with various conditions of presbycusis into acquired deafblindness. Hearing impairment may combine with primary visual impairment, and primary deafness or partial hearing may combine with age related visual impairment. More than half of all adult cases of deafblindness are supposed to be caused by Usher syndrome (Pollard, Miner & Cioffi, 2000). This syndrome is a genetic condition associated with hearing loss and Retinitis Pigmentosa, a condition leading to degeneration of the retina. The prevalence of Usher syndrome (Type 1 and Type 2) is not clear but is assumed to be circa. 4 per 100 000 (Rosenberg, Haim, Hauch and Parving, 1997).

The far most frequent cause of deafblindness in old age is a combination of age related auditory and visual handicaps. This makes it impossible to make a true estimate of the prevalence of acquired deafblindness in old age. In studies of acquired deafblindness estimates of prevalence vary from 57 to 3000 per 100,000 for people of 65 years and above (Balder, 1999; Svingen, Olafsen & Lyng, 1998; Lyng & Svingen, 2001; Saarinen, 1998; Jorritsma, 2001). The different findings can be explained by differences in the populations studied and their age composition, and the criteria used (Svingen, Olafsen & Lyng, 1998).

Acquired deafblindness in old age is expected to be

under diagnosed. One reason for this is that the behaviours associated with severe vision or hearing disorders are often attributed to reductions associated with age related cognitive decline and dementia.

## How to identify deafblindness

There is no precise definition of deafblindness based on quantitative measures of impairment. Usually a more qualitative and functionally oriented definition is used. Here the term deafblindness is used when a dual sensory loss creates severe problems for mastering 'daily life' issues to an extent that technical aids and rehabilitation methods for deaf or blind people cannot be used successfully (Nordiska Nämnden för Händicaprågor, 1979; Pollard, Miner & Cioffi, 2000). The condition leads to great difficulties in communication, reduced access to information, and creates a mobility problem. A multiplication effect is observed because of the lack of available compensatory resources (Horowitz & Reinhardt 1993). It should be well known that without adequate remediation the condition easily leads to profound isolation.

The condition can, however, be identified. We have developed a method for identification based on a checklist for typical behavioural difficulties observed in severe hearing or vision losses (Lyng & Svingen, 2001). Six questions in the checklist are related to vision and six to hearing. If one positive check for both vision and hearing problems is obtained, the person goes through a standardised interview focusing on self-evaluation of vision and hearing. Based on the checklist and the person's own evaluation of his own vision and hearing it is possible to identify everyone with deafblindness, successfully. For identification purposes only two questions have to be asked in addition to the checklist information (Lyng & Svingen, 2001).

## How frequent is this combination

Searching the literature for prevalent estimates of deafblindness in old age show that nothing is published in scientific journals. What is done in the field is published as "grey" literature and leaves the issue of deafblindness in old age as a non-existing scientific topic. Estimates vary from 57 to 978 per 100,000 in this literature. The great variability in estimates is probably due to different methodology used and to different sample characteristics. When we compare our own two studies in Norway, one national and one based on a municipality, with previous work, we believe deafblindness in old age is in the range from 1 to 3% of the population over 67, and as many as 10 % among those living in institutions. The greatest proportion found (75%) are over 80.

## How can the condition be remedied: rehabilitative practice

There is already a lot of practical experience with remediating severe combined sensory loss. However, doing rehabilitative work with older people is different from working with younger people. As already mentioned, a first challenge is to acknowledge the sensory losses and to come to an agreement with the individual that something can be achieved. Having severe impairment in both senses is an extremely serious situation that also requires serious work to be done at the psychological level. One should keep in mind that the elderly adults we are talking about here have been seeing and hearing people with full access to their societies. It therefore essential to know that they accept the situation, creating hope that life can be worth living and that various forms of aids and support systems will work for them to achieve important goals in life. For the professional the situation is different from working with children in the sense that, full, self-determination must be fundamental in the interaction from the first moment. Motivational work and mapping resources, interests and values in co-operation with the client will be of basic importance for the work.

So far no systematic scientific studies have been conducted on the success and failure in rehabilitation work with elderly people with severe combined sensory losses -deafblindness.

## NOVA's Research Project

The Norwegian Social Research (NOVA) has received a research grant from the Norwegian Research Council for the period 2001 to 2003 to investigate the effectiveness of rehabilitative work on quality of life for elderly people with acquired deafblindness. The study investigates the impact of severe combined sensory impairment on living conditions and quality of the life in old age. The aim of the study is to reveal:

- the variations found in severe dual sensory loss in old age,
- the consequences for quality of life, and
- how people cope with them.

The study also addresses whether interventions supporting visual and auditory rehabilitation (ergonomic and compensatory aids and strategies) can improve the functional abilities and quality of life for the group.

The interventions are based on a problem oriented mapping of residual functions, coping resources, and objective and subjective measures of sensory functions. Effects are measured as the impact on observed and perceived functional abilities and quality of life at 6, 12 and 18 months after the interventions. It is an essential issue to investigate interrelations between type of sensory impairment, coping resources, interventions and changes in quality of life. The interventions are

accomplished by the ordinary care system (Long Term Care, Assistive Technical Centres, National Services for the Deafblind, and Regional Resource Centres-Units for the Deafblind).

The participants consist of a previously identified group of elderly people with severe dual sensory loss. Comparisons are made with groups with unimodal losses and a group of elderly people without known impairments.

## Conclusions and recommendations

The predicted changes in population within the first 30 years of the new millennium demands a sharper focus on the sensory problems the older segment of the populations are facing, and in particular the serious condition of age related acquired deafblindness. At present we do not have large epidemiological studies of the condition that allows a safe estimate of the prevalence of the condition to be made. However, studies of vision and hearing alone, together with our own surveys in Norway indicate that the condition may be found in 1 to 3% of the population over 67. The frequency of the condition increases with age and institutionalisation. Independent of the size of the prevalence of the condition, an increase in the number of elderly adults with deafblindness follows the increased number of individuals in the older segment of the population. If we use a prevalence of 1% for the population over 65, nearly 1.4 million adults over 65 years within the OECD area had a severe combined vision and hearing loss in year 2000. The number increases to 1.7 millions in 2010 and to 2.5 millions in 2030, which are increases of 25% for the ten years and over 80% for the whole period. The increases will be particularly strong within the United States, Canada and Australia with increases of 108,120 and 113 percent during the 30 years from year 2000.

In order to deal with the increased number of elderly adults with sensory losses a focus is required on identification and rehabilitation. A golden rule for successful rehabilitation is to intervene as soon as possible. In any condition of a progressive nature, like most age related diseases, it is very important to start rehabilitation when residual vision and hearing still can be used. For that reason it is important to identify severe combined vision and hearing loss before it has become too severe. For that purpose it important to establish routines for screening in settings where most old adults can be reached. A screening instrument is available now. A checklist and two additional questions will be enough to identify the severe cases, and this instrument has been developed at NOVA.

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# Learning to play or playing to learn?

## Fostering play development patterns in deafblind children



In this article Julia Martín Cuerdo, who is a teacher of deafblind children and Juan José Martínez González, a psychologist in social services, report their work on the importance of play for deafblind children. They both work for ONCE in Spain.

**In general, deafblind children tended to make restricted use of space, with inhibited movement.**

### Why Play?

Most children, as we have all had occasion to note, spend a good deal of their time playing. Each game is an excuse to explore, handle, or create, all of which contributes to their cognitive development.

We often see, however, that deafblind children do not spend their time doing what other children of their age do: play.

How can we help them play and how important is it to do so?

Our purpose in this article is to reflect on the significance of some results from our everyday work at ONCE and share the observational records we use in different play situations.

The play sessions were organised to provide:

- ▶ time for exploring objects and toys, in which the adult remained at the child's side, participating in the game;
- ▶ free play time with no directional participation on the part of the adult;
- ▶ and free play time in which the child played alone, with the adult nearby but not participating.

### Dimensions analysed

The aspects of play recorded in our observations were:

- ▶ space
- ▶ approach to and use of objects and toys
- ▶ communication and the scenarios where activities take place

### Use of space

In this dimension we consider aspects relating to moving about and the child's capacity to undertake complex and co-ordinated movements in space (motility) in connection with game content.

In general, deafblind children tended to make restricted use of space, with inhibited movement. Nonetheless, certain differences were noted depending on their remaining vision and hearing, which favoured mobility and spatial organisation and allowed for better control of the surrounding space.

The restrictions observed may be considered as adaptive behaviour to control space and enjoy the playful aspects of the activity. But, we should be alert to such restrictions so we can detect when they form a part of a general pattern of inhibited behaviour that may obstruct play altogether.

Generally speaking, the tendency towards restricted movement decreased when the child was accompanied by an adult. In such situations children were more flexible and their movements more expansive.

The objectives of our action were geared to providing

children with the resources that would allow them to control the space reserved for playing, to reduce the level of hyper-surveillance and facilitate playful attitudes.

## Approach to and use of objects and toys

We are all aware of deafblind children's difficulties when it comes to interacting with objects. For this reason, we were interested in observing how such children approach toys and what use they made of them.

The children usually did not make expected use of the objects; their behaviour was geared more to movement and handling objects than to making any functional use of them.

Some children avoided direct contact with objects, especially objects that were new to them. Another

**Generally speaking, the tendency towards restricted movement decreased when the child was accompanied by an adult. In such situations children were more flexible and their movements more expansive.**

approach to exploration was intrusive, perhaps related to a prolongation of the oral phase. In our intervention, then, we had to bear in mind that these two attitudes, avoidance and intrusion, obstructed any opportunity to gain adapted knowledge of the object.

In an attempt to overcome the children's inherent difficulty in recognising objects, we attempted to:

- ▶ promote experience, seeking to reduce the effects of the children's sensorial impairment or an insufficiently stimulating environment.
- ▶ teach children to use their sense of touch for full and systematic exploration.

We worked systematically: asking them to pick up a toy and helping them to explore and discover its various uses.

Over time, a change was observed in most of the children: on the one hand, they began to understand what "play" meant, and were able to distinguish it from "work". And on the other, they began to express preferences for certain objects, searching for them instead of resigning themselves to whatever was closest at hand.

When the amount of time a child devoted to a given action or object, (making noise with a toy or moving it or squeezing it), was felt to be no longer useful – becoming repetitive or indicative of isolated behaviour – we interrupted the game and suggested other activities to encourage experimentation with the object.

## Communication

Play is an ideal scenario for promoting interaction and the expression of emotion and intention.

We tried, on the one hand, to appraise the child's ability to take advantage of adult availability by asking for help and, on the other hand, to ascertain whether they could

share their interest in an object with others.

As a general rule, at first the children either did not know how or found it very difficult to take full advantage of the adult's presence, tending towards passive, dependent or falsely independent attitudes.

Rejection of an object was something that all children expressed very clearly; expressions of pleasure, smiles and vocalisation of sounds, however, were not as obvious in all of them.

To be more effective, we tried to observe when their demands were in response to a real need for help and when they were formulated merely to maintain consistent contact with the adult. In the latter case we felt it was more beneficial to make the child aware of our presence and availability than to try to respond to each and every one of his/her specific demands, since that could dissipate play even further. In short, what we sought was for the children to learn to make adequate use of the available adult and encourage them to use their own resources to respond to some of their needs.

In most cases, contact with the adult was observed to be predominantly physical. Some of the children demanded the adult's attention not only to ask for help but to show him/her an object and share their interest in it.

## Play scenarios

The scenarios we used were a table and a rug, both inside the classroom. We attempted to ascertain whether each child had a preference for one space or the other and

whether his/her attitude towards toys and behaviour in play was the same or different, depending on where it took place.

In play involving food, small building toys, dolls and so on, the children were more active when at the table, where they control space better and felt safer. Children with some ability to make decisions and more independent in their movements were observed to pick up the toys and move them from one scenario to the other.

When the game involved large building toys, all the children accepted the rug as their playground and none of them attempted to change to the table.

In role-playing games, such as doctors, hairdressers and so on, the children preferred to sit at the table or stand up. When on the rug

they were more passive, generally waiting for the adult to take the initiative.

Our initial intention was to help children to play on their own, which is something they were not doing, but since they were in a classroom context with a group of classmates, we also tried to set up group play situations. This was easier in games involving movement, since they all seemed to like this sort of activity and were more highly motivated to participate.

## What did we find out?

Not only are deafblind children able to play; they need to play. Despite the difficulties, we must bear in mind that play is an opportunity, as it is for any child, to enjoy themselves

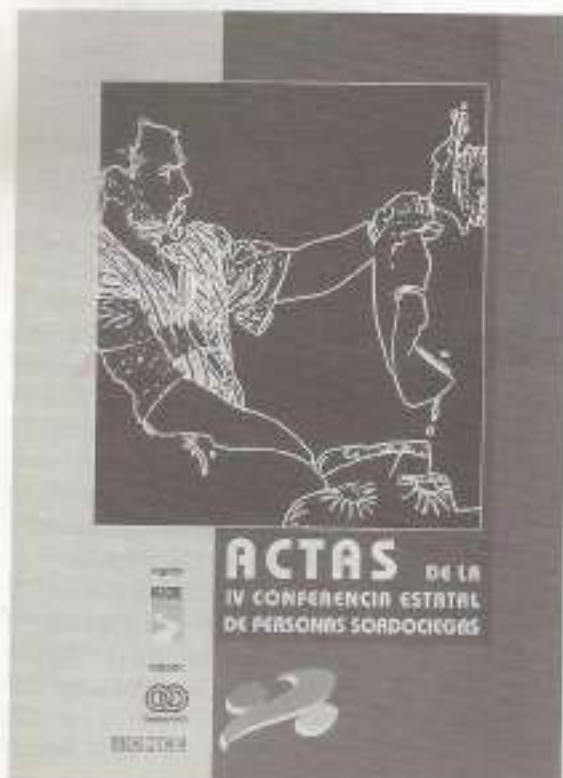
**It is we adults who need to strike the proper balance in offering them the help they need without interfering with their independence and growth.**

and express their emotions. It also contributes to the development of symbolic thought.

It is we adults who need to strike the proper balance in offering them the help they need without interfering with their independence and growth. And this can only be achieved in a warm and stimulating environment that is at the same time respectful of the child's developmental process.

For all these reasons, we believe that educational programmes should lend special attention to these activities from the outset, for what can be better than learning at play or playing to learn?

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This publication is the written Proceedings of the 4th Conference of Deafblind People which was held in Spain in July 2001. It represents 12 years of hard work during which time the recognition of the needs of deafblind people has grown and grown through the efforts of deafblind people themselves.

The report, which is a clear and attractive publication, is written in Spanish. It contains a number of contributions covering a range of key issues including, what it means to be a deafblind person, living with deafblindness and overcoming communication barriers.

The report is a collaboration between Asocide and ONCE.

# Personal and sexual development

## A vital part of life for young people who are deafblind and their families

... Imagine being on holiday as a family, relaxing on the beach, when suddenly your son starts to make inappropriate sexual advances to you – his mother. Horror, loathing, nausea, worry, disappointment and above all sorrow flood in ... sadness and disbelief take control. The son, unaware of social propriety and unable to channel his sexual desires and needs, turns to his mother, who has brought him into the world, to help him cope. Is this a case of Oedipus complex or problems learning about personal and social development? ...

Through this article a mother, who prefers to remain anonymous, but who we will call Didi, shares an intensely personal dilemma.

**M**y son, Jack, is now 26 years old and had congenital Rubella syndrome. He was born by Caesarean and immediately put into an incubator due to a ductus botalli. He spent his first two and a half months there before he underwent a heart operation to correct the problem. For parents and child this period was characterised by our family fighting spirit. On the one hand coping with grief, on the other hand fighting for the survival of our child. It was a

period of great stress: Jack found feeding difficult and during this time he had four cataract operations and one for glaucoma.

For us parents it was a period of strong-minded determination to teach Jack to master fine and gross motor skills and to enrol him in a local school for deaf children where he was rejected.

Soon Jack went off to a residential boarding school in Europe, specialising in deafblindness, leaving his parents and elder brother on

a different continent. In spite of the operations mentioned earlier Jack still had visual impairments, including a damaged retina, which made it difficult for him to see properly in sunlight and shade. He was totally deaf with learning disabilities and even some autistic spectrum behaviour but nevertheless he was lovingly welcomed at the school, where he was taught to communicate.

The big communication calendar with its drawings started to help him begin to make sense of his life and, during this period, he was rapidly absorbing information about the world around him.

Once he reached puberty he encountered a period of enormous physical change. It was at this point that reports began to arrive from the school about Jack. He was occasional behaving in sexually inappropriate ways. At home we managed this behaviour by encouraging Jack to understand the difference between the public and private domains of his life. In this way he could have privacy in his own room without causing any offence to others. Also during this period he was

prescribed with a drug to suppress his moodiness and compulsive patterns of behaviour.

From approximately the age of 18 up until now there have been continuing concerns about Jack's sexual behaviour. This has caused great stress to both family and the staff at his residence – neither being able to solve the difficulty. The difficulties in controlling this behaviour led, during this period to the administration of both Lithium and Prozac.

## My anxieties

After the incident mentioned in the introduction to this article took place, I never again embraced or hugged Jack, afraid that the scene would be repeated again. Physical contact has been limited on purpose. When I take him up to his bedroom at night I only give him a wave "goodnight". Being aloof seems very unnatural to me. Keeping a distance cools the relationship and creates a bigger gap between us. This is magnified as we only see Jack at home for a month in the summer these days.

## Thoughts around the subject

The place where Jack lives provides support of a high standard. The education, the communication methods, the recreation, the scientific research, the personnel, the professionals and everything else are superb.

Before becoming an adult at the age of eighteen, parents get all kind of economic and legal advice but one of the areas which causes most of the difficulty is that of sexual development

and its emotional and social impact.

The following ideas and questions come to mind:

- Sexuality is a part of life and of the total development of mankind, and as such, personal sexual development should be part of the curriculum for all people including the deafblind.
  - When proposing that there is a right for 'self determination' we should not only stress on the word "self" and the development of "self", but also emphasise that also the sexual self has to be developed.
  - If determination means having control, having the power and having the ability to make decisions of one's own, then that would mean the same for Jack with regard to his sexual needs.
  - Administering drugs like Prozac or Lithium may apparently suppress or channel unacceptable sexual behaviour but does it really solve the core of the 'sexual problems'. Before prescribing those drugs one should do a lot of research.
  - What are the findings over the years regarding sexuality and adolescents with the Rubella-syndrome? And if research has been done, have the parents been informed about these findings?
- I could go on formulating a lot of questions but I am just a layperson. Nevertheless I would like to make some recommendations (opposite).

(The names of the Author and her son have been changed in this article.)

It would be my wish that the theme of sexuality becomes one that involves everyone who is working with and supporting deafblind young people. This will help to ensure that issues of sexuality are included in the developing personality.

- 1 It would be good to speak with candour about the theme "sexuality and disabled people".
- 2 There is a necessity that caregivers, teachers and professionals instruct parents about what they can expect when their child with multiple disabilities enters puberty.
- 3 Professionals should mention the existing books or articles on sexuality concerning this specific child.
- 4 During conferences parents should have the opportunity to exchange ideas about their experiences in connection with sexuality of their child.
- 5 In the magazines published by and for Deaf and/or Deafblind people, there should also be articles about sexuality.
- 6 All institutions for deafblind people should appoint a specialist counsellor in sexual health and development.
- 7 Parents should be involved in the personal sexual development from when the child is about ten onwards to be partners in their sexual education.

## Developing identity

**In this article Jan Jakeš puts forward his personal view, as a deafblind person.**

This article suggests some intellectual starting points, which serve as a basis for preparing and teaching a one-semester course, "The Deafblind Person", in the Special Pedagogy study programme at Charles University in Prague. The course was prepared and taught/co-taught by the author and created by Boris Titzl, a teacher in the same department. Every year about sixty students specialising in the field of Special Pedagogy/Education and Psychology complete this course.

**D**eafblindness substantially influences a human being's identity. Its effect on the possibilities of one's self-realisation is undeniable. That does not mean, however, that a deafblind

person is relieved of the human duty of developing his or her identity and taking care of his or her self-realisation.

We live in a community whose members talk to each other, educate each other, co-operate on common work,

**... it should serve as a challenge to stimulate ...**

accept each other as human beings, and, maybe because of that they urge each other to realise their hopes and ideas for the future. Deafblind individuals also form part of this mesh of relationships and therefore they are part of the community. They not only accept, but provide stimuli to develop and bring to fruition humanity. They participate in that which was expressed in Martin Buber's words "People give each other the heavenly bread of being themselves".

Deafblindness cannot and must not be a reason for resignation; it should serve as a challenge to stimulate intensive development of all human relationships. This challenge is often understood as one solely for the surrounding environment of the deafblind person. Less frequently this is seen as a challenge for the deafblind person themselves.

It is only by accepting the challenge to freely act and by doing so to participate in the development of their own humanity that deafblind people have a chance of



becoming positive members of the whole human community. A person, and a deafblind person especially, is not a self-contained unit, resting on itself, but it is something that is formed by its relationship to other people. A person does not exist per se; we find ourselves only with the help of other people. A human being does not become a person by understanding something but by understanding others and being understood by them. I am taking directly to you all – readers of *Dbi Review* – you are the people I refer to!

A human being matures into a person by realising his or her own identity. This is an important point for the deafblind person as this process takes place in interactions with other people and their surrounding environment and it is complicated considerably by the communication and information barriers caused by deafblindness. It is, however, a problem for which a competent solution lies utterly with the deafblind person themselves. The role of experts is only a supporting one, though this role is also irreplaceable as they can arrange for a variety of quality services, for example, effective psychological assistance, quality services of all kinds, and modern practical aids.

Human beings develop their identity on the basis of their relationship to the world, to themselves, and to other people. This is why the answer to the question "Who am I?" comprises of the following three areas by means of which individuals define themselves against the surrounding environment.

- a One's own body**
  - realises that they are unique and independent and original in their body
  - identifies themselves as a living physical (biological) being;
- b One's own psyche**
  - realises that their individual psyche is also unique and independent and original;
  - identifies themselves as a free individual human mind (spirit);
- c Personal relationships in which he or she takes part and his or her share in human co-operation**
  - forms their relationship to other people – (yes you!)
  - defines themselves as a free person among other people.

The primary element of the identity of the deafblind person is probably the deafblindness itself. (I base this assumption on the opinion that such a serious impairment of distance perception impacts the process of communication - understanding and making oneself understood – to such an extent that the other fundamental personality characteristics of a deafblind person can be concealed.) It may become more obvious if we look at the following definition of deafblindness:

*Deafblindness is a unique disability caused by a combination of severe auditive and visual impairments. It causes the deafblind person problems both socially and psychologically and it manifests itself in all ordinary situations of daily*

*life. It is an autonomous impairment distinguishing itself by the necessity of an individual and specific approach towards people both for education and social rehabilitation.*

*People with this impairment represent a heterogeneous group, where the extent of disadvantage to each individual depends not only on the degree of the defect, but also when it emerged and the length of time it lasts.<sup>1</sup>*

Deafblindness represents a serious interference in the natural development of a human being. Therefore the attributes that demonstrate this reality are perceived as undesirable, and as negative elements of identity. These are not only limited to the hearing and visual

**Human beings develop their identity on the basis of their relationship to the world, to themselves, and to other people**

<sup>1</sup> The definition I use is an amended version in the formulation suggested by B. Titzl in 2001, of a definition the first version of which was formulated by V. Husáková in 1993 in her diploma thesis at Philosophical Faculty of Charles University in Prague. See also her article *Pojem hluchoslepoty in Speciální pedagogika 1997, Nr. 2.*





**Only if and when a human being aims at self-fulfilment for others, he or she becomes himself or herself**

Impairments, but also difficulties concerning mobility and communication, psychological and social isolation, the risk of mental and social under development and considerable dependence on the help of others in a number of activities.

One of the natural consequences of deafblindness is the reaction to it – particularly the reaction

of the deafblind person themselves. If they make an effort to actively reconcile themselves to deafblindness, then they can be a force to improve the life of a deafblind person. This applies to the red-and-white stick, which is not only a useful aid but is also symbolic. It represents positive attitudes, social competence, characteristic ways of communication and engagement in general co-

operation with life.

If a deafblind person develops positive elements of his or her own identity, they can represent their self-fulfilment. This self-fulfilment is part of human nature. It ranges from biological and sensory needs to realising humanity. In other words, starting from self-fulfilment for oneself it is possible to reach self-fulfilment for others. Only if and when a human being aims at self-fulfilment for others, he or she has a true identity for himself or herself.



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Website of Charles University: [www.pdf.cuni.cz](http://www.pdf.cuni.cz)

Email: [jajakes@volny.cz](mailto:jajakes@volny.cz)





## Canadian report on causes of deafblindness

**SUMMARY of Report (ISBN 0-921434-18-9)**

**Stan Munroe**

Fifty (50) organizations throughout Canada were involved in locating persons with deafblindness to participate in this study.

- Seven hundred and seventy-seven (777) individuals volunteered to be part of the Registry, 370 males and 407 females. The oldest person reporting their age was born in January, 1900, while the youngest was born in June, 1998. Twenty persons or 2.6% of the sample were of pre-school age; 121 or 15.7% were school aged (6 to 21 years); 463 or 60.1% were aged 22-64 and 166 or 21.6% were aged 65+.
- The vast majority (86.4%) of these individuals had been previously identified as having the disability and were receiving some level of service from an organization.
- In the sample of 777 individuals, 44.7% of the respondents had congenital deafblindness, while 55.3% reported their deafblindness as acquired.
- Causes of deafblindness for all respondents are summarized in the following categories:
  - inherited rare disorders (35%);
  - intra-uterine infections (19.5%);
  - congenital brain damage (8%);
  - aging (8%);
  - non-inherited chromosomal abnormalities (6.5%);
  - post natal/early childhood infections (5.4%);
  - acquired brain injury (5.2%);
  - prematurity (3.6%);- metabolic conditions (2.7%);
  - birth trauma (2.3%);
  - Sexually Transmitted Diseases (1%)
  - others (2.5%).
- Usher Syndrome and Congenital Rubella Syndrome are the primary reported causes of deafblindness, accounting for 29.9% and 18.7%, respectively
- Fifty-five percent (55%) of the respondents reported receiving the services of an Intervenor
- Almost 26% reported completing some form of education. Just over 19% of respondents are currently in an education program.
- Eighty-one (81) persons or 10.4% of the total respondents indicated they were working, 51 working in competitive employment and 30 working in sheltered programs. The majority (74.5%) working competitively had acquired deafblindness; the majority (86.7%) working in sheltered programs had congenital deafblindness.
- Persons with acquired deafblindness tend to have a higher rate of use of such modes of communication as writing/printing, sign language (American Sign Language and Signed English), manual alphabet, and speech, than those with congenital deafblindness.
- The living arrangements of the respondents were reported as follows: lives independently (34.3%); lives with birth family (23.3%); lives in Provincial facility (15.5%); lives in supported living facility (8.6%); lives in retirement home (8.5%); lives in supervised living facility (5.5%); Lives with Adoptive Parents or in Foster Care (3.7%) and lives in nursing home (0.6%).
- Of those respondents born before 1980, 72% reported their marital status as single; 18% married; 9% widowed and 1% divorced.
- A safe estimate of the deafblindness ratio in Canada is 10 to 15/ 100,000, or a population of 3,100 to 4,650 persons.
- The findings of this report show significant distinctions between congenital and acquired deafblindness in almost every category where comparisons were available. In addition, one major distinction exists; the wide variance between the two groups in terms of the type and extent of services available to each.

*Copies of this report are available in French or English for \$20.*

*For copies please contact CDBRA at [cdbra.net@sympatico.ca](mailto:cdbra.net@sympatico.ca)*

## The European Conference in The Netherlands – July 2001

### A personal view from Colin Bennett

The sun was blazing down as I walked to the bus station in Brighton on 23 July 2001. I knew the sea was shimmering but the glare was far too fierce for me to see it. I have Usher Type 2.



**One of the joys of the Conference was the fine quality of the induction loops in the various rooms where all the events were held.**

I was on my way to the 5th European Deafblind Conference to be held at Noordwijkerhout near the Hague in The Netherlands from 24 to 29 July 2001.

It was not a day to travel. The girl at the booking office had told me to allow PLENTY of time for the journey to Victoria Bus Station, London, so I had a couple of hours to take in this international staging-post before I caught the Eurolines bus for the Hague.

The sea was as calm as a mill-pond as we crossed from Dover to Calais. To my delight the ship was well-lit but I sat in a lounge bar near the Green Stairs ready to descend to Deck E. I don't trust myself to explore when I have to board the bus at a certain time. As always, I had taken the registration number of the bus in case I lost it! These are the kinds of things you do if you have little sight.

As we docked, I found the driver, Rob from Dordrecht, waiting at the stairs. This was his 453rd trip (or something) so I think he had got the hang of it! It was about 4:30am and we were travelling between Rotterdam

and The Hague. I was looking to the east willing the sun to rise. Not surprisingly it was reluctant to move on my command and when we pulled into the stop over the railway station at the Hague, there was only a glimmer in the sky. The bus departed and I found myself standing in a large bus station with no-one around. I had two hours to find the bus-stop for the Golden Tulip Hotel, Noordwijkerhout where the Conference was to take place. I could do little until the sun came up. Eventually it did and just after 7am the local bus arrived. It left promptly, Dutch style, and I fell asleep. I awoke an hour later and, just in time, realised I was at my stop.

It was a glorious Summer morning. I walked over the road and after a few hundred metres found myself in the Golden Tulip Hotel. One of the ever-cheerful receptionists showed me where I could lock up my suitcase. After a wash and change in the washroom I felt like a million dollars. I was hoping to find some breakfast when two cheerful voices hailed me. They belonged to two Sense workers. They took me to the breakfast area where I began my six-day love-affair with that place. In the days to come, every morning at seven I would sit



in the window and begin a leisurely breakfast.

Every morning I would discover something new: one day the yoghurt, another day the fruit. It was very exciting. The world came to me and I met a lot of people like that.

On the first day we all started to find our way around. I discovered Father Christmas in civvies who turned out to be Jan van Dijk. Together we made sure the induction loop in the main Conference chamber, the Rotunde, worked well.

One of the joys of the Conference was the fine quality of the induction loops in the various rooms where all the events were held. I was asked to test all the induction loops. I was rewarded for this arduous task with a swish shirt which I have worn day and night ever since. The Conference was

arranged as a series of Plenary sessions and a great number of workshops which ran in parallel so one had to choose, which was not always easy!

I found the plenaries interesting for the most part although some were a little contrived for my taste.

I could always find a workshop that interested me. What I liked best in both the Plenaries and the workshops were descriptions of actual experiences in different countries. I think the workshops where the presenters merely read an account, with no time for questions, were less successful.

If I had had the chance to contribute to the planning, I would have suggested the subject of technology to assist people with sensory loss. Also, I personally would

have liked a Plenary explaining the impressive systems of schools etc for people with disabilities in The Netherlands.

The Conference was a tremendous success and I enjoyed it enormously. The accommodation was first-class and the food superb. The organisation was excellent and the staff, of the Hotel and of the Conference, were always willing. Our Dutch hosts did a marvellous job.

I, myself, was spoilt rotten by having the services of some very competent interpreters from the signing college at Utrecht.

The crescendo of the event was a Dinner and Dance on the Saturday night which was a great success. I think we were all sad when the Conference ended the next day. I just didn't want to go home!!

**The Conference was a tremendous success and I enjoyed it enormously. The accommodation was first-class and the food superb**



*The Golden Tulip Hotel*



**5<sup>TH</sup> EUROPEAN  
CONFERENCE  
ON DEAFBLINDNESS**

*The opening address was made by  
H.E. Vigdis Finnbogadottir from Iceland*



*The Conference Hall was full every day for  
the Plenary sessions.*

*Seija Troyano  
from Finland  
started the  
Conference  
programme*



*Knut Johanssen with fellow delegates after his Plenary session.*



*Ms Soghra Nikpour shared  
information from Iran*





Dr Brian Abery set the Conference theme: Self Determination – a life long process.



The authors of "Staying in Touch – communicating with deafblind people". Irma, Lieve, Ton and Anneke. (Trude was absent).

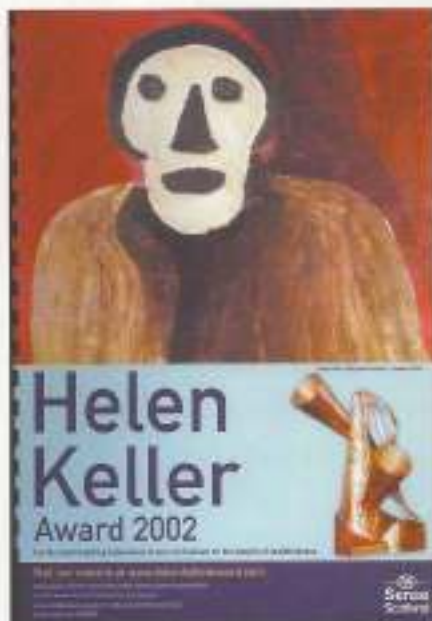


"I Will Survive" ... the anthem of The Interpreters. They did a fantastic job all week.

# Helen Keller Award 2002

Sense Scotland's 5th Helen Keller Arts Award was launched by the Scottish Executive Deputy Minister for Sports, the Arts and Culture, Allan Wilson, on 12 November 2001 at The People's Palace in Glasgow. It saw its international launch at the Deafblind European Conference in the Netherlands in July of this year.

Sense Scotland developed this art award to demonstrate the value of all individuals regardless of their disability.



## What is the Helen Keller Award?

The American campaigner Dr Helen Keller remains the world's most famous deafblind person. During a lecture-tour to Scotland in 1933 she helped auction a bullock and established a fund for deafblind people with the proceeds. In 1989 the fund was transferred to Sense Scotland who transformed the award into a multi-media arts competition and launched the first arts competition on the subject of deafblindness. Sense Scotland now holds the Helen Keller Award every two years.

The Award is given for the most inspiring submission in any art medium on the subject of deafblindness and is open to professional and non-professional artists and disabled and non-disabled artists. Further commendations may be made at the discretion of the judges. Entries can be accepted in any form: print, braille, audio tape, video tape, photography, paint, sculpture, music or any other medium. Entries from people with a dual sensory impairment are especially welcome.

The winner will receive a trophy and a top prize of £1000. There are two further prizes of £200 for highly commended entries. The Helen



**Lewis Scott (above), deafblind artist based in Glasgow. Previous winner of the Helen Keller Award.**

Keller Award 2002 is generously sponsored by Barclays.

More information can be found on the Helen Keller website at: [www.helenkelleraward.com](http://www.helenkelleraward.com)

**Patricia McGowan**  
Arts Development Officer  
Sense Scotland  
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**Brian Crichton (right), deafblind artist based in Glasgow. Highly commended entrant, 1998.**





## Congenitally Deafblind Persons' Exposure to Language (International Course) 23–27 October 2002

### First Announcement

#### International training course

On the 2002 agenda NUD has a training course designed for Co-constructing meaning. Congenitally deafblind persons exposure to language/elements of language

#### Target group

The course is primarily offered to key staff who work with congenitally deafblind persons, such as staff with supervising and co-ordinating functions.

#### Objective

The objective of the training course is to give the participants increased knowledge about how to contribute to the development of communication in persons who are congenitally deafblind.

The course will focus on the current knowledge of the very basic meaning making processes that are operative throughout all phases of communicative development. These basic cognitive creative (generative) processes blend with the dialogical practice in creating shared meaning, shared vocabularies, and shared narrative discourses.

The introduction of linguistic practise of the culture will be focused as well. The identified salient features of exposure for language will be addressed and discussed concerning different groups of congenitally deafblind persons.

A model of the different logical levels in communication, which can be used as a tool for the analysis, will be presented. The model will be presented and used in practice analysing the videotapes of the participants, and suggestions for further intervention will be discussed.

Relevance to the participants' working situation is secured through a video based analysis of cases of their own.

#### Venue

The course will take place at the Nordic Staff Training Centre for Deafblind Services (NUD) in Dronninglund in Denmark from 23–27 October 2002.

#### Language interpretation

The working language is English. The Nordic Staff Training Centre can provide equipment for simultaneous interpretation for participants who need to bring interpreters.

### Other NUD Training Courses 2002

#### February 13–17

Training course on physical exercise and body awareness in persons with acquired deafblindness

#### March 3–22

Basic course on congenitally deafblind persons

#### April 7–19 and September 15–27

Basic courses on persons with acquired deafblindness

#### May 1–5

Training course on Cochlear implantation in persons who are developing or have acquired deafblindness.

#### August 29–1 September

Specialist conference on "Sensation, perception and construction of meaning in persons who are congenitally deafblind"

#### 5–9 October

Conference on "The adaptation of the school situation for children who acquire deafblindness"

#### 27 November–1 December

Training course focusing on "Environments and activities for a meaningful life for congenitally deafblind adults in sheltered living and working situations"

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**EUSN - EUROPEAN USHER SYNDROME NETWORK**

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**MULTIPLY DISABLED VISUALLY IMPAIRED EUROPEAN NETWORK**

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**CHARGE Network**



**David Levey**

David Levey has CAUSE for celebration. An exciting new project is now under way involving collaboration between the CHARGE Network and the European Usher Syndrome Network (EUSN).

This eighteen month long project is funded by the European Union and goes by the name of CAUSE which stands for CHARGE And Usher Syndrome in Europe.

The project developed from both Networks independently approaching Sense International for support in finding new sources of funding. To have a better chance of success Sense International suggested a collaboration between the two Networks, which has brought us to this point today. Our thanks go to Richard Hawkes, Director of Sense International, and his team for the hard work they have put into achieving this result.

The project is transnational and involves the following organisations:

- CRESAM, France
- Retina France, France
- Blindeninstitutstiftung, Germany
- Fighting Blindness, Ireland
- Lega del Filo d'Oro, Italy
- ONCE, Spain
- Sense, United Kingdom

I am coordinating the project and Marilyn Kilby (EUSN Coordinator) will represent Sense on the transnational committee.

The two Networks have much in common, for example:

- raising awareness of their particular syndromes
- increasing international contacts particularly with people who have the syndromes and their families.

Some of the aims of the project are:

- A survey to cover existing information and the nature / extent of services available in the partner countries with regard to the two conditions
- Production of information translated into the partner languages, to raise awareness of both conditions
- A joint conference on CHARGE and Usher to be held in the UK in January 2003.

This project is an excellent opportunity for both Networks to further raise awareness of CHARGE and USHER in Europe. It will help bring us into contact with a wider audience of professionals and potential sources of future funding, as well as establishing strong links between the people involved with two of the major causes of deafblindness.

**David Levey**  
**CHARGE Network Coordinator**  
**CAUSE Project Coordinator**  
levey2000@cs.com



# Acquired Deafblindness Network

## Report from the meeting in the Netherlands

In the preparation of the Acquired Deafblindness Network Morning, the decision was made to have a morning with real networking around shared problems. For that reason, the meeting began by asking all participants to identify areas of interest which would be group discussion topics. Several common themes emerged which were then discussed.

- 1 The elderly group
- 2 Research and definitions
- 3 Staff training
- 4 Development of services

### 1 The elderly group:

A particular area of interest was communication systems for the elderly who are not sign language users and how to develop systems for couples and families. The group requested that this topic should be considered at the next Acquired Deafblindness Seminar in Switzerland (Zürich) in autumn 2002.

The group also discussed how to breakdown isolation and how to get better co-operation with other specialist workers. We then shared information about the contact persons in Denmark.

### 2 Research and definitions:

This group discussed definitions and concluded that it may not be possible or necessary to have a precise definition. However, they felt that it is important that there are common tools in use, which can assist in the identification of those with acquired deafblindness, particularly in the elderly group.

The group discussed the lack of



**Anneke Balder**

published material on acquired deafblindness and agreed that colleagues should try to get more research and practice materials published, preferably in English so that it is widely accessible. It was also felt that we should begin to evaluate practice within the field of acquired deafblindness and to collect data. The group recognised that there were issues related to this including the reliability and validity of the data obtained from personal reporting and how general or specific the measurements should be.

### 3 Staff training:

The group discussed the various training models which are used in Europe and how to make training available to non-specialists in local areas. During the discussion it became obvious that there was material available which could be of use to colleagues in other countries, but people were not aware of it. This led to a discussion about how to ensure the network is really working for people. The group made the following suggestion that a co-ordinator be appointed who has the job of making information available and enabling us to share it. This should be funded and resourced properly.

### 4 Development of services:

This group came from two perspectives:

- a Canada, where very little exists
- b Scandinavia, where services are better developed.

They shared experiences and discussed how to reach staff in local areas who are vital in the lives of deafblind people. These staff need training and information.

The group wanted to establish an exchange of information, research and materials through the network.

After the groupwork, there was a general discussion about how to use future network meetings and seminars. Participants felt that in the future more detailed discussions would be helpful. People wanted the opportunity to explore issues in depth and share experiences in a more structured way in order to develop practice and expertise. Others felt that the groupwork was very effective and were happy with the opportunity to discuss issues. There was a suggestion that a website should be established with a named person responsible for maintaining it and keeping it up-to-date.

At the end, the conclusion was that many of the topics that were discussed during the network morning are potential subjects for the next seminar in Switzerland in 2002. This seminar will be very important in the progress of the development of the Acquired Deafblindness Network.

Liz Duncan and Anneke Balder.

# Report of the Staff Development Network

**T**he group of people who have formed the EUCO Unit over the past years have agreed, after long discussion, to disband the Unit with its present format and membership in order to allow networks to form around specific issues of interest. The old remit of the EUCO Unit had proved too broad and diverse to be achievable. The members of the EUCO Unit have enjoyed their time and believe that the achievements of the EUCO Unit over the years are to be commended. The proceedings of earlier conferences at Osimo and the reports from seminars held are still valuable and worthy of study. Grateful thanks are also due to NUD and Instituut voor Doven for financially and administratively supporting the Unit over the last six years. Thanks are also due to colleagues in Poland, Spain and Holland who have hosted meetings and special thanks go to Krista at the NUD and to Lieve at IvD for their meticulous and efficient planning and administration.

During the Network Morning at the 5th European conference on Deafblindness, this initiative was discussed. In addition, Inger and Virginia presented information on some staff development activities in the Nordic countries and the UK, to help fuel ideas.

Those present were then invited to help begin a new phase of staff development networking. The subject of staff development is very broad and we agreed to encourage small sub-groups to form, concentrating on different interests in the broader area.

The outcome was that four groups immediately came together



**Virginia von Malachowski**

to network and to agree to share information, ideas and problems. The areas of networking are:

- ▶ staff practice development – using techniques like practice supervision, work-based mentoring and other support methods that help maintain and develop practice skills in all workers;
- ▶ training for new and inexperienced workers in social care settings during their first year of work. It was acknowledged that this was mostly with staff who had no professional background and who were working with congenitally deafblind adults;
- ▶ service standards and how to establish a training framework to cover all areas of deafblind work;
- ▶ technology within staff development and learning methods such as video-conferencing, e-groups, etc., that would support some of the challenges of distance in the deafblind field.

Virginia von Malachowski agreed to continue to be the link person for all the networks that might form and to act as a contact point with Dbl until

the next conference. Each of the four groups at the Network Morning nominated a key person and we realised that networking arrangements in the small groups and within the overall network would have to be established in the next month or so.

Any significant overlaps with other existing networks were acknowledged as an advantage and reminded everyone of the need to work collaboratively. Interest was particularly expressed in reviving the network on congenitally deafblind adults.

The group discussed cost-effective ways of linking and staying in contact, exploring ideas of possibly expanding the role of the Dbl website in setting up network groups, noticeboards, etc. Details will be published in the next edition of Dbl Review and on the Dbl Website.

**Virginia von Malachowski**

# EUSN – European Usher Syndrome Network

## DbI European Conference, Noordwijkerhout, report of the Network morning

**M**arylin Kilsby, Miriam Bruggemann and Charlotte van de Molengraft, all members of the EUSN Conference Planning Team, prepared the programme for the network morning. All the planning was done via e-mail, except for a meeting one lunch-time earlier in the conference, to finalise the programme. We had a lot of problems and it took a lot of flexibility to fix it, but we succeeded!

The main aims of the Network Morning were:

- 1 to introduce the EUSN and to explain why it needs to exist.
- 2 to encourage more people to join the EUSN and also perhaps to join the Planning Team.
- 3 to gather ideas for the agenda of the coming Usher conference next year.

On the Friday morning a very large problem emerged. The loop didn't work at all, despite the fact that Charlotte had checked it. We tried everything but the loop refused to work. After half an hour we all decided to start, even though there were about twenty people in the room who needed the loop. Fortunately the microphone was very clear! About 50 people attended the Network Morning and many of them, probably about half, were people with Usher.

Charlotte was the Chair of the morning. She opened the meeting, spoke a word of welcome and explained the context of the programme. Marylin then gave a short history of the EUSN.

Miriam was next on the agenda, explaining about the membership of the EUSN. She distributed a questionnaire, which the people



**Marylin Kilsby**

were asked to fill in and return after the coffee break. We received a lot of the questionnaires back from people from many different countries.

Bill Kimberling from the USA was due to be our guest speaker. Unfortunately, Bill's family had a serious medical crisis and Bill had to return to the US. Mary Guest, Principal Research Officer, Usher, Sense, was asked to be our guest speaker at very little notice. Mary gave a very clear summary of the European Usher Study Group weekend, which had taken place just before the main Deafblind International conference.

After the coffee break there was a panel in which were two people with Usher I, two people with Usher II and the husband of a person with Usher II. Miriam was the panel chair and sometime she took off her Chair's "hat" so that she could speak as a mother of a young adult with Usher I. There were many questions from the audience. It was a very interesting part of the morning. Although the title of this session was "Usher in the Family", other subjects were covered, the main one being Usher identity.

Last but not least we spoke about the future of the EUSN. Marylin told us some very good news. She was able to tell us that EUSN will receive some money

from the EU. This is repeated elsewhere in the magazine.

The result was that lots of people were willing to become members of the EUSN, and were also interested in attending the EUSN conference, which will probably take place in Autumn 2002 in Switzerland.

Charlotte closed the meeting and said a big thank to the people. One statement was made which is so important that we feel that it should be told everywhere and to everyone.

**We don't want to be labelled as 'usher'. That sounds too negative. We want to be seen as persons with Usher syndrome or as persons who have Usher syndrome.**

### Conclusion

Despite a lot of unexpected problems such as the loop (which was mended eventually) and the absence of Bill Kimberling who was replaced by Mary Guest (by the way an excellent speaker), many felt that the network morning was a success!

The morning has raised awareness of the EUSN and, we trust, has given us many more contacts in many different countries.

**Charlotte van de Molengraft  
The Netherlands  
Marylin Kilsby  
Sense, UK  
Eusn/netmornreport  
cvdmmk.doc**

## European Usher Study Group



The theme, 'Ethical Implications of New Genetic Discoveries in Usher syndrome', generated some excellent papers and discussion in

our 10th Usher Study Group in Holland in July 2001. We plan to publish some of them in the next issue of the *DbI Review*.

The Study Group though small – under 30, represented a nice cross section of interest within the Usher field, including families. As a result people who would not normally meet had an opportunity to share views and learn about each other.

It was encouraging to welcome some new members, in particular from Great Ormond Street Hospital for Children, in London, and from France.



We hope that the 10th Usher Study Group will encourage more collaboration between the various disciplines and the families and we

that we can look forward to some wider national studies being carried out into Usher Syndrome.  
**Mary Guest, Sec EUSG**



## The World Federation of the Deafblind

### Moving forward

Originally, a draft charter, written by Rod McDonald, USA, was sent around for comments before the latest Helen Keller conference, which took place in New Zealand, October 2001.

Since then Lex Grandia rewrote the draft charter into a constitution, which is required in order that the organisation can be legally registered in some of the countries in the world and can be recognised by United Nations organisations and institutions. Many changes were made but one thing we should mention here is the complicated matter of membership. We have decided to speak about countries instead of organisations. Each country can appoint or elect a



**Lex Grandia**

representative to the General Assembly, no matter how deafblind people are organised in that country. The only criterion is that the person who acts as a representative of the deafblind population of that country is deafblind, otherwise he or she cannot represent the deafblind population of that country.

If you have any questions or comments, or for more information, please contact Stig Ohlson, President of the preparative Committee, World Federation of the Deafblind at the address below;

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Fax: +46 86595042  
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e-mail: [Lex.grandia@tp44.frukt.org](mailto:Lex.grandia@tp44.frukt.org)  
(text only, no attachments)  
or: [Annth@post3.tele.dk](mailto:Annth@post3.tele.dk)

*Join Us In Canada!*

# 13th DbI

## World Conference On Deafblindness

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Resort & Conference  
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Mississauga  
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Canada

AUGUST 5-10, 2003



*Canada's doors will be wide open as we prepare to welcome you to the 13th Deafblind International (DbI) World Conference in Southern Ontario, Canada during the summer of 2003.*

*Watch for the promotional announcement coming to you in Spring, 2002. This will include 'A Call for Papers' on the Conference Theme: Communication is the Key to Opening Doors Worldwide For People Who Are Deafblind.*

*The Conference Program, Special Events, Registration and Accommodation will be detailed in a subsequent announcement coming in Fall 2002.*

*Check Out The  
Conference Website!*

[www.dbiconferencecanada.com](http://www.dbiconferencecanada.com)  
Register On-line Soon!

(519) 372-2068 Fax: (519) 372-0312

E-mail:

[mail@dbiconferencecanada.com](mailto:mail@dbiconferencecanada.com)





## Ecuador

Sonia Margarita Villacres of Ecuador describes her interview with the broadcasting company CNN:

I had my first contact with CNN at the Conference "An International Celebration of Empowerment: Sharing dreams and visions for children and young adults who are deafblind" in August 2001 in Miami. This conference was supported and organized by the Hilton Perkins Program and FOAL (Spanish National Foundation of Blind for Latin America).

During this Conference CNN told me that they would be sending journalists to interview me at home in Ecuador.

The interview was undertaken by CNN journalists from Quito in Ecuador. They filmed the Municipal School for the Blind in Guayaquil, where I work as a teacher, then they also filmed the Deafblind foundation of Ecuador "Ecos y Luz", where I am the

president. They filmed my home as well!

The interview was based on my job with deafblind children, blind children and those with multiple disabilities. Likewise, they interviewed mothers, the Principal and a teaching assistant. I did a brief description of my personal life, since my accident that left me with this sensory impairment. Also about the work I, and others, are doing in the Foundation to help children, young adults, relatives and professionals. Then, at home, I described my present life, after the death of all my family members, which means I have to do all the domestic activities absolutely alone. The journalists were very surprised to see that people with sensory disabilities can do so many household

chores, live alone and, even more so, to help others!

At the end of the interview Rodolfo Muñoz, the journalist, was moved and told me that meeting me had been one of the nicest experiences for him and it had taught him a lesson. Finally, he told he wanted to be my friend because he now understood the value of living.

I pointed out that without the help of the Hilton Perkins Program in Ecuador we could not have initiated the work with deafblind people in my country. We are very satisfied with the staff of Hilton Perkins Program and also with Poscal that helps deafblind adults. All these programs, FOAL, POSCAL and Hilton Perkins, give light and hope to thousands of deafblind people in Latin America.

## Canada

Cindy Babineau, Executive Director, Rotary Cheshire Homes writes:

If you live in Canada or making a visit you can help the Canadian Helen Keller Centre to raise money by buying 2002 Entertainment Books.

Entertainment books are filled with great savings at places people go and for things people love to do.

Two for one dinners at restaurants and fast food places, discount movie tickets, sporting events, theatre and local attractions. There are also savings on airfare, hotels, car rentals, cruises and much more!

The Entertainment books are \$32.00 each. You will get this money back in savings the first few times you use the book! Over one year you can



save hundreds of dollars. The great thing is that for every book sold \$15.00 will go to the Canadian Helen Keller Centre.

If you would like to buy a book please contact Rotary Cheshire Homes at 416-730-9501 voice, 416-730-9187 TTY or via e-mail at You can also order books online at and direct the \$15 to Rotary Cheshire Homes - The Canadian Helen Keller Centre. What a great way to save a lot of money and support CHKC!

## A reminder about the Website

If you'd like more information on Rotary Cheshire's new division, please see our web site at [www.chkc.org](http://www.chkc.org). It is a fantastic web site filled with a huge amount of information on the dual disability of deafblindness, the new Canadian Helen Keller Centre, communication methods used by persons who are deafblind and many links to our supporters and other organizations.



## Croatia



Martina Stabi, Development Manager at the Croatian Association of Deafblind People – Dodir, updates us on the achievements of the organisation and the exciting work that they are undertaking in Croatia.

The Croatian Association of deafblind persons 'Dodir' is a national, non-governmental and non-profit making organisation that was founded at Christmas 1994 by a group of deafblind people living in Zagreb. Since then it has grown to become a national voice for deafblind people in Croatia and works with all age groups.

Dodir's activities include: supporting the development of one-on-one communication and the physical rehabilitation of institutionalised young children; lobbying and campaigning to combat discrimination against deafblind people within the public policy position of the government; identifying deafblind people in residential care and household settings; providing communicator-guides (interpreters) for deafblind people; organising respite and leisure activities for deafblind children and their families.

The Croatian Association of Deafblind People 'DODIR' was named after the prose poem Dodir that was written by the poet, Stjepan Lice. During the past seven years Dodir has become a synonym for deafblindness, inside and outside Croatia. Dodir is the only association in Croatia that recognises the problems and needs of deafblind people and offers help and support in solving these problems. Dodir's wish is to help deafblind people by including them in the every day flow of life.

DODIR has 125 deafblind members, 25 permanently active volunteers and 55 volunteers who are included from time to time in Dodir's activities. This number does not include the family members of our deafblind members who are also included in our activities. We

have three people who are employed part time in management, four people who are employed part time in education and one part time person employed to work for the rights of deafblind people.

We are currently working through several important programs and these are:

- 1 education and rehabilitation of deafblind children in Croatia;
- 2 identifying evidence of the existence of deafblind people in Croatia;
- 3 informing and educating the public about the complex problems of deafblindness;
- 4 supporting volunteers in the service of humanity;
- 5 keeping up to date with new knowledge and achievements related to deafblindness, participating in conferences and working with other disability organisations who are promoting the rights of deafblind people in Croatia;
- 6 locating and offering support services to older deafblind people.

Because of the visible results of its work, Dodir was rewarded with the prestigious, 'Award of the town of Zagreb' in 1998, and in the year 2000 we received the 'Award of the Assembly of Young Businessmen' for our pioneering work in the field of deafblindness. Dodir co-operates with a number of world organisations; since 1998 we have been a member of the most important world and European organisations, DBI (Deafblind International), WFDb (World Federation of the Deafblind) and EdbN (European Deafblind Network). We also have our representative on the

administrative board of the world network for communication, the Interpreting Development Network. From October 2001, Dodir president Sanja Tarczay, second Year student in the Faculty of Special Education and Rehabilitation, has been a member of the executive board of the World Federation of the Deafblind and a representative for Europe.

This year, from 3rd-5th May 2001, Dodir collaborated with the Department of Hearing Impairments, the Faculty of Special Education and Rehabilitation and the Faculty of Philosophy of the Society of Jesus in order to organise the International Symposium of Sign Language and Deaf Culture held in Zagreb.

In order to educate and qualify our staff to work with our members we have sent two deaf students to Gallaudet University, Washington DC. One of them will learn to work with young deafblind children and the elderly and the other one to be a trainer of communicator guides for deafblind people.

Next year, in 2002, Dodir is hosting the European Holiday for Deafblind people 2002, which you read about in the last edition of Dbl Review. This will be held on the island of Brac on the Adriatic coast from 22nd-29th of June 2002. The hotel is Hotel Zlatni Rat and the price per person is 350 Euro. For more details about these holidays or the work of Dodir please contact our new office in the centre of Zagreb at: *Croatian Association of Deafblind Persons – Dodir Nova cesta 54, 10 000 Zagreb, Croatia Phone: 00385 1 3821922 www.dodir.hr*



## Latin America

### Three Meetings in One

The 1st Usher Symposium • The 2nd National Meeting of Families and Institutions  
• The 4th National Meeting of the Deafblind

21-24 November 2001, INES auditorium

Grupo Brasil de Apoio ao Surdocego e Múltiplo Deficiente Sensorial, with the support of INES – Instituto Nacional de Educação de Surdos – Rio de Janeiro, MEC/SEESP, Hilton Perkins Program – USA, Sense International – UK and IBC – Instituto Benjamin Constant – Rio de Janeiro, will present at INES auditorium the first Usher Symposium, the National Meeting of Families and Institutions and the fourth National Meeting of the Deafblind.

This event will be very important as it will include

national and international guests that are professionals, parents and deafblind people who are very active in their countries.

As well as interesting themes on deafblindness, the event will have three workshops: families, parents and professionals, where there will be the opportunity to (re)think our practice and structure the future.

The highlight of this event is the 1st Usher Symposium. It is the first time that specialists, families and the people with Usher Syndrome will join us to exchange

experiences and set out goals for the future.

It is important to say that, without the partnerships and the commitment of everybody, these events wouldn't be possible. Therefore, Grupo Brasil de Apoio ao Surdocego e ao Múltiplo Deficiente Sensorial, thanks everybody that is helping us and believes that together we can overcome the barriers.

**Lilla Giacomini**  
**Laura Lebre M Ancillotto**  
(translator)

## Italy

### Breaking News! A Family Conference for 2002

Preparations for a family conference which will possibly be held in Italy in September 2002 are under way. An international investigation group, led by William Green, Lona Poggioni, Miriam Bruggerman and Gill Morbey, are developing ideas for this exciting meeting which will bring together families of deafblind children and adults from all over Europe, and the wider world, to talk about topics that are of particular interest to them. The meeting will include family groups with

deafblind people and, during the conference and activities, there will be staff from different countries to support the involvement of all the participants in creative art activities.

The Scientific programme is being developed at the moment and will involve the opportunity for parents and carers to share and support each other, and a creative programme of activities as well. Everyone's needs will be taken into consideration – mothers, fathers and siblings.

The team are currently

investigating the financial implications of the conference but additional resources are required and the group is making the necessary applications for this now. The likely cost per person will be approx. Lit. 1.000.000 to include accommodation and programme but not travel.

Information about the progress of the conference preparations will be circulated in the New Year but contact William Green to get your name on the mailing list. e-mail: green.lfo@usa.net

## India

Subhash A Datrange is now a consultant and is willing to undertake projects in a wide variety of areas. Mr Datrange is a Senior Rehabilitation Professional and was Head of India's largest NGO in the Blindness Sector, the National Association of the Blind, until his retirement in July of this year. He is very

well known to Dbi members and colleagues and he is now available for assignments from NGO'S in India and International Development Agencies. He has a wealth of experience and can be contacted at:

149 / 5038, Blue Bird  
Nehru Nagar  
Kurla ( E ) Mumbai -400024  
India  
Tel: 91225223448  
E-Mail: subhashdatrange  
@yahoo.com





## South Africa

Sam Beshielo reports:

### 1st South African National Conference on Deafblindness

The South African National Council for the Blind (SANCB) committee for people with multiple disabilities has had its first National Conference on Deafblindness on March 26th-30th, 2001. This was, in fact, a working conference with presentations that covered awareness as well as intervention.

Even though most speakers were from South Africa, we had our friends, Tom Miller and Marianne Riggio from Hilton Perkins who have experience of Africa, to make presentations. The

delegates for this conference were teachers from schools for deaf learners and schools for blind learners. The president of Dbl, Mr Mike Collins, and the President of Deafblind World Federation, Mr Stig Olhson, spoke at the Award ceremony where certificates of recognition were presented to the following:

- Ms Anlo van Heerden: the first teacher for the Deafblind in South Africa
- Professor Theo Pauw for his work in promoting services of the deafblind in South Africa

- Mr Sam Beshielo for his services to deafblind learners.

The award certificates were presented by the National Director General of Education in South Africa, Mr. Thami Mseleku. The success of the conference was measured by interest in the following:

- starting other units for deafblind learners in other parts of the country
- the need for teacher training in the education of the Deafblind
- the need to reach out to countries closer to South Africa to serve the Southern African region.

## USA

News from The Charge Syndrome Foundation



The CHARGE Syndrome Foundation held a very successful conference in Indianapolis, Indiana, during the summer, and, as always, the event was very well supported by families and professionals alike. Families from all over the world joined US families for this special event.

In addition to the conference, the Board of the

CHARGE Syndrome Foundation Inc. recognised the critical importance of raising public awareness about this devastating condition. As a result, their goal now is to increase awareness of CHARGE and its consequences in the medical and educational communities and among the general public. To accomplish this goal the

Foundation has launched its first national campaign to promote public awareness of this rare and complicated medical condition. You can help if you live in the United States. Contact Marion Norbury who is the Executive Director on [marion@chargesyndrome.org](mailto:marion@chargesyndrome.org) and she will let you know about how you can make a difference.

## Romania

Cristiana Salomie



New Achievements in Romania

In collaboration with the Romanian University of Education, Sense International Romania has set up the first two Units for deafblind children in Bucharest and Cluj. These units are funded by the Romanian government and supported by Sense International who have provided training for the teachers, financial resources for equipment and hosted Inspector Vlad (Head of Special Education) in the UK. Sense International have also sponsored two teachers to complete the Professional

Development Programme and established a Teachers' Network; this has enabled the teachers and parents to work internationally.

The programme has been evaluated by a joint team from Sense and the Romanian Ministry of Education. The evaluation has showed us that, within a very short period of time, the teachers have learnt how to work with individual children and how to assess their progress. As a result of this evaluation, a new deafblind unit was opened in October in Budapest in the school for

Low Vision. At the moment there are three children in the unit and the teacher to child ratio is 1:1. The new teachers benefit from the considerable assistance from their colleagues in the other two units.

We are very keen to develop other units for deafblind children and to maintain standards in the existing units. We have adapted the experiences from the UK to fit a Romanian reality. We have developed innovative practice and have experimented to understand more about deafblindness.



6th EUROPEAN CONGRESS

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MENTAL HEALTH AND DEAFNESS



HEALTH & WELL - BEING  
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## Mental Health and Deafness



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21-24 May 2003

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LAND  
OBERÖSTERREICH  
LANDRAT JOHANNES  
KREIER



## Cheryl Ramey

Cheryl lives in Winnipeg, Manitoba where she works as a Consultant with Intervention Manitoba, an organization which provides independent living services for adults with congenital deafblindness. Intervention Manitoba, an affiliate of the Canadian Deafblind and Rubella Association (Manitoba Chapter) also supplies outreach services to several other individuals with congenital deafblindness who live throughout the province of Manitoba. One of the individuals that Cheryl is working with is a young child diagnosed with congenital rubella syndrome from the small rubella epidemic in Manitoba in 1996.

Cheryl has demonstrated wonderful success providing intervention support to adults from the Manitoba Developmental



Centre, who were previously undiagnosed with deafblindness. She has also developed an innovative program using art and massage therapy for individuals in Manitoba with deafblindness.

Prior to arriving in Winnipeg, Cheryl worked for a number of years as a consultant with Deafblind Resource Services for the W Ross Macdonald School in Brantford, Ontario.

## Joyce Thompson

Joyce recently retired after a very productive career working with people with acquired deafblindness. Joyce began her career in deafblindness in 1977 with the Canadian National Institute for the Blind as an Intervenor in the new Deaf-Blind Services Department and later moved on to be a Case Manager. While there, Joyce observed how many of the clients



were improperly housed. Her dream for specialized housing resulted in the creation, in 1992, of the first, and still only facility in Canada designed for adults with acquired deafblindness known as Rotary Cheshire Apartments. Joyce became the Executive Director of Rotary Cheshire Homes in Toronto and continued in this position until her retirement this past summer. Joyce also conceived the Canadian Helen Keller Centre which recently opened in Toronto. This centre, which is in its early developmental stages, is offering training for individuals to gain skills for independent living, adapted communications and the use of technology. In her retirement Joyce will no doubt continue as a fierce advocate for services for people with acquired deafblindness. Joyce serves on several Boards and is a member of the Board of Directors of CDBRA and will be heading up a sub-committee on Accessibility for the 13th Dbl Conference on Deafblindness.

## Calling all Interpreters

Sandrine Schwartz, a French Sign Language Interpreter living in Paris, France, would like to let us know about a new internet discussion group that she has set up called [DeafBlind\\_Terps](#).

The aim of this international group is to share experiences and ideas about interpretation for deafblind people, as well as other communication related topics. Everyone can participate in the discussion: deaf or hearing interpreters, deafblind people, deaf people, professionals, or any people who are just interested in the subject... jump aboard and enjoy the discussion on this group! To subscribe to [DeafBlind\\_Terps](#), please send a blank email to: [DeafBlind\\_Terps-subscribe@yahoogroups.com](mailto:DeafBlind_Terps-subscribe@yahoogroups.com) We hope to see you soon on this group!

## Dbl Distinguished Service Awards

### ***Congratulations to Dietrich Bunck and Marjaana Suosalmi!***

During the opening ceremony of the 5th Dbl European Conference in the Netherlands, both Dietrich and Marjaana were awarded the Dbl Distinguished award for their outstanding contribution to the deafblind field.

Mike Collins, President of Dbl, reflects on their successful careers and the impact they have both made within the field of deafblindness.

Dietrich Bunck has been a teacher of deafblind children, and a manager of programs, for several decades. When his boss, the founding director of his country's national center for deafblind services, retired, he stepped forward to take the leadership. He has also contributed significantly to the organization of Deafblind International over his decades of service. He has been very involved in networks, especially the committee on Staff Development and the EVCO unit. He was a key figure in the hosting of the World Conference in Hanover, in 1980. He then went on to serve on the IAEDB executive committee for several years. And later, he was one of the members of the host committee for the European Conference in Potsdam, in 1993.

He plans to retire in the not too distant future, so the award is very well timed. He has had an illustrious career in service to



deafblind people, and it is fitting that we honour him now. He expects to have much more time in the future to pursue his passion for rowing. An impeccable dresser, you can always identify Dietrich by the fashionable bow ties he wears, especially when driving his Jaguar. We are proud to have presented the Dbl Distinguished Service Award to Dietrich Bunck.

I first met Marjaana Suosalmi in Poitiers in 1987, when I became a member of IAEDB Executive



Committee. Having worked as a leader of deaf and deafblind services in her own country, she had recently been appointed as only the second director of NUD, The Nordic Resource Center for

the deafblind. While serving in that capacity, she built up her own organization, and also served as a strong contributing member of the executive committee, challenging us to be thoughtful about the need to include women in the management of this organization.

She went on to live her own recommendation, chairing the scientific committee of the next World Conference in 1991, in Orebro, Sweden. It was at this conference that she was elected President of IAEDB, and I had the honour of being elected to serve as her Vice President. Thanks to her typical Nordic accent, I took a lot of joking about being the "wise" President; however the teasing abated when I suggested this might make her the "unwise" President.

However, as you know, just the contrary was true. Under her able leadership, IAEDB undertook the most radical strategic planning and reorganization in its history, reinventing itself as DBI and defining itself as an organization of networks. I dare say that, without her thoughtful and challenging leadership over 8 years, such a sea change in the organization would have been unthinkable.

Due to changes in employment, she is now moving away from full involvement in our management committee. Nevertheless, she has once again committed herself to continued roles of involvement in our Strategic Planning and Nominations Committees. It is with great pride that Dbl has presented our Distinguished Service Award to a great leader, and a darn good dancer, Marjaana Suosalmi.



## Anne Sullivan Award Winner – Eddie Keir

**nominated by  
The Deaf-Blind Association, Australia**

**“Mr Eddie Keir has been a significant factor in the inception and development of The Deaf-Blind Association from a parent support group to an organisation that provides a range of services for people with multiple disabilities including deafblindness. His strong stance on the rights of deafblind people to live in the community led to The Deaf-Blind Association being a forerunner in the provision of community based services. He has served on the Board of Directors for almost the entire 34 years of the Association’s existence, both as Vice President and currently as President.**

His experience in his various professions as teacher, psychologist and audiologist made him keenly aware of the inadequate training, support and knowledge available in the sensory disability field. His career has been consistently oriented towards rectifying this situation.

He has been a major influence on the perceptions that Governments, professionals and



the community have of people with deafblindness, particularly with regard to the abilities and potential of deafblind children.

He was one of the key people responsible for the innovation of early intervention programs for deafblind children. He revolutionised the assessment of deafblind children by using longitudinal methods, realising the need to provide appropriate stimulation over a given time before any accurate assessment of the child’s abilities could be made.

With these insights he was able to equip parents with the knowledge required to assist their deafblind children to develop, such as providing signals to

anticipate certain activities.

The success of the early intervention sessions eventually convinced the Education Department that deafblind children were educable and resulted in the setting up of a school for deafblind children called Carronbank.

He is also noted for his contribution to psychiatry on the impact of sensory disabilities. In particular, he was the first to offer therapy work for deafblind adolescents on issues such as sexuality.

Mr Keir is also highly regarded for the enormous support, empathy and understanding that he has given to deafblind children and their families.’

## Membership update

### Corporate membership fees 2001

There are still a few corporate members who are outstanding on their membership payment fees for 2001. If you still need to send your payment through, please contact either Emma Fisher at the Dbl Secretariat ([dbi@sense.org.uk](mailto:dbi@sense.org.uk)) or Ton Visser at the Dbl Treasury ([A.Visser@ivd.nl](mailto:A.Visser@ivd.nl))

### Corporate membership fees 2002

It is customary for fee reminders to be posted at the beginning of each year. A reminder for 2002 fees will be circulated in January 2002 in spite of the recent reminder for 2001. We do apologise if this causes any inconvenience but this notice should equip you with adequate warning. We would recommend for your ease that corporate membership dues for 2002 are paid as early in the year as possible.

### Dbl Management Committee

Dbl's Strategic Officer, Marjaana Suosalmi, is no longer able to dedicate as much of her time to Management Committee activities but will still be overseeing Dbl's strategic planning discussions.

The next meeting of the Dbl Management Committee will take place during the first weekend of March 2002 in Toronto, Canada. Please could all members of Council and Networks inform the Secretariat of any subjects they would like the Management Committee

to consider? During this time the Management Committee will take the opportunity to visit the host site of the Dbl World Conference in 2003.

As you are aware, the Treasurer function of Dbl is managed by the Instituut voor Doven in Sint Michielsgestel in the Netherlands and the Dbl Secretariat function is managed by Sense International in London. With Jan van Dijk stepping down and Rodney Clark retiring, we welcome Ton Visser as the new Treasurer and Emanuela Brahamsha as the new Secretary. Both functions will remain as they are at least until the next World Conference in August 2003.

### Dbl Council

A meeting of the Dbl Council took place in the Netherlands on the 24th July 2001. The main outcomes are noted below but if you require a copy of the full minutes please contact the Secretariat at [dbi@sense.org.uk](mailto:dbi@sense.org.uk)

Council members spent an afternoon discussing Dbl's current strategic plan and offering their thoughts on future developments. The session was facilitated by Marjaana Suosalmi, who the Management Committee would like to thank. A full summary of the discussions will be circulated in due course.

A nominations committee, chaired by Marjaana Suosalmi, has been appointed. The President and Vice-President will be elected at the World Conference in Canada in 2003 and nominations will be called next autumn 2002.

However, please do feel free to start thinking about potential nominations now.

The next meeting of the Dbl Council will take place in Greece during autumn 2002. Exact dates will be confirmed in the next Dbl Bulletin.

### Conference News

The 5th Dbl European Conference took place in the Netherlands from 24th to 29th July 2001. Over 400 people from 40 different countries took part, including over 60 sponsored delegates from Central and Eastern Europe. Special thanks to the Local Planning and Scientific Committees.

Preparations are well underway for the 13th Dbl World Conference in Mississauga, Ontario, the theme of which is *Communication is the Key to Opening Doors Worldwide for Persons who are Deafblind*. This will take place from 5th to 10th August 2003 and the first announcement will be sent in winter 2001. The Conference website can be visited at [dbiconferencecanada.com](http://dbiconferencecanada.com)

A planned **Dbl Africa Conference** has been put on hold until further notice. With Johan van der Poel stepping down from his post, Sam Boshielo and Anlo van Heerden will continue investigating the possibilities of a South African Conference. Don't forget to check out the Dbl Website on <http://www.deafblindinternational.org>

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

**Non-Voting Members** consist of individuals, national networks and non-subscribing Corporates. Non-voting members can contribute to the decision making process of Dbl through either a corporate member or an international network. Non-voting members will receive a copy of Dbl Review and other relevant Dbl information. Non-voting membership is free, but an annual donation of US\$30 is requested to cover costs.

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

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

*Large Corporates:*

Annual Fees between 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.

# DBI MEMBERSHIP

## Non-Voting Membership

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

I wish to make a donation of US\$30  or £20

I wish to make a donation of \_\_\_\_\_ (please specify)

Please debit my  Visa  American Express  
 Mastercard

Expiry Date

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

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) \_\_\_\_\_

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**Dbl Review** (*tick one box in each category*)

I would prefer to receive *Dbl Review* in:

English  Spanish

I would prefer to receive *Dbl Review* on:

paper  disk

**Please return to:** Emma Fisher, Dbl,  
c/o 11-13 Clifton Terrace,  
Finsbury Park, London N4 3SR, UK.

The following person is a member of Dbl:

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Signed: \_\_\_\_\_

## Corporate Membership

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

**Large corporates:**

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

**Small corporates:**

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

We would like to join Dbl 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 *Dbl 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:**

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Representative \_\_\_\_\_

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